George Latimer
County Executive

Department of Community Mental Health
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Commissioner

Testimony to the Joint Legislative Budget Hearing
Proposed 2023-24 NYS Budget
Hearing on Mental Hygiene
February 16, 2023

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And;
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Mental Health and Trauma Informed Practice

Good afternoon, and thank you for the opportunity to testify to this Joint Legislative Hearing on Governor Hochul's proposed Budget for NYS Fiscal Year 2023-24. My name is Joseph Glazer, the Deputy Commissioner of the Westchester County Department of Community Mental Health. I am also Co-chair of the NYS Bar Association Task Force on Mental Health and Trauma Informed Representation.

I today look back on my more than 25 years' experience working in the behavioral health field, in roles as various as statewide nonprofit President and CEO, private practice attorney, government official, and even state senate staffer. I cherish that I have had the pleasure of working with some of the assembled legislators here over the years.

I look at my current role, working with Westchester County government and our partner nonprofits where together we are the primary provider of services at the local level. In the last five years, under the leadership of County Executive George Latimer, Westchester has made substantial strides in working toward a seamless system of care. We strive for an integrated system to ensure people with co-occurring mental health and substance misuse needs have access to the treatment services and modalities they need. And we are, every day, working towards it.

We are "Reimagining Policing", instituting a tremendous model that includes 911 Diversion and Mobile Crisis Response Teams across the county working with all 42 law enforcement agencies, as well as providing copious mental health and crisis training for not just police but all first responders. This will ultimately give us an interconnected and seamless system of behavioral health crisis diversion in Westchester.

We are working with our District Attorney, Mimi Rocah, as well as with the NYS Office of Court Administration, to build new models of criminal justice diversion, expanding our ability to redirect people from the criminal justice system to the appropriate level of care. This work improves outcomes and reduces recidivism in our communities.

We are building out substance misuse and opioid treatment and prevention programs, and working with schools to expand services in educational settings.

And, up until now, we have done all this with very little, if any, additional state funding. Rather, we have mostly managed with local funds, federal funds, Medicaid expansion, and increased efficiency in utilizing our resources. And

frankly, that has been the rule of thumb for county governments in our state in addressing the behavioral health needs of communities for many, many years.

As I look forward, I can say that this year's governor's proposed budget offers an amazing opportunity for progress. In its overarching themes and goals, it does more to address the needs of people living with behavioral health and co-occurring disorders than any single undertaking since the 1993 Community Mental Health Reinvestment Act.

As per the analysis of our statewide organization, the Conference of Local Mental Hygiene Providers, Governor Hochul's proposed budget includes broad expansion and development of services:

- Expand Residential Programs. Investing $890 million in capital to build 2,150 new residential beds for people with mental illness who need varying levels of supports. This includes 500 new Community Residence – Single Room Occupancy (CR-SRO) beds, 900 Transitional Step-Down Beds, and 750 permanent Supportive Housing beds.
- 600 licensed Apartment Treatment beds and 750 scattered site Supportive Housing beds, for a total of 3,500 new units throughout the State.
- Budget also provides $25 million in capital resources to develop 60 community step-down units designed to serve formerly unhoused individuals who are transitioning from inpatient care.
- Expand Outpatient Services - funding 12 new Comprehensive Psychiatric Emergency Programs, including $60 million in capital; 42 new Assertive Community Treatment teams; eight new Safe Options Support teams, to expand the Critical Time Intervention (CTI) initiative started in 2022; 42 new Health Home Plus Care Managers; and start-up funding and operating costs for expanded clinic capacity at 20 sites.
- Expand Inpatient Bed Capacity - includes funding for the opening of 1,000 inpatient psychiatric beds which is part of a multi-year plan to increase operational capacity at mental health facilities. Added beds include 850 currently offline, inpatient psychiatric beds at public hospitals licensed under Article 28; and 150 new State-operated inpatient psychiatric beds.
- Support the Development of the 988 Crisis Hotline - the Executive Budget provides $60 million in FY 2024, to fund the expanded crisis center network to support people contacting the 988 Crisis Hotline in New York State through call, chat, and text.
- Suicide Prevention Programs - invests $10 million in grants to suicide prevention programs targeting high-risk youth and $400,000 to fund

FarmNet, which works with Cornell University to support farmers and their family members.

- Increase Support for Existing Residential Programs - $39 million in FY 2024 – for existing community-based residential programs and included legislation to extend property pass-through provisions to include OMH's supported housing.
- Enhance Children's Mental Health Programs – invests an additional $12 million in the HealthySteps program and HomeBased Crisis Intervention (HBCI) teams, $5 million for High Fidelity wrap around supports, and $10 million to develop school-based clinics.
- Expand INSET Program - includes $2.8 million to expand the Intensive and Sustained Engagement Treatment (INSET) program. Funding supports the creation of three new teams which will offer peer-based outreach and engagement for adults with serious mental illness. INSET helps to support recovery, reduce emergency room visits and hospitalizations, and ensures the appropriate utilization of Assisted Outpatient Treatment (AOT) orders, where possible.
- Cost Of Living Adjustment (COLA) - The Executive Budget includes a 2.5% COLA to human services providers in FY 2024. The COLA applies to voluntary operated providers of services for OPWDD, OMH, OASAS, Office of Children and Family Services (OCFS), Office of Temporary and Disability Assistance (OTDA), and the State Office for the Aging (SOFA).
    - For the Mental Hygiene agencies, this amounts to $188.6 million ($314.1 million including federal matching funds) for OPWDD, OMH, and OASAS voluntary operated programs, and will provide fiscal relief to providers, enabling them to offer more competitive wages to their staff to address workforce recruitment and retention issues and better support the individuals they serve. Minimum Wage.

- The Executive Budget leverages an additional $38 million in State funds to support minimum wage increases, including indexing minimum wage to inflation, for staff at programs licensed, certified, or otherwise authorized by OPWDD, OMH, and OASAS.

And while I stress that this is the greatest single proposed undertaking to address this state's broken mental health system since Reinvestment, it comes with a caveat…

Our service providers are in a staffing crisis, and our housing providers are in a staffing and rent crisis.

Should these concomitant crises be left unaddressed, the Governor's proposed budget will effectively bring little change in our system. We will have a huge, robust system on paper, and the static inability to fill new apartments and hire employees, unless the legislature addresses the on-going woeful inadequacy of funding for our workforce and our rental allowances. These two financial deficit areas tag team to reduce the available number of residential beds and available services for people with mental health and co-occurring needs in many communities, and Westchester is among those.

Specific to my county of Westchester, the failure of state funding to grow with the needs and demands has created a substantial gap in the provision of housing and services.

Currently the Supported Housing allocation and guidelines for Westchester County provide $1669 for a one bedroom. The median rental rate in Westchester County, is $1796 a month for a one bedroom apartment. That means that well over 50% of available apartments are not available to our population in need. The minimal increases in rental allowance included in the last two years have proven to be insufficient to keep up with skyrocketing rental rates.

Our mental health housing programs currently have a waitlist of 750 people on the Supported Housing referral list. There are people on our waitlist for housing who have been on the list for up to five years. The average wait time for each program is:

Community Residence - 2 years

Treatment Apartment - 9 months

Supported Housing - 5 years

Beyond the overall insufficiency of the number of allocated beds, there are currently 60 vacant openings in Supported Housing because we cannot find rental apartments willing to accept the amount provided in the rental guidelines. Simply put, this means we have "residential beds" that exist on paper in our housing system, but they do not actually exist because we cannot find landlords willing to accept the rental rate. We fear that without more state funding the Governor's robust proposal will perpetuate and exacerbate this problem.

But beyond rent allocations and subsidies, staff for these programs is a huge issue. We have vacancies in all three levels of housing programming because of staffing. Workforce is now the number 1 issue for all of the Human Service nonprofits in our county. Since the beginning of COVID, our estimate is that the workforce employment vacancy rate has doubled.

Staffing levels in some of our housing programs hover below 50%, which means half the staff required to meet requisite service levels and operational needs per house or per bed simply are not there. Without sufficient staffing, beds that could help vulnerable people with the greatest needs remain empty in Westchester.

Further, we generally, across the human service system, struggle to accommodate Spanish speaking clients because our nonprofit housing partners are not sufficiently funded to be able to hire Spanish speaking staff, a skill that is currently in great demand. This applies as well to the many other primary languages in our communities.

Because of the low staff reimbursements rates, people can make more working in retail or food service, while many of our nonprofits are struggling to pay more than a fraction above the minimum wage to direct care workers.

For example, there are job titles attached to the treatment housing service continuum that require years of experience, and do not pay commensurate with those requirements.

Because of these staffing deficiencies, we have agency management staff covering overnight shifts so more people can be housed, including 2 Nonprofit Executive Directors that we know have done shift work.

Quite frankly, the Governor's proposed 2.5% COLA is insufficient to remedy this situation.

Having outlined this, there are others areas worthy of review as well. We are extremely deficient in meeting the needs of children and adolescents. Westchester, a county of a million people has a handful of youth population community residences, which providing care to children with lower level residential needs. And while we have residential treatment facilities operated by OCFS (forensic) for high needs children, there are none that are OMH licensed. Thus we lack voluntary residential services for very high needs children and adolescents anywhere in Westchester, including substance misuse.

As state government looks to increase treatment beds, we must ensure we address the needs in all populations.

One further issue that clearly needs to be reviewed is the statutory framework for those deemed to be incapacitated in assist in their own defense under Criminal Procedure Law Section 730. CPL 730 creates a statutory process by which the criminal justice system determines whether or not a defendant is competent, and if not, they are placed in a state operated forensic psychiatric hospital -- often for months. And the bill for it, up to $1000 a day or more, is sent to the counties. It is estimated that our bill for the current year for restoration will exceed $2 million.

But the cost is not the sole problem with CPL 730. The statute requires restoration, which is a very different function than broad-based treatment. Formerly in my private practice, I have had individuals removed from their coordinated treatment because of pending charges and their situational decompensation, and placed in state psychiatric hospitals where much of their core treatment was either discontinued or changed.

The much needed reform of CPL 730 requires a review of funding and payment, complete care, and recognizing that the roots of CPL 730 reach back to the 19th century, CPL 730 must evolve to keep up with and incorporate our modern behavioral health care system. We should be considering alternatives to the triggering of CPL 730, and allowing crisis, respite and enhanced and intensive community-based services to be utilized before a person is deemed CPL 730 incapacitated, which results in their hospitalization and long delays in the justice system. We should limit the time a person can remain in "restoration", and more quickly determine when a person will likely never be able to participate in their own defense. And we should make it a requirement that all individuals placed in the custody of any of the "O" agency Commissioners must receive full and co-occurring competent care.

That said, I go back to a point I made earlier: In Governor Hochul's proposed state budget, New York has been presented the best opportunity in 30 years to fix our long broken behavioral health system. We hope that this is an opportunity that is fully grasped.

Thank you, for your time and the opportunity to be heard.

Report to the Executive Committee of the New York State Bar Association on the Use and Efficacy of Penal Law § 40.15 and Criminal Procedure Law § 330.20 and Recommendation to Establish a Mental Health Task Force or Committee

Committee on Mandated Representation
Robert Dean, Chair

Mental Health Subcommittee
Chris Liberati-Conant, Chair
Mardi Crawford
Majer Gold
Justine Luongo
Lisa Schreibersdorf
Sheila Shea
Sherry Levin Wallach

November 2018

"You have to be crazy to plead insanity."

—*Charles P. Ewing, SUNY Distinguished Service Professor, University at Buffalo School of Law*

Overview and Recommendation

This report will first undertake a brief historical overview of the "insanity defense"[1] in New York, highlighting how much it remains a child of *M'Naghten's Case*. It will then explore how the insanity defense is used and the effects of its invocation, including the ever-more-restrictive post-acquittal confinement apparatus. Lastly, it will discuss the need for deeper inquiry into this and other questions related to mental health that affect society in general and the bar in particular. Such inquiry requires resources beyond the scope of the Committee on Mandated Representation and, to the knowledge of the authors of this report, any existing committee or section. Thus, this report ultimately recommends that the Executive Committee establish a permanent committee or task force to examine and recommend necessary action on the insanity defense and other issues related to mental health and the law.

M'Naghten's Legacy in New York

New York's "insanity defense" has its roots in ancient common law.[2] As in nearly every state, New York's statutory provisions applicable to criminal defendants who lack criminal culpability due to a mental illness stem directly from the English common law *M'Naghten's Case*. In that case, a woodturner who suffered from delusions of political persecution was acquitted of the murder of a civil servant and committed to a mental

1 The authors of this report use the term "insanity defense" with some discomfort. Although the term is obsolete and stigmatizing, it is the term most commonly used in both caselaw and research.

2 *See* People v. Kohl, 72 N.Y.2d 191, 203, 532 N.Y.S.2d 45 (1988) (Hancock, Jr., dissenting); Michael Perlin, The Jurisprudence of the Insanity Defense (1994).

institution.[3] In 1843, following public outcry at the acquittal and inquiry from the House of Lords, the Court of Common Pleas announced the rule that criminal liability could be excused only if the accused "clearly proved that, at the time of committing the act, the accused was labouring under such a defect of reason, from disease of the mind, as not to know the nature and quality of the act he was doing, or, if he did know it, that he did not know he was doing what was wrong."[4]

When the rule was imported to New York, the courts placed on the prosecution the burden of proving beyond a reasonable doubt that the defendant was not insane.[5] The difficulty of carrying this burden was eased by a presumption of sanity that required the defendant to introduce substantial evidence of his insanity.[6] Burden aside, in 1915, 70 years after *M'Naghten*, the rule remained essentially unchanged in form: "a person is not excused from criminal liability as an idiot, imbecile, lunatic or insane person, except upon proof that, at the time of committing the alleged criminal act, he was laboring under such a defect of reason as: (1) not to know the nature and quality of the act he was doing; or (2) not to know that the act was wrong."[7] Judge Cardozo expanded the breadth of the defense when he interpreted not knowing the act was wrong as referring to knowledge of both the act's illegality and immorality.[8]

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3 8 Eng. Rep 718 (1843).

4 *People v. Schmidt*, 216 N.Y. 324, 332-33 (1913).

5 *Kohl*, 72 N.Y.2d at 202-03 ("Our earliest statute on the subject declared that '[n]o act done by a person in a state of insanity can be punished as an offence' (Rev Stat of 1828, part IV, ch 1, tit 7, § 2)." The dissenting opinion provides a further history of the prosecution's burden in these matters.

6 *People v. Silver*, 33 N.Y.2d 475, 482, 354 N.Y.S.2d 915 (1974), defined substantial evidence as "the degree of proof required to rebut 'most, but not all' presumptions recognized in this State (Richardson, Evidence [10th ed.], § 58, p. 37)."

7 *People v. Schmidt*, 216 N.Y. 324, 329 (1915) (citing Penal Law § 1120).

8 *Id*. at 333-34. Cases that followed *Schmidt* further specified that an appreciation of moral wrongfulness refers to the standards of the community, as opposed to one's own moral structure. *See People v. Wood*, 12 N.Y.2d 69, 236 N.Y.S.2d 44 (1962).

By 1964, the harshness of New York's strict adherence to *M'Naghten* led to legislative reform.[9] The Legislature enacted Penal Law § 30.05,[10] which provided: "A person is not criminally responsible for his conduct if at the time of such conduct as a result of mental disease or defect he lacks substantial capacity to know or appreciate either: (a) The nature and consequences of such conduct; or (b) That such conduct was wrong." The revision ameliorated the strict *M'Naghten* rule in that a defendant's lack of capacity to know or appreciate was not required to be total, but substantial.[11] It also changed "nature and quality" to "nature and consequences." The Legislature declined, however, to accept in full the recommendation of the Temporary Commission on Revision of the Penal Law and Criminal Code, which followed the Model Penal Code in providing that the defense applies to one who, due to a mental disease or defect, lacked substantial capacity "to conform his conduct to the requirements of law."[12]

By 1970, the Court of Appeals had restricted the defense by approving of a jury instruction that explained that to be held criminally responsible, "the defendant must have realized that the act was against the law and against the commonly accepted standards of morality."[13] Thus, regardless of how pervasive a delusion, so long as a defendant

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9 Note, Legislative Changes in New York Criminal Insanity Statutes, 40 St. John's L. Rev. 75, 80-81 (1965).

10 L. 1965, ch. 593, § 1.

11 Note, Legislative Changes in New York Criminal Insanity Statutes, 40 St. John's L. Rev. 75, 78-81 (1965).

12 *Id.* at 81. Under the Model Penal Code, a defendant is not guilty if a mental illness renders him unable to conform his conduct to the law. MPC § 4.01. The Model Penal Code has been adopted by a majority of states. *See* Henry Fradella, *From Insanity to Beyond Diminished Capacity: Mental Illness and Criminal Excuse in the Post*-Clark *Era*, 18 U. Fla. J.L. & Pub. Pol'y 7 (2007).

13 *People v. Adams*, 26 N.Y.2d 129, 135-36, 309 N.Y.S.2d 145 (1970).

understood that conduct was illegal and generally considered immoral, the insanity defense would fail as a matter of law.[14]

In 1984, following the attempted assassination of Ronald Reagan and the public furor at his would-be assassin John Hinckley's insanity acquittal,[15] the federal government and multiple states, including New York, tightened insanity statutes.[16] The New York Legislature did so by repealing Penal Law § 30.05 and replacing it with Penal Law § 40.15, thereby shifting the burden to the defendant, making insanity an affirmative defense to be proved by a preponderance of the evidence. The statements of agencies and stakeholders contained within the bill jacket for Penal Law § 40.15 overwhelmingly

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14 The Pattern Jury Instructions describe lack of substantial capacity to know or appreciate that conduct is wrong as "either that the conduct was against the law or that it was against commonly held moral principles, or both." CJI2d[NY] Defenses: Insanity. Lack of substantial capacity to know or appreciate the wrongfulness of an act need not be so restricted. Arguably, a defendant acting on beliefs caused by mental illness may lack substantial capacity to appreciate the wrongfulness of an act despite being able to articulate that it is both illegal and against commonly accepted moral principles. For instance, a person who believes that he is being persecuted by the government and that nearly everyone he meets is either a dupe or conspirator may be able to articulate that an act he believes will stop the persecution is both illegal and contradictory to commonly accepted moral values. Yet, that person may nevertheless lack substantial capacity to appreciate the wrongfulness of his conduct because his delusions make commonly accepted moral values appear to him to be the products of wickedness, corruption, and conspiracy. A restrictive definition of substantial capacity to appreciate that an act is wrong also ignores the magical thinking attendant to some delusions, i.e., that everything will be fixed after the fact.

15 According to an ABC news poll taken the day after the verdict, 83% of Americans believed "justice was not done." Douglas O. Linder, *The Trial of John W. Hinckley, Jr.*, http://www.famous-trials.com/johnhinckley/537-home (last visited July 6, 2018).

16 *Id.* (The House and Senate began hearings regarding shifting the burden of the insanity defense within one month of the Hinckley verdict. Within three years, two-thirds of the states shifted the burden to the defense to prove insanity, eight states adopted the verdict of "guilty but mentally ill," and Utah abolished the insanity defense). *See also* Joe Palazzolo, *John Hinckley Case Led to Vast Narrowing of Insanity Defense*, WALL ST. J., July 27, 2016, https://www.wsj.com/articles/john-hinckley-case-led-to-vast-narrowing-of-insanity-defense-1469663770. (Following the Hinckley verdict, Kansas, Idaho, and Nevada also abolished the insanity defense, although Nevada later reinstated it.)

supported the change.[17] Most echoed the arguments offered by the Governor's statement in support: that insanity acquittals had risen in the decade prior and that placement of the burden of disproving insanity on the prosecution favored the defendant too heavily, thus creating a risk that defendants would "get away with murder." Governor Mario Cuomo's Criminal Justice Coordinator argued: "It makes the law fairer. You'll no longer be able to hide behind this defense."[18]

Whether the new law was fairer was a matter of debate at the State's highest court. In *People v. Kohl*, the Court of Appeals upheld Penal Law § 40.15's shifting to the defendant of the burden of proving insanity.[19] Judge Stewart F. Hancock, Jr. dissented, arguing that the Court had abandoned fundamental and ancient principles of criminal responsibility: "the majority holds that legal sanity is not an essential element of the crime of murder, that sanity and murder may be defined as the Legislature chooses, and that mere 'conscious objective'—without regard to the capacity to appreciate that one's conduct is wrong—is all the mental culpability necessary to constitute the crime of murder."[20]

The statute has not been amended since 1984 and *Kohl* remains good law. Two cases, one from 1994 and one from 2018, illustrate the insanity defense's continued narrowness in practice.

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17 *See, e.g.*, Memorandum from Linda J. Valenti, NYS Division of Probation General Counsel, to Gerald C. Crotty, Counsel to the Governor, et al. (June 25, 1984); Letter from Paul Litwak, N.Y.S. Office of Mental Health, to Gerald C. Crotty, Counsel to the Governor (June 21, 1984); Memorandum from Jay M. Cohen, N.Y.S. Division of Criminal Justice Services to Matthew T. Crosson (June 19, 1984) (included in N.Y. Laws 1984, ch. 668 legislative bill jacket).

18 Edward A. Gargan, *Limit on Insanity Defense Is Approved in Albany*, N.Y. TIMES, June 13, 1984, http://www.nytimes.com/1984/06/13/nyregion/limit-on-insanity-defense-is-approved-in-albany.html; *cf. People v. Kohl*, 72 N.Y.2d 191, 196, 532 N.Y.S.2d 45 (1988).

19 72 N.Y.2d 191, 197-98 (1988).

20 *Id.* at 200-01.

In 1994, brandishing a rifle, Ralph Tortorici took a classroom full of University of Albany students hostage. "He claimed that he was the victim of an experiment in which a microchip was implanted in his brain, and [he] wanted to expose the people responsible for victimizing him."[21] One of the student hostages, Jason McEnaney, charged Tortorici and managed to wrestle the rifle away from him, allowing other students to pin him to the ground. During the struggle, Tortorici shot and wounded McEnaney.[22] Tortorici was indicted on 15 counts, including attempted murder, kidnapping, and first degree assault.

Once the trial began, Tortorici declined to attend, instead remaining in his holding cell.[23] The People did not present any psychiatric evidence, while the defense presented four psychiatric experts, all of whom agreed that Tortorici did not understand the nature and consequences of his conduct.[24] The jury, deliberating for an hour, convicted Tortorici of multiple felonies, including kidnapping and assault, but acquitted him of attempted murder. The court sentenced Tortorici to an aggregate term of 15½ to 40 years' imprisonment.[25] The Appellate Division and Court of Appeals affirmed the verdict.[26]

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21 *People v. Tortorici*, 92 N.Y.2d 757, 759, 686 N.Y.S.2d 346 (1999).

22 Jacques Steinberg, *He Disarmed a Gunman But Insists He's No Hero*, N.Y. TIMES, Dec. 28, 1994, https://www.nytimes.com/1994/12/28/nyregion/he-disarmed-a-gunman-but-insists-he-s-no-hero.html. *But see* Paul Grondahl, *20 years after Ralph Tortorici took class hostage at UAlbany*, TIMES UNION, Dec. 17, 2014, https://www.timesunion.com/local/article/Recalling-three-hours-of-terror-in-Lecture-Center-5961566.php (according to this account, McEnaney grabbed and held onto the barrel of Tortorici's gun, and another student, Jason Alexander, was the first to tackle Tortorici).

23 *Tortorici*, 92 N.Y.2d at 762.

24 A Crime of Insanity, *The Defense's Summation*, FRONTLINE, https://www.pbs.org/wgbh/pages/frontline/shows/crime/ralph/dsummation.html (last visited July 6, 2018) (excepts from the defense summation including discussion of Tortorici's medical history and medical expert testimony).

25 *Tortorici*, 249 A.D.2d 588, 589, 671 N.Y.S.2d 162 (3d Dep't 1998), *aff'd,* 92 N.Y.2d 757, 686 N.Y.S.2d 346 (1999), *cert. denied*, 528 U.S. 834 (1999).

26 *Id*.

Despite receiving Office of Mental Health services while in custody, Tortorici hanged himself in his cell in 1999.[27]

A juror explained why they had rejected Tortorici's insanity defense: "if he had just grabbed a gun and run into a McDonald's, it would have been a different situation. We would have looked at it differently. The fact that [there] was so much planning weighed heavily on us."[28] The juror's interpretation of the insanity defense is consonant with the Pattern Jury Instructions for Penal Law § 40.15, which describe a lack of substantial capacity to know the nature and consequences of an act or that it was wrong in terms of children who "sometimes recite things that they cannot understand."[29] Although people with mental illnesses were once thought of as insensible wild animals or infants,[30] we have long known that even where a mental illness impairs reasoning in some areas

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27 Press Release, N.Y.S. Dep't of Corr. Servs. Inmate Tortorici hangs self in prison cell (Aug. 10, 1999), http://www.doccs.ny.gov/PressRel/1999/torthang.html.

28 A Case of Insanity, *Interview: Norm LaMarche*, FRONTLINE, https://www.pbs.org/wgbh/pages/frontline/shows/crime/interviews/lamarche.html (last visited July 6, 2018); *see also* James C. McKinley Jr. & Jan Ransom, *Manhattan Nanny Is Convicted in Murders of Two Children*, N.Y. TIMES, April 18, 2018, https://www.nytimes.com/2018/04/18/nyregion/nanny-trial-verdict.html ("The prosecutors . . . also focused on evidence suggesting that Ms. Ortega had planned the murders.").

29 "Children can sometimes recite things that they cannot understand. In those circumstances, the children may be said to have surface knowledge of what they recited, but no true understanding. Thus, a lack of substantial capacity to know or appreciate either the nature and consequences of the prohibited conduct, or that such conduct was wrong, means a lack of substantial capacity to have some true understanding beyond surface knowledge… ." CJI2d[NY] Defenses: Insanity.

30 For a discussion of the origins of the idea of people with mental illness as wild animals or children, see Anthony M. Platt, The Origins and Development of the "Wild Beast" Concept of Mental Illness and Its Relation to Theories of Criminal Responsibility, Vol. 1, ISSUES IN CRIMINOLOGY, No.1, Criminal Responsibility (Fall 1965) at 1.

(i.e., so that a person believes that taking a college class hostage will stop the government from experimenting on him), it does not often destroy all rational thought.[31]

In 2013, Lakime Spratley, seemingly at random and without planning or provocation, shot a woman in a grocery store, killing her.[32] The evidence at trial indicated that he suffered from schizoaffective disorder, heard voices, and suffered from delusions of persecution. In a police interview he offered as a partial explanation that he believed the victim had stolen his clothes and was wearing his shorts, and that she had made trigger gestures at him.[33] A jury convicted him of murder in the second degree and criminal possession of a weapon in the second degree. The Appellate Division, Second Department, reversed the verdict, explaining that "the rational inferences which can be drawn from the evidence presented at trial do not support the conviction," finding as a matter of law that the defendant had established that he lacked substantial capacity to know or appreciate that his conduct was wrong.[34] One justice dissented.

More than 80 years before Tortorici's conviction, and 100 years before Spratley's, Judge Cardozo posited that a mother who, at what she believes to be God's command, murders her child, is not guilty by reason of insanity.[35] To Cardozo, it would be a

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31 *See People v. Jackson*, 60 A.D.3d 599, 877 N.Y.S.2d 244 (1st Dep't 2009) ("Although two psychiatric examiners opined that defendant was not competent because he insisted on pursuing a defense of posthypnotic suggestion derived from his delusions, the ultimate determination of whether a defendant is an incapacitated person is a judicial, not a medical, one… Defendant expressed a rational understanding of the judicial proceedings, the charges against him, the choices available to him, and the consequences of his decision to pursue a hypnosis defense rather than an insanity defense.") (citations omitted). For an examination of the decision making abilities of those diagnosed with mental illness as compared to those without, see Paul Appelbaum & Thomas Grisso, *The MacArthur Treatment Competence Study*, MACARTHUR RESEARCH NETWORK ON MENTAL HEALTH AND THE LAW (May 2004), http://www.macarthur.virginia.edu/treatment.html (last visited July 9, 2018).

32 *People v. Spratley*, 159 A.D.3d 725, 71 N.Y.S.3d 582 (2d Dep't 2018).

33 *Id.*

34 *Id*. at 731.

35 *People v. Schmidt*, 216 N.Y. 324 (1915).

"mockery" and "abhorent" to hold that she knew what she did was wrong, even if she did understand it to be illegal, because she could not comprehend its moral repugnance. Tortorici, like Judge Cardozo's hypothetical mother and even *M'Naghten* himself, committed his crimes while under the influence of delusions that appear to have compromised his moral judgment.[36] He believed that government agents were following him by means of a microchip implanted in his body[37] and that holding the class hostage would alleviate the persecution.[38] It strains credulity to argue that he possessed substantial capacity to understand the nature and consequences of his conduct or that his conduct was wrong.[39] His reasoning and apparent motivations were so irrational as to appear comparable to a child's magical thinking. For his part, Spratley appears to have not even possessed the understanding of a child at the time he committed the crime—he did not know what he was doing. Yet, both were convicted, and the Appellate Division's reversal of Spratley's conviction was not unanimous.

These cases highlight the narrowness of New York's ostensibly evolved *M'Naghten* rule. Cardozo's distinction between knowledge of legal right and wrong and moral right and wrong is illusory. For the defense to succeed, the defendant must have been insensible to the point that the line between lack of mens rea and the insanity defense disappears. But mental illness is not all or nothing; one need not conform to the

36 *People v. Tortorici*, 92 N.Y.2d 757, 696 N.Y.S.2d 346 (1999) (Smith, J., dissenting). Tortorici's delusions bear more than a passing resemblance to M'Naghten's delusions.

37 *Tortorici*, 92 N.Y.2d at 771.

38 *Id.* at 759.

39 *Id.* at 771*;* Vincent Bonventre, *Editor's Foreword, State Constitutional Commentary*, 68 Alb. L. Rev. 2 (2005) (referring to Tortorici's conviction as "highly questionable").

medieval notion of lunacy by howling at the moon to lack—or have diminished—criminal culpability.[40]

In response to an inquiry sent by the Committee on Mandated Representation's Mental Health Subcommittee to chief defenders, 18 of 19 respondents endorsed the belief that Penal Law § 40.15 is insufficient to ensure justice for criminal defendants who lack criminal culpability due to mental disease or defect. In addition, multiple respondents questioned the all-or-nothing nature of the defense, noting that culpability, ability to appreciate the nature of one's conduct, and the ability to tell right from wrong are more appropriately viewed as matters of degree. Unfortunately, while societal and medical understanding of mental illness has evolved, the insanity defense has stood still.

The Insanity Defense in Practice

The comments in support of the enactment of Penal Law § 40.15 in 1984 would suggest that the insanity defense was being routinely abused.[41] In the eyes of the public and legislators, it presented an unacceptable opportunity for murderers to walk free by faking a mental illness. Attorneys and the public alike "believe that the defense is invoked frequently and principally in cases involving murder."[42] Yet social science research suggests that the insanity defense may only be invoked in one percent of felony

40 *Rivers v. Katz*, 67 N.Y.2d 485, 494, 504 N.Y.S.2d 74 (1986) (regarding mentally ill patients' ability to make decisions regarding their own care, "neither the fact that appellants are mentally ill nor that they have been involuntarily committed, without more, constitutes a sufficient basis to conclude that they lack the mental capacity to comprehend the consequences of their decision to refuse medication that poses a significant risk to their physical well-being").

41 *E.g.*, Letter from Paul Litwak, N.Y.S. Office of Mental Health, to Gerald Crotty, Counsel to the Governor (June 21, 2018); Memorandum from Jay M. Cohen, N.Y.S. Division of Criminal Justice Services, to Matthew T. Crosson (June 19, 1984); Memorandum in Support, From Robert B. Tierney, City of New York Office of the Mayor (included in N.Y. Laws 1984, ch. 668 legislative bill jacket).

42 Bonita M. Veysey, Gender Role Incongruence and the Adjudication of Criminal Responsibility, 78 Alb. L. Rev. 1087, 1088 (2014-2015) (citing Eric Silver et al., Demythologizing Inaccurate Perceptions of the Insanity Defense, 18 Law & Hum. Behav. 63 (1994)).

cases, and that, when invoked, it is rarely successful.[43] While research varies widely, some studies conclude that the defense succeeds in only one out of four cases, while others have found a success rate as low as one in 1,000.[44] New York State does not track how often the defense is invoked, but the Department of Criminal Justice Statistics reports that over the five-year period from 2013-2017, only 11 defendants, out of 19,041 felony and misdemeanor trials statewide, were found not responsible by reason of mental disease or defect after a trial. During the same five-year period, 241 defendants entered a plea of not responsible, compared to 1,375,096 convictions for felonies and misdemeanors.[45] According to the Office of Mental Health, as of June 30, 2018, 260 insanity acquittees were in secure confinement and 452 were in the community subject to orders of conditions. Meanwhile, as of 2016, approximately 20 percent of sentence-serving inmates in New York State correctional facilities carried mental health diagnoses that required Office of Mental Health services.[46] In other words, based on a reported total

43 Lisa A. Callahan et al., The Volume and Characteristics of Insanity Defense Pleas: An Eight-State Study, 19 Bull. Am. Acad. Psychiatry & L. 331, 334-35 (1991); Jeffrey S. Janofsky, MD, et al., Defendants Pleading Insanity: An Analysis of Outcome, 19 Bull. Am. Acad. Psychiatry & L. 203, 205-07 (1989).

44 Henry F. Fradella, *From Insanity to Beyond Diminished Capacity: Mental Illness and Criminal Excuse in the Post*-Clark *Era*, 18 U. Fla. J.L. & Pub. Pol'y 7, 11-12 (2007) (citing a success rate of under 25 percent); Heather Leigh Stangle, *Murderous Madonna: Femininity, Violence, and the Myth of Postpartum Mental Disorder in Cases of Maternal Infanticide and Filicide*, 50 Wm. & Mary L. Rev. 699, 728 (2008) (citing a success rate of 1 in 1,000 criminal trials); Stephen G. Valdes, Comment, *Frequency and Success: An Empirical Study of Criminal Law Defenses, Federal Constitutional Evidentiary Claims, and Plea Negotiations*, 153 U. Pa. L. Rev. 1709, 1723 (2005) (citing success rates ranging from 0.87 percent to 26 percent).

45 Division of Criminal Justice Services, emails dated April 9, 2018 (on file with authors).

46 N.Y.S. Corrections and Community Supervision, Under Custody Report: Profile of Under Custody Population as of January 1, 2016, at 25, http://www.doccs.ny.gov/Research/Reports/2016/UnderCustody_Report_2016.pdf.

prison population of 51,000, over 10,000 inmates receive services from Office of Mental Health.[47]

The insanity defense's low usage rates paired with the high incidence of mental illness in prisons raises a question: why are more defendants not invoking a defense that would send them to treatment instead of prison? First, the overall low success rate may deter defendants from interposing the defense. Second, defendants pay a penalty for arguing insanity and losing.[48] Defendants whose insanity defenses are unsuccessful—which, as noted above, represents the vast majority of those who raise it at trial—receive significantly longer sentences than those who are convicted without having argued insanity.[49] Third, defendants may be unwilling to assert the defense because they decline to accept a mental illness diagnosis. Fourth, as discussed in the next section, New York's civil commitment system may itself deter defendants with viable insanity defenses from raising them. For example, defendants acquitted based on insanity may remain confined for longer than the maximum term of the prison sentence they would have served if

47 *See id*.; Emily Masters, *By the Numbers: New York's Prison Population*, TIMES UNION, Sept. 21, 2017, https://www.timesunion.com/news/article/By-the-numbers-New-York-s-prison-population-12216340.php.

48 Fatma Marouf, *Assumed Sane*, 101 Cornell L. Rev. 25, 30 (2016).

49 Michael L. Perlin, Myths, Realities, and the Political World: The Anthropology of Insanity Defense Attitudes, 24 Bull. Am. Acad. Psychiatry & L. 5, 12 (1996); Michael L. Perlin, Unpacking the Myths: The Symbolism Mythology of Insanity Defense Jurisprudence, 40 Case W. Res. L. Rev. 599, 650 (1990); Joseph Rodriguez et al., The Insanity Defense Under Siege: Legislative Assaults and Legal Rejoinders, 14 Rutgers L.J. 397, 40102 (1983).

convicted.[50] In the words of Charles P. Ewing, forensic psychologist, lawyer and professor at Buffalo Law School, "You have to be crazy to plead insanity . . . and I say that because the consequences are so grave."[51]

Get Out of Jail Free? Criminal Procedure Law § 330.20

Whether the insanity defense should be reformed cannot be considered absent an examination of what happens to an individual after an insanity acquittal. The retention, care, treatment, and release of persons found not responsible of crimes after successfully invoking the insanity defense is a complex process involving the balancing of individual liberties and the protection of society.[52] In New York, the current procedures that follow a verdict or plea of not guilty by reason of mental disease or defect were enacted in 1980[53] following a study by the New York State Law Revision Committee and to comply with the constitutional mandates of *Matter of Torsney*.[54]

In *Matter of Torsney,* the Court of Appeals held that, because insanity acquittees lack criminal culpability, "[b]eyond automatic commitment . . . for a reasonable period to

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50 Mac McClelland, *When Not Guilty Is a Life Sentence*, N.Y. TIMES MAG., Sept. 27, 2017, https://www.nytimes.com/2017/09/27/magazine/when-not-guilty-is-a-life-sentence.html; *People v. D.D.G.*, 27 Misc. 3d 1224(A), 911 N.Y.S.2d 694 (Sup. Ct., Queens Co., 2010). In determining whether to release a defendant from custody following an adjudication of not guilty by reason of mental disease or defect, "a court may consider … the length of confinement and treatment [and] the lapse of time since the underlying criminal acts" (internal citations omitted). In this case, defendant was released after more than 20 years of confinement, but the length of confinement was not the only factor the court considered, and standing alone would have been insufficient to secure his release.

51 Russ Buettner, *Mentally Ill, but Insanity Plea Is a Long Shot*, N.Y. TIMES, April 3, 2013, https://www.nytimes.com/2013/04/04/nyregion/mental-illness-is-no-guarantee-insanity-defense-will-work-for-tarloff.html; *see, e.g*., Michael Perlin, *The Borderline Which Separated You from Me: The Insanity Defense, the Authoritarian Spirit, the Fear of Faking, and the Culture of Punishment*, 82 Iowa L. Rev. 1375 (1997); Mac McClelland, *When 'Not Guilty' Is a Life Sentence*, N.Y. TIMES MAG., Sept. 27, 2017, https://www.nytimes.com/2017/09/27/magazine/when-not-guilty-is-a-life-sentence.html.

52 Barbara E. McDermott et al, The Conditional Release of Insanity Acquittees: Three Decades of Decision-Making, 36 J. Am. Acad. Psychiatry & L. 329 (2008).

53 In Defense of Insanity in New York State, 1980 Report of N.Y. Law Rev. Comm'n, Reprinted in 1961 McKinney's Session Laws of N.Y.

54 47 N.Y.2d 667, 420 N.Y.S.2d 192 (1979).

determine [acquittees'] present sanity, justification for distinctions in treatment between persons involuntarily committed under the Mental Hygiene Law and persons committed under CPL § 330.20 draws impermissibly thin."[55] Nevertheless, due to a judicially imposed presumption that the defendant acquitted by reason of mental disease or defect is perpetually dangerous, in practice the CPL § 330.20 commitment scheme has become "increasingly onerous, bearing little resemblance to [Mental Hygiene Law] article 9 (civil) commitments."[56]

Stages of the Proceeding

"Track status, as determined by the initial commitment order, governs the acquittee's level of supervision in future proceedings and may be overturned only on appeal from that order, not by means of a rehearing and review."[57] Following an insanity verdict or plea, the trial judge must immediately order a psychiatric examination of the defendant, to be followed by an initial hearing to determine the acquittee's mental condition.[58] This hearing, in which the district attorney continues to participate, determines the level of judicial and prosecutorial involvement in future decisions concerning the acquittee's confinement, transfer and release.[59] Based on its findings at the

55 *Id*. at 674-75.

56 Sheila E. Shea & Robert Goldman, *Ending Disparities and Achieving Justice for Individuals with Mental Disabilities*, 80 Alb. L. Rev. 1037, 1089 (2016/2017) (citing *In re Torsney*, 47 N.Y.2d 667, 420 N.Y.S.2d 667 (1979)).

57 *In re Norman D.*, 3 N.Y.3d 150, 152, 785 N.Y.S.2d 1 (2004). As observed by the Court of Appeals in *In re Norman D.*, "track one status is significantly more restrictive than track two status." *Id*. at 155.

58 CPL § 330.20(2)-(6).

59 *In re Brian HH*, 39 A.D.3d 1007, 1009, 833 N.Y.S.2d 718 (3d Dep't 2007).

initial hearing the court then assigns the acquittee to one of the three "tracks."[60] Track-one acquittees are those found by the trial judge to suffer from a dangerous mental disorder that makes them "a physical danger to [themselves] or others."[61] Track-two acquittees are mentally ill, but not dangerous,[62] while track-three acquittees are neither dangerous nor mentally ill.[63]

The trial judge must issue a commitment order consigning track-one defendants to the custody of the Commissioner for confinement in a secure facility for care and treatment for six months.[64] A court order is thereafter required for any transfer to a non-secure facility, off-ground furlough, release or discharge. The district attorney's office continues to be notified of, and may participate in, further court proceedings involving the defendant's retention, care and treatment.[65]

Track-two defendants are ordered into the Commissioner's custody for detention in a non-secure (civil) facility, subject to an order of conditions.[66] The order committing a track-two defendant is deemed made pursuant to the Mental Hygiene Law rather than section 330.20; concomitantly, subsequent proceedings regarding retention, conditional release or discharge of a track-two defendant are generally governed by articles 9

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60 *In re Norman D*, 3 N.Y.3d at 154. The "track" nomenclature does not appear in CPL § 330.20 but is derived from the Law Revision Commission report that accompanied the proposed legislation, which states that "[t]he post-verdict scheme of proposed CPL § 330.20 provides for three alternative 'tracks' based upon the court's determination of the defendant's mental condition at the time of [the initial] hearing." (1980 Report at 2265).

61 CPL § 330.20(1)(c), (6).

62 CPL § 330.20(1)(d), (6), (7).

63 CPL § 330.20(7); *People v. Stone*, 73 N.Y.2d 296, 539 N.Y.S.2d 718 (1989).

64 CPL § 330.20(1)(f), (6). The "Commissioner" taking custody of the acquittee may be the Commissioner of the Office of Mental Health or the Commissioner of the Office for People with Developmental Disabilities (OPWDD).

65 *Id.*

66 CPL § 330.20(1)(o), (7).

(mentally ill) or 15 (developmentally disabled) of the Mental Hygiene Law.[67] Track-three defendants are discharged either unconditionally or, in the judge's discretion, with an order of conditions.[68]

Although the statute is silent as to the quantum of proof needed to satisfy the court in a post-insanity-acquittal commitment proceeding, in *People v. Escobar* the Court of Appeals declined to apply the clear and convincing evidentiary standard that governs other civil commitment proceedings, instead applying the preponderance of the evidence standard.[69]

The most onerous aspect of the statutory scheme is the "recommitment" process, which is used to return outpatient acquittees to inpatient status in the event of psychiatric decompensation. As interpreted by the Court of Appeals, an acquittee on conditional release can be committed to secure confinement under the Criminal Procedure Law without the enhanced procedural due process protections afforded to people subject to civil hospitalization under section 9 of the Mental Hygiene Law even if at the initial hearing the defendant was found not dangerous and placed in track two or three.[70] In other words, a defendant who was not committed to begin with can nevertheless be

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67 CPL § 330.20(7); *People v. Flockhart*, 96 A.D.2d 843, 465 N.Y.S.2d 601 (2d Dep't 1983); *In re Jill ZZ*, 83 N.Y.2d 133, 608 N.Y.S.2d 161 (1994). Notwithstanding the statutory requirement that the "conditional release or discharge" of the track two defendant shall be in accordance with the provisions of the Mental Hygiene Law, the Court of Appeals held in *In re Jill ZZ* that the conditional release of the track two defendant shall be subject to a CPL order of conditions.

68 CPL § 330.20(1)(n). A discharge order is defined as an order terminating an order of conditions or unconditionally discharging a defendant from supervision under the provisions of section 330.20. An order of conditions is "an order directing a defendant to comply with [the] prescribed treatment plan, or any other condition which the court determines to be reasonably necessary or appropriate, and, in addition, where a defendant is in custody of the commissioner, not to leave the facility without authorization." CPL § 330.20(1)(o). *See also* CPL § 330.20(12). Orders of conditions are valid for five years and may be extended for additional five-year periods indefinitely upon a mere finding of "good cause shown." CPL § 330.20(1)(o); *In re Oswald N.*, 87 N.Y.2d 98, 637 N.Y.S.2d 949 (1995).

69 61 N.Y.2d 431, 440, 474 N.Y.S.2d 453 (1984).

70 *People v. Stone*, 73 N.Y.2d 296, 539 N.Y.S.2d 718 (1989).

"recommitted" under CPL § 330.20. Appellate courts in New York have been completely unpersuaded that the initial findings of a criminal court placing defendants in one of the three available "tracks" have any constitutional significance.[71] "All such persons have committed criminal acts, and this underlies the permissible distinction between them and all others."[72] Federal constitutional challenges to the New York statutory scheme have to date failed, albeit narrowly.[73]

In 1995, in *In re George L.*,[74] the Court of Appeals determined that section 330.20 does not constrain a court to determining dangerousness as of the time when the hearing is conducted.[75] Instead, the Court held that the State was permitted to engage in a presumption that the causative mental illness continues beyond the date of the criminal conduct.[76] Stated another way, *George L.* adopted a presumption that the mental illness that led to the criminal act continues after the plea or verdict of not responsible and that assessments of dangerousness should not be limited to a point in time, but rather should be contextual and prospective in nature.[77] Further, the presumption of dangerousness continues, in fact, and is not extinguished by a subsequent finding that the defendant no longer suffers from a dangerous mental disorder.[78] Thus, despite the Court's admonition in *In re Torsney* that the Constitution requires insanity acquittees to be treated like people involuntarily confined in

71 *In re Zamichow*, 176 A.D.2d 807, 575 N.Y.S.2d 327 (2d Dep't 1991).
72 *Id*., citing Jones v. United States, 463 U.S. 354, 364-65 (1982).
73 *See Francis S. v. Stone*, 221 F.3d 100, 112 (2d Cir. 2000).
74 *In re George L.*, 85 N.Y.2d 295, 624 N.Y.S.2d 99 (1995).
75 *Id.*
76 *Id.*
77 *Id.*
78 *Francis S. v. Stone*, 221 F. 3d 100, 112 (2000). The Second Circuit observed that a track two defendant's equal protection argument that following his release he could not be recommitted to a secure hospital under the provisions of the Criminal Procedure Law had "considerable force," but denied habeas relief because of the restricted scope of review imposed on federal courts. His claim was premised upon two prior explicit state court findings in his case that he did not suffer from a dangerous mental disorder.

the civil context, the Court has since that time consistently advanced restrictive interpretations of section 330.20 that lead to longer stays and a low burden of proof on the state and district attorneys to keep insanity acquittees confined.

Length of Stay

In addition to the judicial interpretations of CPL § 330.20 discussed above, Office of Mental Health policy has led to an increase in length of stay for confined acquittees. Over time, OMH has become "increasingly risk averse."[79] Lengths of stay have become longer for people committed under the CPL despite the fact that the length of hospitalization has little or no effect on re-arrest.[80] In fact, research indicates that insanity acquittees re-offend at a lower rate than prisoners.[81] Further, statistical trends demonstrate that the while the number of not responsible admissions to hospitals in New York State declined over the past three decades from a high of 77 in 1982 to a low of 22 in 2008, the length of hospitalization of these individuals has increased significantly.[82] More than 40 percent of those admitted in the 1980s were released into the community within seven years of admission.[83] In the 1990s, only 21 percent of the admissions were released into the community within seven years.[84] By the year 2000, only eight percent of admissions were released within a seven-year period.[85] As of June 30, 2018, 452 insanity acquittees were

79 Richard Miraglia & Donna Hall, The Effect of Length of Hospitalization on Re-arrest Among Insanity Plea Acquittees, 39 J. Am. Acad. Psychiatry & L. 524, 526 (2011).

80 *Id*.

81 *See* Debbie Green et al., Factors Associated with Recommitment of NGRI Acquittees to a Forensic Hospital, 32 Behav. Sci. & L. 608, 608 (2014).

82 Richard Miraglia & Donna Hall, *The Effect of Length of Hospitalization on Re-arrest Among Insanity Plea Acquittees,* 39 J. Am. Acad. Psychiatry & L. 524, 524 (2011), *citing* Office of Mental Health: Legally Oriented Forensic Tracking System (LOFTS), Division of Forensics, Albany, NY: N.Y. State Office of Mental Health, 2007.

83 *Id*.

84 *Id.*

85 *Id.* at 524-25.

subject to orders of conditions. From 2015-2017, approximately 20 insanity acquittees per year were released from orders of conditions. And from 2015 to 2017, approximately 30 acquittees per year were released from secure confinement to an order of conditions.

Unlike in other states, the maximum term to which an acquittee could have been sentenced does not limit the time that an acquittee may be confined at a secure forensic facility or subject to an order of conditions. In other words, a defendant whose maximum sentence would have been five years can be confined and/or subject to an order of conditions for the rest of his life. As aptly noted by one commentator, if one asks the question what happens after a defendant successfully invokes the insanity defense, "often the answer is involuntary confinement in a state psychiatric hospital—with no end in sight."[86]

In sum, once a defendant has been acquitted based on insanity and thereby adjudged to lack criminal culpability, she faces indefinite detention that can exceed the maximum time for which she could have been imprisoned. She enters an increasingly risk averse milieu that has enforced an increasing length of confinement despite falling admissions.[87] Even if she is initially determined not to be dangerous and assigned to tracks two or three, she remains subject to re-classification and re-commitment. Once she is placed in secure confinement, even if her Office of Mental Health treatment team at the forensic psychiatric facility recommends her transfer to a civil hospital on an order of

86 Mac McClelland, *When 'Not Guilty' Is a Life Sentence, supra*, N.Y. TIMES MAG., Sept. 27, 2017.

87 *Id.* "The question … 'becomes one of risk tolerance. America has become—to an extreme level that's almost impossible to exaggerate—a risk-intolerant society.' Fears of people with mental illness persist, even though, according to the best estimates, only 4 percent of violent acts in the United States are uniquely attributable to serious mental illness." *Id*.; Richard Miraglia & Donna Hall, *The Effect of Length of Hospitalization on Re-arrest Among Insanity Plea Acquittees*, 39 J. Am. Acad. Psychiatry & L. 526 (2011).

conditions, the district attorney can object and, if the trial or appellate court agrees with the district attorney, override the judgment of the treatment team.

Conclusion

Penal Law § 40.15 and the post-acquittal commitment scheme under Criminal Procedure Law § 330.20 deserve close examination with an eye toward reform. The insanity defense remains essentially unchanged since the reign of King George III and appears insufficient to address the prevalence of mental illness in the prison population or take account of the fact that mental illness is not a an all-or-nothing condition. Meanwhile, the commitment scheme that follows an insanity acquittal appears to have compensated for a drop in the number of insanity acquittal admissions by moving consistently toward longer periods of confinement, in the face of evidence that longer confinement is not correlated with reduced risk of violent recidivism. A defendant who is acquitted based on insanity faces indefinite detention that may continue past the maximum criminal sentence, regardless of the opinions of his treatment team. It is little wonder the defense is so rarely invoked.

Given that approximately 10,000 state prisoners receive services from the Office of Mental Health, the question whether the insanity defense and attendant civil commitment scheme can be revised to better serve the goals of public safety, effective treatment of the mentally ill, efficient expenditure of public funds, and punishment of only morally culpable behavior is of paramount importance. Though New York's system is entrenched, some legislative action may be straightforward. For example, fairness and reason suggest that the length of time for which an acquittee can be confined or subject to an order of conditions should be limited to the maximum sentence that person could have served had he or she

been convicted.[88] After the expiration of the maximum sentence, the patient would be transferred to a civil hospital subject to the civil confinement regime of Mental Hygiene Law Article 9 that governs individuals said to present a risk of serious physical harm to themselves or others.[89]

Nor is New York's restrictive approach to post-acquittal confinement the only model for insanity acquittees. In Tennessee, for example, 45 percent of insanity acquittees are never civilly committed; instead they are treated on an outpatient basis, and the average length of confinement is two years.[90] Its recidivism rates have not changed since it changed its approach to insanity acquittees.[91]

On the other hand, it is also possible that the large-scale incarceration of mentally ill individuals may be most effectively addressed through alternative means. In response to an inquiry from the authors of this report, multiple chief defenders stated that they often prefer to find alternative resolutions to the insanity plea for defendants with mental health issues, such as adjournments in contemplation of dismissal with mental health treatment requirements. And mental health courts have shown promise in diverting defendants with mental health issues to treatment.[92] But only 27 such problem-solving courts operate in New York, and they are inconsistent in their diagnostic techniques and in matching the

88 *See* Warren J. Ingber, Note, Rules for an Exceptional Class: The Commitment and Release of Persons Acquitted of Violent Offenses by Reason of Insanity, 57 N.Y.U. L. Rev. 281, 295-96 (1982).

89 *Cf.* C.P.L. § 730.70 (upon expiration of incapacitated defendant's legal status under CPLR Article 730, MHL Article 9 may be invoked if the patient is alleged to require continued inpatient care and treatment).

90 Mac McClelland, *When 'Not Guilty' Is a Life Sentence*, *supra,* N.Y. TIMES MAG., Sept. 27, 2017.

91 *Id.*

92 *See generally* Carol Fisler, Toward a New Understanding of Mental Health Courts, Judges J. 54:2, 8-13 (Spring 2015).

intensity of the intervention to the intensity of the risk.[93] Alternatives to the insanity defense should therefore also be reviewed to identify successful models to serve as bases for statewide training efforts or legislative action.

It is, however, beyond the scope of this report or the resources of this subcommittee to undertake the inquiries or action outlined above. Such inquiries and action should include a diversity of views, including not only indigent defense counsel, but also prosecutors and advocates for persons with mental illnesses, among others.

This report addresses only one of the myriad issues at the intersection of law and mental health. For example, the root problems of pervasive stigmatizing language and bias suggest the necessity of efforts to examine the Mental Hygiene Law, as well as other bodies of law, to replace such terms as "mental hygiene" with less stigmatizing language, and to educate the courts and the bar on person-centered language.[94] Furthermore, issues like the funding of community-based treatment, the way mental health issues are addressed in schools and other social institutions, and the limitation of the constitutional rights of people with mental illnesses go to the very heart of our societal structure and deserve sustained focus.

Recommendation

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93 *Problem Solving Courts: Mental Health Courts Overview*, New York State Unified Court System (January 26, 2017), https://www.nycourts.gov/courts/problem_solving/mh/home.shtml; *New York State Mental Health Courts: A Policy Study*, Josephine W. Hahn, Center for Court Innovation, Dec. 2015, at 11.

94 *See* Laws of 2007, Chapter 455, as amended by Laws of 2010, Chapter 168, § 48. *And see, e.g.*, Washington State Access to Justice Board Impediments Committee, ENSURING EQUAL ACCESS FOR PEOPLE WITH DISABILITIES: A GUIDE FOR WASHINGTON COURTS (2006), at 27, 40, available at https://www.kingcounty.gov/~/media/exec/civilrights/documents/WAcourtaccess.ashx [last visited Oct. 3, 2018]; Center for Disease Control, "Communicating With and About People with Disabilities," available at https://www.cdc.gov/ncbddd/disabilityandhealth/pdf/disabilityposter_photos.pdf (last visited Oct. 3, 2018).

The Committee on Mandated Representation therefore recommends that the New York State Bar Association form a standing Mental Health Committee or Task Force to address large-scale issues that do not fit within a single Section or Committee's purview. While it is true that other Sections and Committees, including the Committee on Disability Rights, the Mental Health Subcommittee of the Elder Law and Special Needs Section, and the Lawyer Assistance Committee focus on mental health issues as they relate to that Section or Committee's mandate, none of them is poised to address the broad range of issues raised here. So long as effective communication is established among the existing mental health Sections and Subcommittees and the proposed mental health Committee or task force, there is little risk of inefficiency. In the words of Professor Perlin:

> Mental Disability is no longer—if it ever was—an obscure subspecialty of legal practice study. Each of its multiple strands forces us to make hard social policy choices about troubling social issues—psychiatry and social control, the use of institutions, informed consent, personal autonomy, the relationship between public perception and social reality, the many levels of "competency," the role of free will in the criminal law system, the limits of confidentiality, the protection duty of mental health professionals, the role of power in forensic evaluations. These are all difficult and complex questions that are not susceptible to easy, formulistic answers.[95]

Mental illness is often raised in the public consciousness only in association with tragedy, whether it be a person who takes their own life, a person who is killed by others due to illness-driven behavior, or a person whose illness-driven behavior leads to the death

95 Michael L. Perlin, "*Half-Wracked Prejudice Leaped Forth:" Sanism, Pretextuality, and Why and How Mental Disability Law Developed as It Did*, 10 J. Contemp. Legal Issues 3, 31 (1999) (quoting Michael L. Perlin, The Jurisprudence of the Insanity Defense (1994)). For articles covering the dementia crisis, see the January 2017 issue of the New York State Bar *Journal*.

or injury of others. At the same time, the stigma that has long attached to mental illness is now breaking. High-profile athletes, celebrities, and attorneys have publicly acknowledged their struggles with mental illness, shining a welcome light on the issue.[96] That light has begun to eradicate the notion that mental illness is somehow "unclean" -- an archaic attitude enshrined in the name of the Mental Hygiene Law itself. New York has long been a leader in the care of its most vulnerable citizens. A Mental Health Committee or Task Force can help ensure that the law does not further stagnate and that the promise of the New York State Constitution to care for and support those in need is fulfilled.[97]

96 *See, e.g.*, Joseph Milowic III, *Quinn Emanuel Partner Suffers from Depression and He Wants Everyone to Know It*, N.Y. L.J., Mar. 28, 2018, https://www.law.com/newyorklawjournal/2018/03/28/quinn-emanuel-partner-suffers-from-depression-and-he-wants-everyone-to-know/?slreturn=20180610150658; Brian Windhorst, *Cavaliers Coach Tyronn Lue Says He's Being Treated for Anxiety*, ESPN.com, May 31, 2018, http://www.espn.com/nba/story/_/id/23659954/cleveland-cavaliers-coach-tyronn-lue-reveals-being-treated-anxiety; Ruth C. White, *No Stigma, No Shame: Breaking the Silence of Mental Illness*, PSYCHOL. TODAY, May 2, 2016, https://www.psychologytoday.com/us/blog/culture-in-mind/201605/no-stigma-no-shame-breaking-the-silence-mental-illness.

97 This report was aided greatly by information and assistance from Mardi Crawford and the New York State Defenders Association, Professor Michael Perlin, the Office of Mental Health, the Division of Criminal Justice Statistics, and the staff of the New York State Bar Association.

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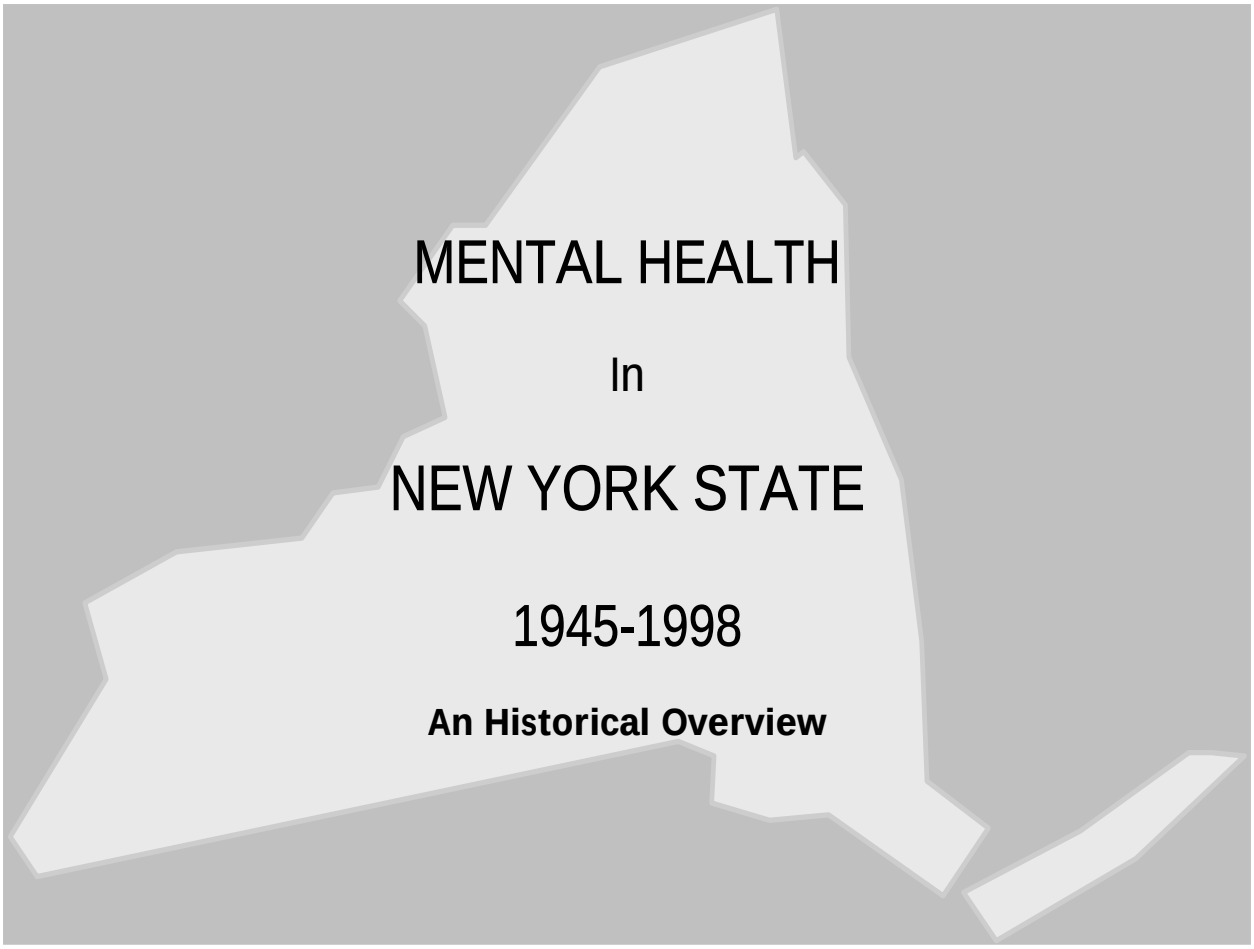

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An Historical Overview

Introduction

New York State has for more than one hundred years been a pioneer in the development of mental health treatment and research. Although it was not the first state to construct state-supported institutions specifically for the mentally ill, it was the first completely to relieve county and city governments of the burden of caring for their mentally ill inhabitants; the 1890 State Care Act, which placed all responsibility for the care and treatment of those suffering from mental disorders in the hands of state government, was emulated by a number of other states in subsequent years. The landmark 1954 Community Mental Health Services Act (CMHSA), which was born of the state's desire to divest itself of some of this responsibility, and policymakers' subsequent efforts to compel localities to improve care and to insure that the needs of the seriously mentally ill were being met also anticipated developments in other states and at the federal level.

The reasons for the state's consistent willingness to embrace innovation are obscure, but they may stem in part from the state's large size and, in the New York City metropolitan area, population density. Gerald Grob, the leading historian of mental health policy in the United States, asserts that the development of state mental institutions was but one of many responses to industrialization, urbanization, and immigration, which rendered ineffective the personal relationships and local social institutions that had during the nation's agrarian past cared for the needy.[1] New York State was among the first states to experience these sweeping changes, and as a result the need to devise effective responses to them arose sooner than it did elsewhere. In addition, New York State's demographic characteristics may have exacerbated the problems arising from past policy decisions; for example, policymakers' support for community-based mental health programs was in large part rooted in their awareness that New York State had the largest number of institutionalized people in the nation and fear that state hospital populations and costs would continue swelling.

New York State has also been unusually rich in the cultural resources and political will needed to develop and implement bold reforms. Grob notes that most nineteenth-century efforts to alter American mental health policy originated in the populous Northeast, which dominated the nation's cultural and intellectual life.[2] Although New York State does not seem to have had a nineteenth-century agitator as prominent as Dorothea Dix, the Massachusetts activist who fought to compel state governments to assume responsibility for the care of the mentally ill, it has had more than its share of individuals and organizations dedicated to improving the care of the mentally ill. A number of important national advocacy organizations such as the National Committee for Mental Hygiene (a forerunner of the National Association for Mental Health) were headquartered in New York City and were thus well placed to influence state policy decisions. In addition, New York State has long been known as a laboratory of political reform. Mental-health advocacy groups working in the state have consistently found governors and state legislators to be far more receptive to change than their counterparts in many other parts of the

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[1]Gerald N. Grob, The Mad Among Us: A History of the Care of America's Mentally Ill (Cambridge: Harvard University Press, 1994), 40, 43, 47-48.
[2]Grob, The Mad Among Us, 43.

United States. However, the state's politicians, like their counterparts elsewhere, have seldom been motivated solely by the desire to do good. Advocates of change have consistently been most successful when they have been able simultaneously to appeal to lawmakers' altruism, fiscal conservatism, and yearning for efficient solutions to bedeviling social problems; for example, the postwar push for community-based treatment and preventative care won adherents because it held out the promise of simultaneously slashing expenditures and reducing human suffering.

The report that follows presents an overview of the complex and often tense relationships that existed between and within the mental health professions, voluntary agencies and political activists, and state and federal politicians. It does not pretend to be definitive, and it deliberately avoids two powerful historiographical traditions that guide many studies of mental health treatment and policy. The first of these traditions, which began taking shape in the late nineteenth century and came of age in the 1940's and 1950's, asserts that state mental institutions are miserable warrens of neglect and suffering. The second, which emerged in the 1960's and continues to inform the arguments of many historians and sociologists, views mental institutions and the very concept of mental illness as means of controlling those who refuse to accept the mental and moral discipline of modern civilization. It seeks primarily to identify the individuals and organizations that shaped mental health policy in New York State, to assess how they interpreted the problems that confronted them, to uncover the mechanisms through which policy was implemented, and, in instances in which policy decisions were particularly ill-informed or inappropriate, to point out these failures. Important as they are, questions of whether state mental hospitals were (or are) inherently bad and whether policymakers were (or are) consciously or unconsciously trying to shore up the social order are in many respects tangential to this endeavor.

The Policy Revolution, 1945-65

Between the enactment of the State Care Act and the passsage of the CMHSA, the government of New York State was almost exclusively responsible for the care of the mentally ill. However, a number of important changes took place during this sixty-year period. During the first decades of the twentieth-century, a growing number of Progressive-era psychiatrists were no longer content to see themselves as state hospital-based purveyors of custodial care and began envisioning a broader role for themselves. Rejecting the nineteenth-century belief that mental illness was biologically based and typically incurable and that psychiatrists' chief responsibility was to furnish humane custodial care, they sought to reestablish psychiatry's ties to the medical profession and adopt its therapeutic orientation. They also sought to bring their expertise to bear upon a broad array of social problems such as alcoholism and venereal disease. Seeing these ills as manifestations of mental disorder, they asserted that safeguarding individual and social mental hygiene would ultimately eradicate these vexing problems. The psychiatrists drawn to the mental hygiene movement, which was spearheaded by the Manhattan-based National Committee for Mental Hygiene (NCMH), were convinced that mental illness had a hereditary component and had little faith in their power to cure it once it had developed.[3] At the

[3]The NCMH was founded in 1909 by psychiatrist Adolf Meyer and Clifford Beers, a Yale University graduate who had been institutionalized for a short period of time. At first, it devoted most of its energies to improving conditions in state hospitals, but within ten years of its foundation focused chiefly upon preventative programs and comprehensive studies of mental illness and treatment; see Gerald N. Grob, Mental Illness and American Society, 1875-1940 (Princeton: Princeton University Press, 1983), 147-66. In 1950, the NCMH merged with the Psychiatric Association, the fundraising division of the American Psychiatric

same time, they were confident that those predisposed to develop mental disorders could remain healthy if they learned how to respond appropriately to their environment; as a result, champions of mental hygiene believed that teaching adults and, in particular, children how to negotiate adverse personal and social circumstances could help to prevent many (generally less serious) forms of mental illness.[4] The psychiatrists who gravitated toward the movement were also confident in their ability to work in concert with social workers, psychologists, occupational therapists, and other professionals who could help to improve people's mental adjustment; however, by the 1930's many of them felt that these other professionals were challenging their authority and expertise.[5]

The activities of those drawn to the mental hygiene movement were varied. The leaders of the NCMH and other mental hygiene organizations were like other Progressive-era reformers in that they were convinced that scientific study of social problems would highlight potential remedies and force policymakers and the public to take action. As a result, these groups sponsored a number of local studies of mental illness and treatment options; however, their firm belief that mental illness was preventable often overcame their objectivity.[6] They also undertook an ambitious and remarkably successful effort to convince social workers, parent-education groups, and teachers that children were vulnerable to mental illness and that intellectual accomplishment should not come at the expense of personality development.[7] In addition, mental-hygiene organizations spurred the creation of a number of community-based mental health programs, which were sponsored by Community Chest groups, private foundations such as the Rockefeller Foundation, the Laura Spellman Rockefeller Memorial Fund, the Milbank Memorial Fund and the Commonwealth Fund, the State Charities Aid Association, medical schools, and, in some urban areas, city governments.[8] Information about specific programs is

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Association (APA), and the National Mental Health Foundation, an outgrowth of the federal government's wartime Mental Hygiene Program of the Civilian Public Service, and became the National Association for Mental Health. The association was supported largely through grants from the Rockefeller Foundation; see Theresa R. Richardson, The Century of the Child: The Mental Hygiene Movement and Social Policy in the United States and Canada (Albany: State University of New York Press, 1989), 155-57.

[4]Grob, Mental Illness and American Society, 144-45, 166-71. Grob notes that the emphasis that psychiatrists within the mental hygiene movement placed upon the preventability of mental illness kept most of them from embracing the less savory aims of some of the movement's other adherents: compulsory sterilization of the mentally ill and developmentally disabled and harsh immigration restrictions designed to keep southern and eastern Europeans out of the country.

[5]Grob, Mental Illness and American Society, 243-65, details the emergence of psychiatric social work, psychology, and occupational therapy and the increasing tension that characterized their relations with the psychiatric profession.

[6]Grob, The Mad Among Us, 156. For an example of the kind of social research undertaken by those active in the mental hygiene movement, see Elizabeth Greene, George K. Pratt, Stanley P. Davies, and V.C. Branham, Report of a Survey of Mental Hygiene Facilities and Resources in New York City (New York: National Committee for Mental Hygiene and New York City Committee on Mental Hygiene, State Charities Aid Association, 1929).

[7]Sol Cohen, "The Mental Hygiene Movement, the Development of Personality and the School: The Medicalization of American Education," History of Education Quarterly 23 (Summer 1983): 124-25, 128-39. By the 1950's, pedagogical theorists had embraced mental-hygienist ideas so fervently that the movement itself no longer existed within educational circles; the movement was a victim of its own success.

[8]Community Chest organizations were peacetime outgrowths of the War Chest charity federations that were formed in order to relieve domestic hardship during the First World War. Like their parent bodies, they were federations that solicited corporate as well as individual contributions. After the Second World War, many Community Chest federations joined forces with the Red Cross and other organizations that were not chiefly concerned with assisting the needy and became United Funds. The federations' adoption of their current name, the United Way, came sometime afterward. For a brief history of the origins of Community Chests, see Community Surveys, Inc., of Indianapolis, Community Chest: A Case Study in Philanthropy (Toronto: University of Toronto Press, 1957), 20, 266-67. For information about the philanthropic foundations that supported mental-hygiene programs, see Richardson, The Century of the Child, 40-41. The New York State Charities Aid Association, which had since its formation in 1872 worked to improve state asylum conditions, created a New York City Committee on Mental Hygiene in 1927. The association, now known as the State Communities Association, still exists and still takes an active interest in state mental health policy; see, e.g., New York State Communities Aid Association, Mental Health at the Crossroads: The Case for

scant, but they existed in Albany and the New York City and it is probable that child guidance clinics and other mental hygiene initiatives took shape in other cities.[9]

Adherents of the mental hygiene movement also sought to alter public policy, and their success in gaining the attention of New York State's legislators is evident in the name given a state agency created in 1926: the Department of Mental Hygiene (DMH). The responsibilities of the DMH as it was first constituted were very modest: the agency was to "visit and inspect all institutions, either public or private, used for the care and treatment of" people who were mentally ill, epileptic, or mentally retarded.[10] However, in the following year the state's new Mental Hygiene Law gave the agency the responsibilities and overall structure that it would have for the next fifty years. It made the DMH responsible for the administration of all state-owned institutions caring for those with mental disorders and for insuring that all mentally ill, developmentally disabled, and epileptic New Yorkers received appropriate care. One provision of the Mental Hygiene Law further testified to the influence of the mental hygiene movement upon state policy: it mandated the creation of a DMH Division of Prevention, which was to monitor "psychiatric field work [and] after care and community supervision" of individuals discharged from state hospitals and perform other activities needed to avert the development of mental disorders.[11]

At the same time as psychiatric champions sought to expand their professional influence beyond the grounds of state mental hospitals, psychiatric activities within these institutions were changing substantially. The years between the First and Second World Wars witnessed the development of new therapies that initially seemed quite promising: fever therapy, which was developed during the 1920's, the surgical procedure known as prefrontal lobotomy, which emerged a decade later and seemed to promise an end to uncontrollable violence and a cure for at least some patients who were not helped by other therapies, insulin and metrazol shock therapies, which also came into use in the 1930's, and electro-convulsive treatment, which was used in the United States from the early 1940's onward and replaced insulin and metrazol as the shock treatment of choice. Psychiatrists were often extremely ambivalent about these therapies, which were drastic and poorly understood. Shock and surgical treatments sometimes produced modest or pronounced improvements, but even their leading proponents did not understand how or why they worked. This uncertainty aside, the aggressive therapeutic stance that underlay these therapies was a manifestation of psychiatrists' desire to prove themselves to be competent physicians.[12]

Psychiatric Rehabilitation (Albany: New York State Communities Aid Association, 1991). For the development of Charities Aid Associations across the nation, see Grob, The Mad Among Us, 131-32. For information about the New York City Committee on Mental Hygiene, see Greene, Pratt, Davies, and Branham, Report of a Survey of Mental Hygiene Facilities and Resources in New York City.

[9]Between 1945-59, the Community Chest of Albany and city social welfare organizations sponsored a program for children with emotional problems; see Stanley P[owell] Davies, Toward Community Mental Health: A Review of the First Five Years of Operations under the Community Mental Health Services Act of the State of New York (New York: New York Association for Mental Health, 1960), 63-64. As of 1939, the New York City's school system had a Bureau of Child Guidance that served children living in four of the city's boroughs; see Central Hanover Bank and Trust Company, Department of Philanthropic Information, The Mental Hygiene Movement: From the Philanthropic Standpoint (New York: Central Hartford Bank & Trust Co., 1939), 52.

[10]The DMH was created as a result of the constitutional reorganization of New York State government approved by the electorate in November 1925; see New York State Constitution (1925), art. 5, § 2, § 11. The DMH's inspection duties had formerly been assigned to the State Mental Hospital Commission and the State Commission for Mental Defectives, which ceased to exist in the wake of the government's reorganization.

[11]Mental Hygiene Law, Laws of New York (1927), Ch. 426, § 4.

[12]Grob, Mental Illness and American Society, 296-306.

As important as these therapeutic innovations were, they were not the only developments shaping psychiatrists' attitudes about state mental institutions. A number of phenomena taking place outside of the mental health field posed great difficulties for state hospital administrators and grave problems for their patients. The economic hardships of the Great Depression resulted in pervasive overcrowding, staff shortages, and deterioration of facilities' physical plants. These problems worsened throughout the Second World War, which siphoned resources and personnel away from state hospitals and other institutions serving the civilian population. After the war ended, this constellation of problems gave rise to a concerted professional and public campaign for improvement of hospital conditions.[13] Reformers had long been critical of the level of care furnished in most state mental hospitals, but after the end of the Second World War their condemnation of state institutions became increasingly vocal. Albert Deutsch, author of the classic postwar polemic, The Shame of the States, and other reformers who penned exposés of institutional conditions began calling not only for dramatic improvements in hospital conditions but a fundamental reevaluation of the role of state facilities in the care and treatment of the mentally ill.[14] Their writings, which almost uniformly depicted state hospitals as dens of great and pointless suffering, to this day exert lingering influence upon popular and scholarly conceptions of mental institutions.

Postwar lay reformers were not alone in questioning the existence of state mental hospitals. Psychiatrists themselves called for nothing less than a revolutionary change in the treatment of the mentally ill. The profession's prewar efforts to broaden its responsibilities and loosen its ties to state institutions came to full fruition as a growing number of its practitioners began denouncing mental hospitals. Psychiatrists who had treated military personnel suffering from combat-related mental illness found that this patient cohort responded best to immediate, short-term care furnished outside of the asylum environment. In addition, many of them shared the public's shock and revulsion at the dilapidation and overcrowding that existed in many state facilities. The combination of wartime therapeutic successes and disgust at existing institutional conditions led a growing number of psychiatrists to see traditional mental hospitals as inherently detrimental to patients. Convinced that the mental illnesses found in the civilian population were essentially identical to those suffered by military personnel and that state institutions were impeding effective treatment, they began stressing the environmental dimensions of mental disease and the efficacy of outpatient-based therapy and preventative care.[15]

The psychiatric profession's postwar shift toward environmental models of mental illness should not be exaggerated. Some practitioners remained convinced that mental disorders were biological in origin or that they were largely incurable, and the American Psychiatric Association (APA) and other psychiatric professional organizations endured bitter battles over theories of etiology, personality formation, behavioral motivation, and treatment models during the late 1940's and 1950's. Furthermore, even die-hard environmentalists embraced Thorazine and other new psychiatric drugs that appeared in the mid-1950's and shared the profession's belief that these new medicines would facilitate outpatient treatment.[16] Nonetheless, those dissatisfied with the traditional inpatient hospital and somatic theories about the etiology of mental illness were very much in the ascendant, and their influence is manifest in post-war legislative

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[13]Gerald N. Grob, From Asylum to Community: Mental Health Policy in Modern America (Princeton: Princeton University Press, 1991), 161-65.
[14] Albert Deutsch, The Shame of the States (New York: Harcourt, Brace, [1948]).
[15]Grob, From Asylum to Community, 8-23, 71-77.
[16]Grob, From Asylum to Community, 146-50.

developments.[17] Even before the end of the Second World War, reform-oriented mental health professionals such as Robert Felix, the head of the Public Health Service's Division of Mental Hygiene, began lobbying for federal funding of treatment of and research concerning mental illness.[18] The efforts of Felix and others gave impetus to the 1946 National Mental Health Act (NMHA), which sanctioned the disbursement of funds to researchers studying the etiology and treatment of mental illness, to institutions educating mental health professionals, and to states desiring to establish or maintain local mental health programs. The NMHA also provided for the establishment of a new division of the National Institute of Health, the National Institute for Mental Health (NIMH), which would be responsible for evaluating grant applications and monitoring funded projects; the NIMH was formally established in 1949, and Robert Felix served as its head from 1949-64.[19] The Hill-Burton Act, also passed in 1946, provided funds for construction of mental hospitals and psychiatric wings in general hospitals and thus further increased federal involvement in mental health care.[20]

Federal developments were paralleled by those taking shape at the state level. Although mental health was rarely their top concern, state politicians shared professional and broader public concerns about institutional conditions, and they were also concerned about the cost of caring for the mentally ill. Those in New York State, which had by far the largest number of institutionalized patients, were particularly eager to alter the manner in which care was provided and funded. Community treatment and prevention programs took shape in almost every state during the 1950's, and state funding for such programs rapidly outstripped federal support.[21] In New York, legislation enacted in 1949 created the New York State Mental Health Commission (SMHC) within the DMH. The SMHC, which was to meet annually between 1949-54 and to submit to the legislature a final report outlining its recommendations in February 1954, was charged with creating a master plan for state mental health programs. Components of this master plan were to include, among other things, facilitating the recruitment and training of needed mental health personnel, planning and developing needed in- and outpatient services for children and adults, sponsoring needed research, and coordinating the activities of public and private agencies working in any given community.[22]

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[17]Grob, From Asylum to Community, 24-43, 124-46. As Grob points out, the psychiatric profession was syncretistic, and few of its practitioners denied that both somatic and environmental factors contributed to mental illness; psychiatrists differed as to which set of factors was most important.

[18]Grob, From Asylum to Community, 44-53.

[19]Grob, From Asylum to Community, 53-56. The status and responsibilities of the NIMH have changed substantially. In 1953, the Public Health Service, of which the NIH and the NIMH were part, was made part of the newly created Department of Health, Education, and Welfare (HEW; renamed the Department of Health and Human Services after the creation of the Department of Education in 1979). The NIMH was severed from the National Institute of Health (NIH) and given bureau status in 1967, but in 1973 it was again made part of the NIH. At the same time, it was made part of HEW's newly-created Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA). Following the ADAMHA Reorganization Act of 1992, which abolished the ADAMHA and replaced it with the Substance Abuse and Mental Health Services Administration (SAMHSA), the NIMH became part of SAMHSA and its research activities were transferred to the NIH. See National Institute of Mental Health, NIMH Legislative Chronology, available [online]: <http://www.nimh.nih.gov/about/legichro.htm> [23 April 1998].

[20]Grob, From Asylum to Community, 166.

[21]Grob, From Asylum to Community, 59.

[22]Act of April 7, 1949, Laws of New York, ch. 733, § 1-2, § 6. As it existed in the wake of the 1949 legislative changes, the SMHC was chaired by Dr. Newton Bigelow (later director of the Marcy State Hospital) and consisted of the state commissioners of health, education, social welfare, and correction; Dr. Ernest M. Gruenberg served as its executive director, Hyman C. Forstenzer as assistant director, and Luther E. Woodward as coordinator of community mental health services in the New York City metropolitan area; see Davies, Toward Community Mental Health, 2. The SMHC apparently enjoyed a de facto existence before it received its legal recognition and mandate: in 1947, it began receiving federal funds allocated in accordance with the 1946 Mental Health Act; see Davies, Toward Community Mental Health, 2-3.

The SMHC ultimately concluded that public demand for community-based mental health care was increasing, that such care was in egregiously short supply in every part of the state, that the availability of such care varied widely from one locality to the next, that there was no single local government agency accountable for community mental health programs, and that the efforts of various state agencies to establish programs for populations in need led to local-level confusion. These findings and politicians' ever-present concerns about the escalating cost of supporting the state's mental hospitals, which cared for roughly one-fifth of the nation's 559,000 psychiatric inpatients, helped to propel passage of New York State's Community Mental Health Services Act (CMHSA), the first legislation of its kind in the United States.[23] State politicians who feared that funding community-based services would place further pressure on the state budget were ultimately persuaded to support the act by the mounting expense of inpatient treatment and predictions that state hospital admissions would increase and that community-based care would be cheaper than treatment furnished in state institutions, and psychiatrists' assertions that community-based care was more humane and effective.[24]

The CMHSA encouraged but did not compel the governments of counties and of cities of more than 50,000 people to establish community mental health boards (CMHB's); New York City was exempted from these guidelines and instructed to create a single CMHB for all five boroughs.[25] By law, CMHB's were composed of the locality's ranking health and welfare officials and at least two physicians and headed by psychiatrists; other local officials and representatives from community service groups were allowed to sit on them.[26] CMHB's were to assume responsibility for identifying and planning to meet the mental health needs of their communities and administering all locally-based in- and outpatient preventative, treatment, rehabilitation, and educational/consultative programs. In effect, the act gave CMHB's a sweeping mandate but little concrete direction. The CMHSA also sought to induce localities to act by compelling the state to reimburse half of a given CMHB's approved expenditures.[27] The CMHSA capped the reimbursement that a given CMHB could request at $1.00 per capita of the general population it served. Although this figure sounds low, the intent of those who drafted the reimbursement provision was to double the existing level of care in the best-served parts of the state.[28] At the same time, legislators passed a bond act designed to raise $350,000,000 for construction of new state hospital facilities and the planned community mental health centers; the act, which attached mental health construction bonds to an existing bond act designed to provide bonuses to World War II veterans and their families, was subsequently approved by voters.[29]

The move toward community-based and -controlled mental health care was given added momentum by changes in the operations of state mental hospitals. The open hospital movement, which emerged in Great Britain in the late 1940's and early 1950's and, in the wake of British presentations at the 1954 World Association for Mental Health conference in Toronto, began shaping inpatient mental health care in the United States during the mid- to late 1950's. Its

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[23]Grob, The Mad Among Us, 234; Grob, Mental Illness and American Society, 317.
[24]Grob, From Asylum to Community, 171-72.
[25]Community Mental Health Services Act, Laws of New York (1954), ch. 10, § 190-a, subd. 1-2.
[26]Community Mental Health Services Act, Laws of New York (1954), ch. 10, § 190-b subd. 1 and subd. 3.
[27]Community Mental Health Services Act, Laws of New York (1954), ch, 10, § 190-c and § 191-a, subd. 1.
[28]Community Mental Health Services Act, Laws of New York (1954), ch. 10, § 191-a. On the goal of doubling care levels, see Davies, Toward Community Health, 8.
[29]Mental Health Construction Bond Act, Laws of New York (1954), ch. 8, § 2. Act of 5 February 1954, Laws of New York, ch. 9, § 1, § 3, created the War Bonus and Mental Health Bond Account, which was financed through a combination of income tax revenue and a one-half cent per pack tax on cigarettes.

adherents believed that state institutions as they then existed infantilized patients and intensified their mental illnesses.[30] They argued that that involuntary commitment and institutional regimentation, no matter how gentle, robbed patients of decision-making abilities and other skills they needed to function in society. They also urged that commitment to mental hospitals be largely voluntary and that hospitals allow patients the greatest possible control over their own movements and behavior; high walls, tight schedules, and security checks were to be replaced by open facilities that allowed patients to choose how and where they would spend their time. Lastly, proponents of the open hospital envisioned a smaller treatment role for the hospital, stressing that institutionalization should be of short duration and that it should become part of an array of in- and outpatient programs designed to allow the mentally ill to return to society as soon as possible.[31] As Gerald Grob notes, their ultimate goal was "to blur the demarcation between . . . hospital and community."[32]

New York State mental health officials and professionals found the open hospital concept highly attractive. In 1957, DMH Commissioner Paul H. Hoch sent six state mental hospital administrators to Britain to study open facilities. All six became adherents of the concept, and by late 1959, seventy percent of the patients at the Central Islip State Hospital, eighty percent of those at the Brooklyn State Hospital, and ninety percent of those at the Hudson River and Middletown State Hospitals resided in open wards.[33] Hoch and other New York State professionals who advocated the creation of open hospitals were aided by the New York City-based Milbank Memorial Fund, which had since 1922 provided money for public health projects and studies in New York State and had become interested in mental health issues during the 1930's. The fund financed the 1957 hospital administrators' tour of British facilities and held annual conferences at which American, Canadian, and British mental health professionals detailed their efforts to create effective prevention, treatment, and rehabilitation projects. In turn, high-ranking New York State mental health officials helped guide the fund's activities: Commissioner Hoch and Hudson River State Hospital head Dr. Robert C. Hunt sat on its Technical Board.[34]

New York State advocates of the open hospital identified several obstacles that stood in their way. They felt that the courts were overly concerned about the possibility that lowering the number of involuntary commitments might increase the crime rate, and they believed that the

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[30]Grob, From Asylum to Community, 140-41, 144-46.

[31]See, e.g., Robert G. Hunt, "Ingredients of a Rehabilitation Program," in Milbank Memorial Fund, An Approach to the Prevention of Disability from Chronic Psychoses: The Open Mental Hospital within the Community (New York: Milbank Memorial Fund, 1958), 9-27.

[32]Grob, From Asylum to Community, 145.

[33]The six administrators sent to Britain were: Dr. Nathan Beckenstein, head of Brooklyn State Hospital; Dr. Robert C. Hunt, head of Hudson River State Hospital; Dr. Francis J. O'Neill, head of Central Islip State Hospital; Dr. Hyman Pleasure, head of Middletown Hospital; Dr. Herman B. Snow, head of St. Lawrence State Hospital; Dr. C.F. Terrence, head of Rochester State Hospital. It is unclear as to just how many patients at the St. Lawrence and Rochester State Hospitals were in open wards; however, Dr. Pleasure reported that sixty-five percent of those at St. Lawrence were in such wards even before he went to Britain and that even more patients were placed in open wards after he returned. For the views of the six psychiatrists who went to Britain and their subsequent efforts to emulate their British counterparts, see "Reports of Group Visits to Great Britain's Community-Based, Open Mental Hospitals," in Milbank Memorial Fund, Steps in the Development of Integrated Psychiatric Services: Report of the Third Meeting of the Advisory Council on Mental Health Demonstrations (New York: Milbank Memorial Fund, 1960), 14-36.

[34]Information about the Milbank Memorial Fund and its activities can be found in Ernest M. Gruenberg and Frank G. Boudreau, "Preface," in An Approach to the Prevention of Disability from Chronic Psychoses, 5, and Grob, From Asylum to Community, 89, 169. Grob asserts that the fund began supporting mental health projects in the 1940's, but a 1939 overview of the mental hygiene movement indicates that the organization's concern with mental health developed at least a decade earlier; see Central Hartford Bank & Trust Co, The Mental Hygiene Movement, 57.

general public's lack of knowledge about the nature of mental illness was impeding progress. They also perceived another hurdle specific to New York State: the 1890 State Care Act, which made treatment of the mentally ill the exclusive responsibility of the state. In 1957, Robert Hunt charged that:

> "The state [had] . . . in effect established a system that allows everyone else to be irresponsible. Local government, general hospitals, practicing physicians, individual citizens, and patients long since abdicated to the state all responsibility for caring for their fellow man when he becomes mentally ill. In New York State local officials can . . . dispose of a problem case with no cost whatever [sic] to any local agency or to the family. They may actually make a profit by removing a name from the welfare rolls."[35]

Not all advocates of community mental health care believed that local politicians were obsessively stingy.[36] However, Hunt's argument continually resurfaced in subsequent decades. In 1965, the New York State Planning Committee on Mental Disorders, which was composed of state officials, mental health professionals, CMHB members, and representatives from interested private groups, argued that "choice of treatment facility should be based on the needs of the patient" and implied that ending "exclusive State fiscal responsibility for State hospital care" would result in more appropriate treatment.[37] In 1976, the Assembly Joint Committee to Study the Department of Mental Hygiene noted that "the presence of a State facility in a county [could] inhibit the development of local programs because it [was] easier and less costly for the locality to use the State facility."[38]

Not surprisingly, the enthusiasm of Hoch, Hunt, and other New York State mental health professionals for community health care programs far exceeded the rate of program development. Community-based programs took shape gradually and CMHB personnel benefited from the creation in 1956 of the Association of Community Mental Health Boards (ACMHB), which from 1957 onward sponsored annual conferences intended to allow CMHB members to share their experiences.[39] However, progress did not occur at the speed that reformers wanted. Stanley Davies, who in 1959 conducted a study of CMHB's for the New York Association for Mental Health, underscored the slow rate of change.[40] Davies visited thirty of the thirty-one

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[35]Hunt, "Ingredients of a Rehabilitation Program," 16.

[36]In 1959, Dr. William Carson, the chair of the St. Lawrence County CMHB, asserted that he was "constantly amazed" that many of his colleagues seemed to regard "elected officials, particularly boards of supervisors [,]. . . as backwoodsmen without any thought except guarding the county treasury" and stressed that officials generally wanted what was best for their communities; see New York State Department of Mental Hygiene, Association of Community Mental Health Boards, Fourth Annual Conference of Community Mental Health Boards ([Albany, NY: Department of Mental Hygiene, 1959]), 69-70.

[37]New York State Planning Committee on Mental Disorders, A Plan for a Comprehensive Mental Health and Mental Retardation Program for New York State, vol 1., Report of the Mental Health and Mental Retardation Sections of the State Planning Committee (Albany, NY: , 1965), 8.

[38]New York State Assembly, Assembly Joint Committee to Study the Department of Mental Hygiene, Mental Health in New York: A Report To Speaker Stanley Steingut from the Assembly Joint Committee to Study the Department of Mental Hygiene (Albany: New York State Assembly, 1976). It is important to note that local officials in certain areas may have had another reason for relying upon state facilities: fear that the hospitals would be shut down. Rural state hospitals brought money and jobs into the villages and small towns adjacent to them, and local officials might have feared that community mental health programs would ultimately lead to hospital closure.

[39][New York State Department of Mental Hygiene, Association of Community Mental Health Boards], Second Annual Conference of New York State Community Mental Health Boards. [Albany: Department of Mental Hygiene, 1957], 11.

[40]Davies was Director of Special Studies for the New York State Association for Mental Health at the time he carried out the study. At various times, he had been associate director of the New York State Charities Aid Association, executive secretary of the New York State Committee on Mental Hygiene, general director of the Community Service Society of New York City, president of the New York State Association for Mental Health, a board member of the National Association for Mental Health,

counties that had CMHB's or community mental health programs in place in late 1959, and found that there were 171 outpatient mental health clinics in operation (seventy-nine of which were in New York City), general psychiatric wards in eighteen hospitals, thirty-six consultative and educational programs, and four rehabilitation programs.[41] The sole responsibility of the CMHB's in the thirteen rural counties, which he defined as those that had less than 200,000 inhabitants, was the administration of all-purpose part- or full-time clinics; in six of these counties, these clinics did not exist prior to the formation of the county CMHB.

In explaining why the pace of change was so slow, Davies pointed to a number of issues. Funding was a persistent problem, and CMHB's that operated in rural areas often found it particularly difficult to secure adequate funds. Rural CMHB's also found it hard to induce qualified psychiatrists, psychologists, social workers, and other needed personnel to move away from cities.[42] In addition, those that were established in counties without existing social-welfare and child-services agencies were besieged by people with needs and problems that fell outside of the CMHB's legal mandate.[43] Urban-area CMHB's, which typically inherited control of programs that were already in existence and worked with voluntary organizations seeking state reimbursement, encountered a different set of problems. Local governments that had financed community initiatives and voluntary mental-health programs were eager to secure state funds, and urban CMHB's were beset by reimbursement demands as soon as they were formed. These demands and the administrative functions that these CMHB's were forced to perform almost immediately after they came into existence often consumed all of their time and resources, and they were unable to fulfil the planning component of their mission. In addition, CMHB's that assumed control over or, as was more common, established service contracts with existing programs sometimes found that program personnel saw them as usurpers.[44] The CMHB governing community health programs in New York City, which furnished the highest level of local services in New York State, encountered particular difficulties. Demand for reimbursement was such that the city's CMHB quickly reached the maximum established by the CMHSA and could not establish any other programs.[45]

Davies also discovered that the availability of care continued to vary widely from one part of the state to the next, and he identified another difficulty stemming from the provisions of the CMHSA: localities that did not wish to establish a CMHB were under no obligation to do so, and a number of counties, almost all of which were rural, had witnessed failed attempts at persuading county officials and the broader public that community-based mental health services were needed. Stressing that the solution to this problem lay in the education of citizens and local politicians, Davies did not argue that communities should be compelled to create CMHB's or to allocate funds for community programs.[46] However, in highlighting the role of citizen resistance in retarding the creation community programs he identified a problem that in future decades

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president of the Family Service Association of America, and president of the Mental Health Materials Center; see New York State Department of Mental Hygiene, New York State Association of Community Mental Health Boards, Sixth Annual Conference of New York State Community Mental Health Boards ([Albany: Department of Mental Hygiene, 1961]), 53.

[41]Davies, Toward Community Mental Health, 9-10. The Chemung County CMHB refused to allow Davies to assess its activities. CMHB's existed in Albany, Broome, Cayuga, Chemung, Dutchess, Erie, Greene, Jefferson, Monroe, Nassau, Niagara, Oneida, Onondaga, Ontario, Orange, Putnam, Rockland, St. Lawrence, Saratoga, Schenectady, Suffolk, Ulster, Warren, Washington, Wayne and Westchester counties and in the New York City.

[42]Davies, Toward Community Mental Health, 11-13.

[43]Davies, Toward Community Mental Health, 32.

[44]Davies, Toward Community Mental Health, 14-15, 22.

[45]Davies, Toward Community Mental Health, 204-05.

[46]Davies, Toward Community Mental Health, 24.

would continue to bedevil advocates of locally-based prevention, treatment, and rehabilitation: the public's ongoing ignorance about mental illness and persistent preference for segregation of the mentally ill in isolated institutions.

Davies did not explicitly single out one other factor that helped to retard the development of community mental-health programs: the imprecision of the CMHSA as to priorities and target clienteles. Responsibility for making such assessments was placed in the hands of individual CMHB's with the laudable intent of allowing each community to create programs and policies that best met its unique circumstances and needs. However, assigning primary responsibility for effecting radical changes in mental health policy to inexperienced local organizations virtually guaranteed that progress would be slow. State officials became increasingly aware that CMHB's were in need of guidance, and in 1959 the DMH created ten Regional Mental Health Advisory Committees (RMHAC's) that were charged with helping CMHB's plan, implement, and administer programs.[47] In 1962, the DMH created the positions of Associate Commissioner for Community Services and Assistant Commissioner for Community Services in an effort to facilitate the development of local programs.[48] In 1965, it underwent a structural reorganization that made the newly created Division of Local Services one of its three main operating divisions.[49]

The lack of coordination between state and local efforts nonetheless persisted. The obstacles encountered by CMHB's and their champions within the DMH were many and their origins complex. The difficulty of coordinating local and state initiatives and creating a comprehensive array of in- and outpatient services was the subject of the 1961 annual conference of the Milbank Memorial Fund. At the conference, future Commissioner of Mental Hygiene Dr. Lawrence R. Kolb argued that research- oriented and teaching hospitals, long noted for furnishing high levels of care to the mentally ill, could nonetheless act in ways that were counterproductive. Their admissions policies were guided in part by the need for exemplary teaching and research cases, and as a result some patients who were in great need of care were turned away. Such policies often resulted in a poor fit between the hospital and community it served and also served students and researchers poorly: those exposed only to these carefully selected cases failed to grasp the actual distribution of mental illness within communities or to appreciate the role of community-based programs in aiding the mentally ill.[50] Others present at the conference highlighted the persistence of staffing shortages, localities' reluctance to fund

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[47]The RMHAC's, which consisted of CMHB and state hospital administrators, were: New York City Region (Bronx, Kings, New York, Queens, and Richmond counties); Albany Region (Albany, Rensselaer, Saratoga, Schenectady, Warren, and Washington counties); Binghamton Region (Broome, Chemung, Chenango, Cortland, Delaware, Otsego, Schoharie, and Tioga counties); Buffalo Region (Allegany, Cattaraugus, Chautauqua, Erie, and Niagara counties); Catskill Region (Orange, Rockland, Sullivan, and Ulster counties); Hudson River Region (Columbia, Dutchess, Greene, Putnam, and Westchester counties); Long Island Region (Nassau and Suffolk counties); Rochester region (Cayuga, Genesee, Livingston, Monroe, Ontario, Orleans, Schuyler, Seneca, Steuben, Tompkins, Wayne, Wyoming, and Yates counties); St. Lawrence Region (Clinton, Essex, Franklin, Jefferson, Lewis, and St. Lawrence counties); and Syracuse Region (Fulton, Hamilton, Herkimer, Madison, Montgomery, Oneida, Onondaga, and Oswego counties).

[48]New York State Department of Mental Hygiene, Summary Statement of Reorganization of Department of Mental Hygiene, October 1, 1962 (Albany: Department of Mental Hygiene, 1961), [4]. The actual implementation of the reorganization plan seems to have occurred somewhat later. Dr. Leonard Lang served as Associate Commissioner for Community Services for a short time; he was subsequently made Commissioner for Mental Hospitals. Lang was replaced by Dr. Alan D. Miller, who also vacated the office shortly after being appointed: he was made Commissioner for Mental Hygiene in February 1966 and remained in that post until his retirement in 1974.

[49]New York State Department of Mental Hygiene, 1965 Annual Report (Albany, NY: Department of Mental Hygiene, 1965), 7.

[50]Lawrence R. Kolb, "Problems of Integration . . . in New York City: The Voluntary Hospitals and Psychiatric Care in the Metropolitan Area," in Milbank Memorial Fund, Decentralization of Psychiatric Services and Continuity of Care: Proceedings of the Thirty-Eighth Annual Conference of the Milbank Memorial Fund (New York: Milbank Memorial Fund, 1962), 67-68, 70.

programs, and the dearth of rehabilitative programs designed to ease the return from the mental hospital to society.[51]

Despite these difficulties in implementation, the New York State CMHSA anticipated developments taking place in other states. California, New Jersey, and Minnesota passed similar laws in 1957, and mental health authorities in other states began implementing similar programs without benefit of legislative mandate.[52] New York State's new mental health policy also set the course changes that took place on the federal level. In the early 1950's interested members of Congress, federal officials working within the NIMH and the Department of Health, Education, and Welfare (HEW), and mental health professionals active in the APA and the American Medical Association (AMA) agreed that the federal government should take a more active role in financing and directing mental health care. In 1955, they established the Joint Commission on Mental Illness and Health (JCMIH), which was sponsored by APA and AMA but supported in part by federal funds. The JCMIH issued its final report, entitled Action for Mental Health, in 1961. Action for Mental Health outlined a comprehensive plan that called for federal support for construction and staffing of community mental health centers. Neither the AMA nor the APA unconditionally accepted the recommendations of the JCMIH, which nonetheless guided the development of federal mental health policy.[53] In 1963, the Community Mental Health Centers Construction Act (CMHCCA), which authorized funds to help defray the costs of constructing (but not staffing) local clinics, was enacted; federal support for staffing, which was administered by HEW, was passed in August 1965. The CMHCCA also established federal funding for the care and training of the mentally retarded and developmentally disabled, whose circumstances were of particular concern to President John F. Kennedy, other members of the Kennedy family, and a growing number of citizen advocates.[54] However, the CMHCCA, which constituted a radical break from previous national mental health policy in both the kind of facilities it supported and the degree of direct federal involvement that it represented, did not clearly define the functions and target clientele of the community centers or their relationship to other local health-care institutions.[55] In its imprecision, it strongly resembled New York State's CMHSA.

The CMHCCA reinforced New York State's move toward community-based provision of mental health care. Under its provisions, funds were made available for every state that devised plans for community mental health programs and facility construction, designated an agency to execute them, and appointed a broadly representative advisory council to guide state policy. In New York State, DMH Commissioner Paul Hoch applied for a planning grant from the NIMH and after approval of his request in May 1963 appointed a Planning Committee on Mental Disorders (PCMD) composed of DMH and other state officials, CMHB members, representatives of professional organizations, and leaders of voluntary advocacy groups. Hoch also ordered all of the RMHAC's to appoint regional planning committees that would report to

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[51]Dr. Marvin E. Perkins, "Problems of Integration . . . in New York City," in Milbank Memorial Fund, Decentralization of Psychiatric Services, 76-77; Dr. Harold C. Miles, "Problems of Integration . . . in Monroe County," in Milbank Memorial Fund, Decentralization of Psychiatric Services, 81-84; Dr. C.F. Terrence, "Problems of Integration . . . in Monroe County," in Milbank Memorial Fund, Decentralization of Psychiatric Services, 85-88.

[52]Grob, From Asylum to Community, 173-75.

[53]Grob, From Asylum to Community, 187-214. Grob notes that one of the most vocal critics of the JCMIH's recommendations was New York State DMH official and Psychiatric Quarterly editor Newton Bigelow, who argued that doing as JCMIH advocated and turning large state mental hospitals into chronic care facilities was in effect defining certain patients as hopeless cases and simply warehousing them.

[54]Grob, From Asylum to Community, 233-34, 248.

[55]Grob, From Asylum to Community, 235-238.

the PCMD.[56] In order to take full advantage of the federal funds that the CMHCCA made available, in summer 1964 Governor Nelson Rockefeller made the DMH solely responsible for meeting the needs of New York State's mentally retarded and developmentally disabled citizens. As a result, Commissioner Hoch created a Mental Retardation Section within the PCMD and urged all of the RMHAC's to appoint developmental-disability experts to the regional committees.[57] New York State was one of the first to receive CMHCCA funds, and as of 1966 it had gotten $6,600,000 for construction of community centers and another $1,500,000 for construction of facilities for the mentally disabled.[58]

However, New York State's increasing expenditures upon mental health center construction and staffing were not propelled solely by the availability of federal funds. Elected officials buoyed by the booming economy and promises that community mental health care initiatives would in the long run save money created a number of new funding initiatives. In April 1963, roughly six months before the CMHCCA became law, legislation established the New York State Mental Hygiene Facilities Improvement Corporation (MHFIC), a public-benefit corporation run by the DMH commissioner and two trustees appointed by the governor.[59] The MHFIC, which began its work in January 1964, was empowered to plan, undertake, and direct construction and rehabilitation of facilities for the mentally ill, the mentally retarded, and the developmentally disabled, and it was given control over all local, state, and federal monies intended for these purposes. The MHFIC could also purchase or lease real estate and buildings needed for the creation, expansion, or renovation of mental health facilities.[60] At the same time, the Housing Finance Authority (HFA), which had been established to promote the construction of affordable housing, was given the power to furnish loans for the construction of schools and hospitals; as of 1966, the HFA had loaned $600,000,000 for mental health facility construction.[61] The same piece of legislation also created the Mental Health Services Fund, which was financed out of the surplus monies that the MHFIC returned to the state comptroller at the end of the year and helped to support personnel training and research activities.[62]

In the wake of the CMHCCA's passage, New York State devoted even more funds to facility construction. In early 1965, Governor Nelson Rockefeller announced plans for a mammoth construction initiative. Five hospitals designed to replace outdated facilities, twelve hospitals exclusively for children, and eight state schools for the developmentally disabled were planned; in the following year, work began upon four of the hospitals and nine new rehabilitation

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[56]New York State Planning Committee on Mental Disorders, A Plan for a Comprehensive Mental Health and Mental Retardation Program for New York State: Report to the Governor. vol. 1, Report of the Mental Health and Mental Retardation Sections of the State Planning Committee, (Albany: 1965), vii. A complete listing of all of the members of the PCMD, which was originally named the State Mental Health Planning Committee, can be found on p. 3-4. Lists of members of various task forces and regional committees can be found in subsequent volumes of the report.

[57]Planning Committee on Mental Disorders, A Plan for a Comprehensive Mental Health and Mental Retardation Program, vol. 1, Report of the Mental Health and Mental Retardation Sections of the State Planning Committee, viii.

[58]New York State Department of Mental Hygiene, Control of Mental Disorders in New York State, (Albany: Department of Mental Hygiene, 1966), 9; New York State Department of Mental Hygiene, 1967 Annual Report (Albany, NY, 1967) [8].

[59]Act of 30 April 1963, Laws of New York, ch. 932, § 1-2.

[60]Act of 30 April 1963, Laws of New York, ch, 932, § 2. Section 2 created Article 2-B of the Mental Hygiene Law. § 29-a of Article 2-B established the MHIC. § 29-c charged it with planning, constructing, and improving facilities or contracting with third parties to perform these functions and empowered it to purchase all materials and supplies needed to run facilities; § 29-c also prohibited localities from altering building plans that the MHFIC approved. § 29-g gave the MHIC sole responsibility for facility construction funds.

[61]Act of 30 April 1963, Laws of New York, ch. 932, § 18; New York State Housing Finance Authority, A Report to Governor Nelson A. Rockefeller (Albany: Housing Finance Authority, 1966, [5].

[62]Act of 30 April 1963, Laws of New York, ch, 932, § 23.

wings at existing facilities.[63] In 1965, new state legislation enabled local governments to seek state reimbursement of up to one-third of the capital costs and one-half of the operating costs incurred by community mental health centers and psychiatric wings within public hospitals; this legislation also raised the expenditure ceiling for community mental health programs, which had been raised to $1.20 per capita in 1960, to $1.40 per capita and waived this limit for communities that met certain qualifications.[64] However, the legislative developments of 1963 and 1965 should not be seen as signs that state government was consciously seeking to micro-manage community-based mental health care. State expenditures for construction, equipment, and training certainly increased, but policymakers were convinced that the programs housed within state-financed buildings should be controlled largely by local authorities. A pamphlet sent to local officials during the latter half of the 1960's stressed that even though the MHFIC would design, construct, and equip facilities and the HFA would finance construction, municipalities would be responsible for their maintenance and operation; after the bonds that had financed construction were retired, localities would also assume ownership of the facilities that the HFA and the MHFIC had built.[65]

The Department of Mental Hygiene also moved to take advantage of various sources of federal funds that became available as a result of programs created or expanded during the administration of Lyndon Johnson. In 1966, it published a handbook detailing the monies available to state and local mental-health programs through the NIMH and other divisions of HEW, the Department of Labor, and the Office of Economic Opportunity; the guide also outlined federal funding sources for programs serving the developmentally disabled.[66] However, the most significant new federal programs were Medicare, a federally-funded health insurance program for senior citizens, and Medicaid, a health insurance program for the needy jointly financed by the federal, state, and local governments. Both of these programs, which were enacted in 1965, covered some forms of mental health treatment and greatly altered the care given mentally ill persons. The framers of these laws sharply limited Medicare and Medicaid reimbursement for care furnished in state mental hospitals; in keeping with prevailing opinion, they believed that state facilities placed far less emphasis upon treatment than psychiatric wings situated in general hospitals. They also made impoverished mentally ill persons under the age of sixty-five ineligible for Medicaid coverage. These stipulations had unanticipated and dramatic consequences. Mental hospital administrators across the nation began moving the aged mentally ill, who had long constituted a substantial proportion of the institutionalized population, out of state hospitals. Some mentally ill senior citizens were sent to psychiatric facilities attached to general hospitals, but the great majority ended up in nursing homes. New York State was not an exception to this trend, which was often detrimental to those moved out of state facilities and yet beneficial to those who remained within.[67] In subsequent years, the DMH realized that its rush

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[63]New York State Department of Mental Hygiene, Control of Mental Disorders in New York State, 4, 12.
[64]Act of 28 June 1965, Laws of New York, ch. 647, § 1-2, § 5.
[65]New York State Health and Mental Health Facilities Improvement Corporation, Improved Health Facilities for Your Community: How the State Can Assist in Construction (Albany, New York State Health and Mental Health Facilities Improvement Corporation, n,d).
[66]New York State Department of Mental Hygiene, Catalog of Selected Federal Programs for Financial Assistance and Grants, (Albany,: New York State Department of Mental Hygiene, 1966).
[67]On the provisions of Medicare and Medicaid and their effects on treatment of the mentally ill elderly, see Grob, From Asylum to Community, 267-70. Grob notes that the transfer of the aged mentally ill to nursing homes freed up resources that were then used to improve care for the patients who remained. However, those sent to nursing homes encountered widely varying levels of care and a dearth of psychiatric services. The mortality rate of mentally ill senior citizens increased among those transferred, suggesting that nursing home care was often inadequate; see Grob, The Mad Among Us, 266, 289-90.

to move mental patients into nursing homes was in some respects ill-considered: by the mid-1970's, nursing home operators who had in the past had negative experiences with former state hospital patients and local social welfare agencies that had no desire to fund any of the costs associated with nursing home care heartily resisted the DMH's efforts to place discharged patients in such facilities.[68]

The unexpected consequences of Medicare and Medicaid regulations were not offset by dramatic successes in the creation of community-based mental health facilities. As of early 1967, one hundred centers across the nation had received CMHCCA funds, forty-seven centers had been granted monies for staffing, and twenty-six centers were receiving federal support for both construction and staffing. The pace of center development fell far short of the projections of CMHCCA proponents, who envisioned the relatively rapid creation of some 2,000 centers nationwide. Gerald Grob argues that the slow growth of community centers at the federal level was in part the result of increased competition for funds within HEW and persistent shortages of qualified mental-health personnel. He also underscores the impact of the escalating conflict in Vietnam, which increasingly occupied the attention of President Johnson and the public at large and drained money from social welfare programs, upon federal mental health expenditures.[69]

Grob also highlights the shortcomings inherent in the centers themselves. Beliefs about etiology and treatment held by the staffers of many centers remained nebulous, ensuring wide variation in the scope and kinds of therapies that the centers offered.[70] Furthermore, centers focused increasing attention and resources upon those who had less serious forms of mental illness. In part, this shift was due to the increasing role that psychologists played in furnishing treatment. Psychologists tended to reject somatic explanations of the etiology of mental illness, and they were relatively uninterested in furnishing care to the most seriously mentally ill, were employed in ever-greater numbers in community centers. Relations between psychiatrists and psychologists had been tense since the 1930's, but in the 1960's psychologists' challenges to psychiatry's pre-eminence in the field of mental health at last came to fruition.[71] However, psychologists were not alone in their dislike of treating the acutely mentally ill. Psychiatrists who worked in the centers often saw themselves chiefly as providers of psychotherapy, a therapeutic tool that was resource-intensive and most efficacious when used with educated patients who had relatively minor mental disorders.[72]

Other factors hampered the effectiveness of the centers. Programs designed to help to smooth the transition from institutionalization to life in the larger community often fit poorly with the community center model and were not always eligible for government funding.[73] As a result, these essential components of the new mental health system envisioned by champions of community programs were few and far between. In addition, the CMHCCA's insistence that centers be controlled locally rendered them vulnerable to increasing community demands for services such as substance abuse treatment and counseling designed to help people resolve personal problems.[74] From 1968 onward, federal laws mandating that centers treat substance abuse, a growing public concern, compelled the centers to provide such care. Local control of

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[68]New York State Department of Hygiene, Task Force Report: The Department of Mental Hygiene's Inability to Access Community Skilled Nursing and Health Related Facilities (Albany: New York State Department of Hygiene, 1974), [1]-[2], [4]-[5].
[69]Grob, From Asylum to Community, 249-50.
[70]Grob, From Asylum to Community, 251-52.
[71]Grob, From Asylum to Community, 285-86; Grob, The Mad Among Us, 264.
[72]Grob, From Asylum to Community, 252-53.
[73]Grob, From Asylum to Community, 262-63,
[74]Grob, The Mad Among Us, 264.

centers also gave rise to the same problem that New York State experienced in the wake of the CMHSA: lack of coordination between different treatment programs. Lastly, it set the stage for bitter internal struggles that beset many centers as a result of the social, cultural and political upheavals of the late 1960's and early 1970's.[75]

Mental Health Besieged, 1965-77

From the mid-1960's onward, the problems associated with the slow development of community mental health centers, the inherent shortcomings of the centers themselves, and excessively optimistic discharge policies became increasingly apparent. Politicians and the general public were increasingly critical of the the poorly planned revolution in mental health treatment and policy. However, this criticism had little immediate effect: even as the flaws inherent in the nation's developing mental health policy became too great to ignore, the commitment of state and federal policymakers to community mental health and dramatic reduction in state inpatient censuses intensified. At the same time, society's opinions about mental health and psychiatry changed dramatically as a result of the intense cultural, political, and social ferment that characterized the latter half of the 1960's and early 1970's. People on opposite ends of the political spectrum denounced the very concept of mental health. Psychiatrists, who had formerly been seen as compassionate experts, were instead frequently denounced as ruthless oppressors bent on singling out and crushing the individuality of those who rejected the dominant values of society.

The mental health professions were both instigators and victims of these upheavals. Some psychologists, social workers, and environmentally-oriented psychiatrists were sympathetic to Lyndon Johnson's social welfare initiatives and made commitment to social activism a key component of their professional identities: if mental illness were caused by poor social conditions, then combating racism, poverty, and other social ills was a logical and necessary part of mental health work. Members of the Group for the Advancement of Psychiatry, a liberal professional organization formed in the late 1940's by William Menninger and other sociodynamic psychiatrists, had since the early 1950's advocated psychiatric involvement in social reform causes. During the late 1960's, a growing number of those working in the field embraced the reform-oriented ethos of what Gerald Grob terms "community psychiatry." A smaller number went even further and pronounced themselves champions of the overthrow of capitalism and technocracy.[76]

The pronouncements of the Group for the Advancement of Psychiatry and proponents of community psychiatry focused unwelcome attention upon the profession as a whole. Extremist right-wing organizations had long denounced mental health programs as covert attempts to facilitate the spread of Soviet communism, and their attacks increased as psychiatrists and others voiced their support for the civil rights and anti-war movements, anti-poverty programs, and other causes.[77] By the late 1960's and early 1970's, mainstream conservatives, who were increasingly convinced that the mental health field was composed almost exclusively of their political enemies, were also suspicious of psychiatry. President Richard Nixon sought to eviscerate the CMHCCA and other federal supports for mental health care on the grounds that

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[75]Grob, From Asylum to Community, 254-55.
[76] Grob, The Mad Among Us, 197-98; Grob, From Asylum to Community, 241-44, 281.
[77] Grob, From Asylum to Community, 280.

they had been intended only as pilot measures; however, his efforts to dismantle federal mental health policy were foiled by the courts.[78]

Contrary to the accusations made by reactionaries and conservatives, the majority of psychiatrists refused to embrace social activism. A growing number of those within the profession remained convinced that mental illness was a neurobiological disorder; from the late 1960's onward, psychiatrists have abandoned sociodynamic theories and placed increasing emphasis the somatic dimensions of mental disorder. Others were supporters of the civil rights movement and other liberal goals but were firmly convinced that citing their credentials when supporting political causes was unprofessional. The activists within the profession were a small group.[79] Outside of the profession, however, the influence of this group far exceeded their numbers. This phenomenon is perhaps most evident in the popularity of one of its subgroups: leftist and libertarian practitioners who sought to strip their own profession of its legitimacy. R.D. Laing, a left-wing Scottish practitioner who was an active member of Britain's Campaign for Nuclear Disarmament, asserted that schizophrenia and other serious mental illnesses were in fact logical responses to a society that had become delusional and self-destructive and that defining a person as mentally ill was a means of maintaining the hegemony of the existing order. Laing's ideas were in many respects an outgrowth of the environmental theories of mental illness that had emerged in the immediate postwar period; he simply carried the belief that mental illness was influenced by social conditions to an unprecedented extreme. [80] The work of Thomas Szasz, a Hungarian-born professor at the SUNY Upstate Medical Center at Syracuse University, also won widespread acceptance. A libertarian who believed that psychiatry was nothing more than a covert means of extending the power of the state over its citizens, Szasz argued that mental illness did not exist; those suffering from "mental illness" were in fact abdicating their responsibility to make moral choices.[81]

The writings of scholars outside of the psychiatric profession gave added force to the assault on psychiatric legitimacy, and their influence is to this day evident within a number of academic disciplines. In 1965, the English translation of French philosopher Michel Foucault's Madness and Civilization first appeared.[82] Foucault argued that the altruism that had been associated with psychiatry since the eighteenth century was a facade: psychiatrists were not humane helpers of the mentally ill but coercive figures seeking to force asylum inmates to internalize the moral discipline of bourgeois society. In later writings, Foucault elaborated upon these ideas. Taken together, his writings constitute a history of Western civilization that stresses the shift away from external feudal constrictions on behavior toward modern efforts to induce individuals to internalize the values of the modern state and police their own thoughts and actions. He asserted that the function of insane asylums and prisons is to compel the compliance

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[78] Grob, The Mad Among Us, 281-83.

[79] Grob, From Asylum to Community, 281.

[80] Rael Jean Issac and Virginia C. Armat, Madness in the Streets: How Psychiatry and the Law Abandoned the Mentally Ill (New York: Macmillan, Free Press, 1990), 27-32, furnish a summary of Laing's ideas. However, their work must be read with a certain degree of caution. They make no pretense of hiding their intense anger at deinstitutionalization, which they see as the end product of a determined legal and psychiatric assault upon social order, family rights, and human decency. Their sympathies clearly rest with the families of the seriously mentally ill, whom they see as burdened and abused by unresponsive courts and mental health professionals.

[81] Thomas Szasz, The Myth of Mental Illness: Foundations of a Theory of Personal Conduct (New York: Harper & Bros., Hoeber, 1961).

[82] Michel Foucault, Madness and Civilization: A History of Insanity in the Age of Reason, trans. Richard Howard (New York: Pantheon, 1965).

of those who resist integration into the state's moral and behavioral regime.[83] Foucault's assessment of the inner meaning of madness and other forms of social deviance to this day carries immense weight in the social science and humanities; although Foucault's popularity has waned in Europe and North America, scholars remain divided as to the accuracy and value of his work, his ideas continue to guide many sociologists, historians, and policy analysts.

A number of sociologists working independently of Foucault also stressed the coercive dimensions of mental health diagnosis and treatment. Earving Goffman's Asylums, which was published in 1961, extended Bruno Bettelheim's arguments about the devastating impact of Nazi concentration camps upon the human psyche to mental hospitals. Goffman asserts that the two were alike in that they were "total institutions" that isolated inmates from society, strictly regulated their behavior, and stripped them of all sense of individuality and dignity. In this respect his arguments differ little from those advanced by Paul Hoch, Robert Hunt, and other psychiatric champions of the open hospital movement and community-based mental health care. However, Goffman also had a jaundiced view of psychiatry and its undergirding assumptions. He concluded that the real function of mental hospitals was to sustain the psychiatric profession and its belief in the medical model of diagnosis and treatment: "to get out of the hospital, or to ease their life within it, they [patients] must show acceptance of the place accorded them, and the place accorded to them is to support the occupational role of those who appear to force this bargain."[84]

Other sociologists argued that psychiatry was concerned less about insuring the continued existence of their own profession than about enforcing social order. Sociologists had long been sensitive to the ways in which societies defined and stigmatized aberrant behavior, but in the turbulent political and social climate of the 1960's the study of deviancy became explicitly political. A growing number of them turned their attention to the study of social deviance and found signs of authoritarian social control everywhere they looked. Thomas Scheff and other scholars asserted that psychiatric diagnoses such as schizophrenia were little more than labels attached to those who refused to conform to dominant societal values; in turn, those labeled as deviant came to see themselves as such and became even more insistent upon acting abnormally.[85]

The arguments of Laing, Szasz, Goffman, Scheff, and others critical of psychiatry and mental institutions gained wide currency from the mid-1960's onward, and their impact upon popular culture is readily evident. During the 1950's, books and films had generally depicted psychiatrists as humane and competent professionals, but from the early 1960's onward writers and filmmakers took a much harsher view of them. Acclaimed novels such as One Flew Over the Cuckoo's Nest (1962) and A Fine Madness (1964), documentaries such as The Titicut Follies (1967) and fictional films such as Diary of a Mad Housewife (1970) and the highly-regarded motion-picture version of One Flew Over the Cuckoo's Nest (1975) framed them as malevolent and dictatorial. The press, which had long played an important role in creating public concern about conditions within mental institutions, also became increasingly assertive in challenging the

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[83]See Michel Foucault, Discipline and Punish: The Birth of the Prison, trans. Alan Sheridan (New York: Random House, Vintage Books, 1979.

[84]Earving Goffman, Asylums: Essays on the Social Situation of Mental Patients and Other Inmates (Garden City, NY: , 1961), 364, quoted in Grob, From Asylum to Community, 284.

[85]Thomas J, Scheff, "Schizophrenia as Ideology," Schizophrenia Bulletin no. 2 (Fall 1970): 15-20. Interestingly, the Schizophrenia Bulletin was published by the NIMH.

authority and expertise of state hospital administrators and other members of the psychiatric profession.[86]

However, the effects of the assault upon psychiatry and mental health were most evident within the reform and radical movements that flourished during the latter half of the 1960's. Many of those drawn into these movements readily embraced Laing and Scheff, who were openly sympathetic to leftist causes; the work of Szasz, who never hid his contempt for the New Left, also captivated them.[87] To many drawn into the nascent youth subculture, psychiatry and mental hospitals were little more than an effort to force teenagers and young adults to accept the achievement- and acquisition-oriented ethos of consumer capitalism. However, not all of these activist young people were willing to discard the concept of mental health entirely. In cities across the United States, they established alternative services that sought to cast aside the traditional hierarchical relationship between caregiver and client and treat young people's drug use, sexual behavior and emotional distress with sympathetic concern. Some of these programs were started by altruistic laypeople, others by young psychologists and social workers dissatisfied with existing institutions and programs, and still others through the cooperative efforts of lay and professional people. These activists often contended not only with the hostility of established mental health providers but with the distrust of young people and political radicals, who often suspected them of being police informants or covert supporters of "the Establishment." In addition, they often experienced considerable internal conflict: the pressures associated with commitment to a precarious venture, their ambivalent relationships with both the larger society and the youth subculture, and their attempts to improvise more egalitarian and emotionally honest ways of living sometimes led them to turn upon one another.[88] Many of these programs, which almost always placed far greater emphasis upon resolution of emotional difficulties than upon treatment of serious mental illness, perished shortly after they were started, but others were eventually incorporated into existing networks of community mental health and welfare services.[89]

The hostile attitude of leftist radicals toward the profession of psychiatry and institutionalization was echoed by adherents of the other social movements that emerged during the late 1960's and early 1970's. The resurgent feminist movement was sharply critical of the ways in which mental health providers treated women. In the highly influential The Feminine Mystique, Betty Friedan sharply criticized psychiatrists who tried to treat what she called "the problem with no name" with tranquilizers and psychotherapy; Friedan, whose arguments centered upon educated middle-class homemakers, argued that the "problem" was little more than a frustrated yearning for challenging work.[90] Friedan believed that psychiatrists were acting out of ignorance, but other feminists asserted that mental health professionals were knowingly coercive. Writers such as Phyllis Chesler and psychologist Naomi Weisstein asserted that

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[86]Grob, From Asylum to Community, 292; Grob, The Mad Among Us, 275.

[87] One person who was not captivated by Szasz's work was DMH Commissioner Paul Hoch, who tried to have fired Szasz from the Upstate Medical Center and apparently succeeded in insuring that he had no allies on the faculty; see Issac and Armat, Madness in the Streets, 40.

[88]See Ted Clark and Dennis T. Jaffe, Toward a Radical Therapy: Alternate Services for Personal and Social Change, Social Change Series, ed. Victor Gioscia (New York: Gordon & Breach, Interface, 1973), for discussion of the goals of and problems faced by the founders of a New Haven, CT alternative service.

[89]The extent to which the alternative mental health service movement existed in New York State is unclear. The movement was by its very nature community-based and separate from existing channels of care and funding, and may be hard to document. However, examination of community mental-health and social-service organizations may provide clues to their existence; for example, the Equinox program located in the city of Albany is apparently an outgrowth of efforts to provide alternative counseling and welfare services to troubled young people.

[90]Betty Friedan, The Feminine Mystique (New York: Norton, 1963; reprint, New York: Bantam Doubleday Dell, Dell 1983).

psychiatrists had long sought to force women to accept their subordination and punished women who were aggressive, uncooperative, or sexually unorthodox.[91] At roughly the same time, those involved in the nascent gay rights movement launched stinging assaults on the abuses that the profession, which until 1973 defined homosexuality as a form of mental illness, had inflicted upon gay men and lesbians.[92] Attitudes toward mental health within these movements varied in ways similar to that seen within the youth subculture as a whole: some feminists and gay activists denounced the very concept of mental health as a political weapon, while others sought to create mental health programs that would support women and gay people as they struggled to overcome their internal and external oppression.

Former mental patients also began denouncing psychiatrists and mental institutions. Former patients had in previous decades organized on their own behalf: Clifford Beers, who had been institutionalized in private and state facilities for a short period of time, was the driving force behind the creation of the NCMH, and groups of former patients started self-help programs such as the Manhattan-based Fountain House program.[93] However, the ex-patient movement of the 1960's was notable for its sweeping attacks upon the legitimacy of psychiatry and the very concept of mental illness. Groups such as New York City's Mental Patients Liberation Project and publications such as the Madness Network News declared that psychiatry was a bulwark of the established social order and mental institutions were inhumane. Those active in the movement sponsored numerous demonstrations, boycotts, and sit-ins (including a month-long occupation of the offices of California governor Jerry Brown) in an effort to draw attention to their cause. Politically active former patients were aided by mental health professionals sympathetic to their cause. In 1973, radical therapists and former patients held the first annual North American Conference on Human Rights and Psychiatric Oppression, and the group sponsored annual meetings well into the 1980's. However, tensions between the therapists and former patients eventually became too great to surmount and many patient liberation groups ultimately broke with their supporters in the mental health professions.[94]

Civil libertarians were also influenced by the popularity of Laing, Szasz, and Scheff, and as a result began paying closer attention to the practices of mental health professionals.

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[91]Phyllis Chesler, Women and Madness (Garden City, NY: Doubleday, 1972); Naomi Weisstein, "'Kinder, Küche, Kirche' as Scientific Law: Psychology Constructs the Female," in Sisterhood is Powerful: An Anthology of Writings from the Women's Liberation Movement, ed Robin Morgan (New York: Random House, Vintage Books, 1970), 205-19. This interpretation of the work of the mental health professions remains powerful: see Hannah Lerman, Pigeonholing Women's Misery: A History and Critical Analysis of the Psychodiagnosis of Women in the Twentieth Century (New York: Harper Collins, Basic Books, 1996).

[92]Not all segments of the psychiatric profession supported efforts to have homosexuality removed from its comprehensive listing of mental illnesses, the Diagnostic and Statistical Manual of Psychiatric Disorders; to this day, some members of the profession regard homosexuality as a mental disorder. However, the APA asserted after a 1973 referendum vote that homosexuality was not a mental illness and that it would no longer be classed as such. For an analysis of the bitter conflict that the issue, which gay and feminist activists forced the APA to address, produced, see Ronald Bayer, Homosexuality and American Psychiatry: The Politics of Diagnosis, 2d. ed. (Princeton: Princeton University Press, 1987), 101-55.

[93]The Fountain House program was started in the 1940's by a group of former patients of the Rockland State Hospital who felt that they had been cut adrift after discharge. The program was initially an informal support group, but in 1948 it purchased a Midtown brownstone and created a halfway house. In 1955, it hired professional staffers to oversee the program. Fountain House has always emphasized the importance of work in restoring clients' self-confidence. Staffers and clients work side by side at the same tasks, and in 1960 Fountain House started a job-placement program notable for its policy of insuring that mental illness-related absenteeism will not affect employers: if a Fountain House resident cannot go to work on any given day, one of the program's staffers will substitute for him or her. Fountain House also has a striking open-door policy: any person who has been part of the program is welcome to return at any time if he or she feels the need to do so. See Issac and Armat, Madness in the Streets, 289-90.

[94]Issac and Armat, Madness in the Streets, 58-60, 163-74. The ex-patient movement continues to exist; see Support Coalition International, Support Coalition International, available [online]: <http://www.efn.org/~dendron/home/home/home_main.html> [1 June 1998], for information about the movement as it currently exists.

Organizations such as the American Civil Liberties Union and the American Bar Association had in past years devoted increasing attention to the legal issues raised by commitment procedures, but their efforts were limited largely to outlining the law as it then existed and recommending limited changes. As Gerald Grob asserts, these efforts nonetheless had the effect of drawing attention to patient rights and implying that these rights were being violated. This perception was heightened by the proceedings of the Senate Judiciary Committee's Subcommittee on Constitutional Rights, which in 1961 began investigating commitment procedures in the District of Columbia even though there was little evidence that abuses existed; the subcommittee was chaired by Sam Earvin, a Southerner who may have wanted to look tough on civil rights without having to contend with racial issues.[95] New York State and a number of other states responded to initiative such as these by reforming their commitment laws. New York State's new commitment law, which passed in April 1964 and went into effect the following September, greatly reduced the state's reliance upon courtroom commitment hearings, which were widely regarded as humiliating public ordeals. The law also mandated that every involuntary commitment decisions be subject to periodic review and created the Mental Health Information Service, an advocacy and legal advisory service for patients and their families.[96] In 1967, California went even further, enacting legislation that prohibited those who were neither dangerous nor gravely ill from being involuntarily committed for more than seventeen days.[97]

These changes were not sufficient to prevent judicial scrutiny of institutionalization. By the late 1960's and early 1970's, lower federal and state courts, which had traditionally been content to leave mental health policy to psychiatrists, became increasingly willing to intervene when it seemed that patients' civil liberties were being violated. In 1966, Judge David Bazelon of the District of Columbia Circuit Court of Appeals issued a ruling, Rouse v. Cameron, that set the law on a collision course with state commitment procedures. Bazelon asserted that individuals sent to mental hospitals by criminal courts had a right to therapeutic treatment and that denial of such treatment constituted cruel and unusual punishment, denial of due process, and violation of equal protection of the law. Later that year, Bazelon issued another ruling that established patients' right to treatment in the least restrictive setting suited to their condition. Two years later, the Massachusetts Supreme Court followed Bazelon's line of argument and ruled that patients who had been sent to mental hospitals after being deemed incompetent to stand trial for criminal offenses had a right to expect treatment.[98] In New York State, the Court of Claims ruled in 1968 that a man who had been held in Matteawan State Hospital for more than fourteen years because he had allegedly violated his parole had been treated unjustly and awarded him some $300,000 in damages.[99] In the years that followed, many other state and federal courts ruled that some commitment practices violated the Eighth and Fourteenth Amendments. This trend culminated in the U.S. Supreme Court's 1975 decision in O'Connor v.

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[95]Grob, From Asylum to Community, 289-90, 370. Earvin may have had another reason for focusing on the issue: his late brother-in-law had for a time served as president of the APA.

[96]Act of 22 April 1964, Laws of New York, § 3, § 18. The Mental Health Information Service, which still exists, is an arm of the Appellate Division of the New York State Supreme Court. It has from the outset been completely independent of the DMH.

[97]Issac and Armat, Madness in the Streets, 121-24. The idealists and budget-cutters who championed this law were dismayed to find that it did not lead to a dramatic decrease in the number of patients involuntarily placed in state institutions for lengthy periods of time; the law's provision for involuntary commitment of the gravely ill was used to keep many patients in state hospitals.

[98]Grob, From Asylum to Community, 291; Grob, The Mad Among Us, 274-75; Ann Braden Johnson, "Unravelling of a Social Policy: The History of the Deinstitutionalization of the Mentally Ill in New York State" (Ph.D. dissertation, New York University, 1986), 282..

[99]Whitree v. State of New York, 56 Misc 2d 693 (Court of Claims, 1968), 711.

Donaldson. The court did not find that mental patients had a right to treatment, but it unequivocally stated that people who were not dangerous to themselves or others and who were capable of living independently or with assistance from willing family and friends could not be institutionalized against their will.[100] In addition, a number of lower court rulings, including New York City Health and Hospitals Corporation v. Stein, afforded mental patients the right to refuse treatment if they so chose.[101]

In the wake of these decisions, public-interest lawyers, who had during the 1960's begun working with African-Americans, Latinos, women, and other groups traditionally ill-served by the law, started to defend the rights of the mentally ill and the developmentally disabled. In New York State, the New York Civil Liberties Union (NYCLU) initiated a new campaign upon behalf of mental patients. Led by David Ennis, who had little prior knowledge about the inner workings of the mental health system apart from reading of the works of Thomas Szasz, the campaign was also supported by Brooklyn lawyer Morton Birnbaum, the author of a 1960 American Bar Association Journal article that had heavily influenced David Bazelon.[102] The NYCLU initiated New York State Association for Retarded Children v. Rockefeller, the landmark case more popularly known as Willowbrook. Although the court's 1973 ruling stopped short of asserting that people in New York State facilities for the mentally ill, the mentally retarded, and the developmentally disabled had a right to treatment, it found that overcrowding at the Willowbrook State Hospital, a facility for the mentally retarded and the developmentally disabled, violated patients' right to protection from harm and ultimately handed down a consent decree that mandated that all Willowbrook patients were to be placed in community residences.[103] The Willowbrook case gave added impetus to the discharge of patients from state facilities: at least some DMH and other state health officials were afraid that state hospital administrators might eventually have to contend with a Willowbrook-type ruling.[104] In response to this fear, the department may have assigned discharge quotas to administrators of state mental hospitals in an effort to reduce the inpatient census and avert unfavorable legal rulings.[105]

Other factors hastened the decline in hospital populations in New York State and other states. New federal programs made it possible for increasing numbers of mentally ill people who were incapable of supporting themselves to live independently or to be housed in other institutions. Medicaid and Medicare, which resulted in the transfer of large numbers of the aged mentally ill to nursing homes from the mid-1960's onward, were expanded in 1966 to subsidize alternative forms of care for the mentally ill. At the same time, other new Social Security

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[100]Johnson, "Unravelling of a Social Policy," 280-81.

[101]Johnson, "Unravelling of a Social Policy," 285. The other cases establishing this right were Wyatt v. Stickney, a landmark 1972 federal case that also affirmed the right to treatment, and Winters v. Miller, which afforded institutionalized Christian Scientists the right to refuse psychotropic drugs.

[102]Johnson, "Unravelling of a Social Policy," 273-76.

[103] Johnson, "Unravelling of a Social Policy," 274, 284. Other legal cases also affected the operation of state hospitals. Public interest lawyers filed a number of federal suits that succeeded in barring the use of patient labor that was not compensated at prevailing wage levels. These suits were laudable in that they sought to force hospitals to honor labor laws and to prevent them from retaining patients who were well enough to be discharged but capable of performing important tasks. However, these suits also increased the patient inactivity that hospital critics deplored. For a discussion of these suits, see Issac and Armat, Madness in the Streets, 137-39.

[104]See, e.g., New York State Department of Mental Hygiene, Task Force Report: The Department of Mental Hygiene's Inability to Access Community Skilled Nursing and Health Related Facilities (Albany: New York State Department of Mental Hygiene, 1974), [6].

[105]New York State Assembly Legislative Committee, Mental Health Subcommittee on Community Aftercare, From the Back Wards to the Back Alleys (Albany: New York State Assembly, Mental Health Subcommittee on Aftercare, 1978), 5. It is unclear as to whether the existence of these quotas, which were alleged to have been in force from 1968 onward, can be documented: the subcommittee's report claims only that it received "many reports" about their existence.

programs were created: Old Age Assistance, Aid to the Permanently and Totally Disabled (ATPD), and Old Age and Survivor Insurance. The states took advantage of these programs, which made matching funds available to them, and discharged increasing numbers of patients from state facilities. Deinstitutionalization accelerated even further in the wake of the 1972 legislation that created two new Social Security programs, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). SSI and SSDI were designed to guarantee the mentally and physically disabled a minimum income and to remove the stigma long associated with relief payments; by placing them under the umbrella of Social Security, policymakers hoped that these programs would be regarded as entitlements and thus preserve the dignity of recipients. States, which were concerned less with safeguarding the self-worth of the indigent disabled than with shifting the cost of caring for the disabled to the federal government, rushed to secure SSI and SSDI dollars. All of those receiving APTD benefits before 31 December 1973 were guaranteed SSI benefits, and the states responded by enrolling as many of the seriously mentally ill as they could. In addition, SSI's status as an entitlement meant that the application process could begin before a patient was discharged from a state institution, and hospital personnel often took an active part in helping patients secure SSI benefits.[106]

However, SSI, which gradually superseded APTD and was funded wholly by the federal government, had unanticipated and profound effects upon the treatment of the mentally ill. Ann Braden Johnson notes that the SSI program's emphasis upon the rights and dignity of recipients prevented it from mandating that they seek treatment. In addition, those living in publicly-owned halfway houses designed to ease the transition from the institution to society were not eligible for SSI. Patients who had no desire to continue treatment were not forced to do so, and those who did want to do so at times found it difficult to obtain care. As a result of this combination of program requirements and treatment scarcity, many former state mental patients who received SSI ended up living in nursing homes, single-room occupancy hotels (SRO's), or in the nursing homes and private proprietary homes for adults (PPHA's) that sprang up like mushrooms in the wake of the program's creation.[107] This phenomenon may best be described as reinstitutionalization: life in many PPHA's and nursing homes is every bit as regimented and stultifying as life in the state hospital back wards. Television and print journalists who no longer find the state hospitals rich sources of scandal have not been disappointed by these institutions, some (but not all) of which are characterized by listless and overmedicated residents deprived of all recreation other than television, overworked and sometimes abusive staffers, and administrative corruption.[108]

Mental health care in New York State was also affected by a number of less predictable national developments. The economic stagnation and inflation of the 1970's affected almost every aspect of New York State government, and the DMH encountered its share of cost-cutting initiatives and efforts to ensure its fiscal responsibility. Policymakers' concerns about squandering of resources were almost invariably wedded to criticism of the failures of community mental health programs, which politicians and advocacy organizations saw as inadequate, lacking oversight, and resistant to citizen involvement. The DMH, which remained generally optimistic about the possibility of treating most mental illnesses in community-based outpatient settings, tried to respond to these concerns. In 1973, it created the Office of Citizen Participation in an effort to facilitate public involvement in the creation of community mental

[106]Johnson, "Unravelling of a Social Policy," 414-15.
[107]Johnson, "Unravelling of a Social Policy," 416-19.
[108]Johnson, "Unravelling of a Social Policy," 386-95, 482-84, 487-89.

health programs, and in 1974 established a citizen advisory council charged with drafting recommendations for mental health, mental retardation, and substance abuse treatment.[109] During its 1975 reorganization, it created a new office dedicated to oversight of expenditures and gave greater power to its Office of Evaluation and Inspection.[110]

State policymakers sought to resolve other problems that beset the agency. In 1973, the state sought to improve community services and ensure adequate care for the severely mentally ill who had been discharged from state institutions by passing the Unified Services Act in 1973. The Unified Services Act, which had the backing of the DMH, strongly encouraged CMHB's to devise plans for the treatment of the mentally ill living that tied local services to those provided by the state. Unified services plans had to coordinate state and local programs and to ensure that "all population groups [were] covered, that there [was] coordination and cooperation among local providers of services, . . . and that there [was] continuity of care among all providers of services."[111] Localities were not compelled to devise unified services plans, but those that chose not to still had to create comprehensive local plans; communities that failed to draft approved unified or local service plans that were acceptable to the DMH would not receive state support.[112] In an effort to induce local governments to create unified services plans, state funding to localities that had such plans approved increased according to a complicated population-based formula.[113] In order to make it easier for CMHB's to devise unified services plans, the DMH created eight regional offices designed to support and guide them.[114] In the following year, the DMH gave the directors of these regional offices sole responsibility for oversight of all local and state mental health programs in their jurisdictions in an effort to improve the fit between state and local programs.[115]

However, local governments were hesitant to devise unified services plans. In the three years following the passage of the Unified Services Act, only the counties of Rensselaer, Rockland, Westchester, and Warren and Washington (which put forth one plan for both counties) put forth plans that the state approved.[116] Niagara County also drew up a plan, but the DMH refused to accept it on the grounds that county officials could not secure the cooperation of one of its largest providers.[117] In February 1976, Governor Hugh Carey placed an eighteen-month moratorium on acceptance of unified services plans and charged the DMH with determining why localities were so slow to respond to the Unified Services Act. DMH Commissioner Lawrence Kolb allotted this investigation to a task force charged with improving mental health services.

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[109]New York State Department of Mental Hygiene, 1974 Annual Report (Albany: New York State Department of Mental Hygiene, 1974), 5.
[110]New York State Department of Mental Hygiene, 1975 Annual Report (Albany: New York State Department of Mental Hygiene, 1975), 5.
[111]Unified Services Act (1973), § 11.12, § 11.13; § 11.13, subd. 4 quoted.
[112]Unified Services Act (1973), § 11.17.
[113]Unified Services Act (1973), § 11.23.
[114]Department of Mental Hygiene, 1974 Annual Report, 4. The eight regions were: Western New York (Chautauqua, Cattaraugus, Allegany, Erie, and Niagara counties); Finger Lakes (Steuben, Chemeung, Schuyler, Seneca, Yates, Livingston, Wyoming, Genesee, Orleans, Monroe, Ontario, and Wayne counties); Central New York (Tioga, Broome, Delaware, Otsego, Chenango, Cortland, Cayuga, Onondaga, and Madison counties), North Country (Lewis, Hamilton, Warren, Jefferson, St. Lawrence, Franklin, Clinton, and Essex counties); Northeast New York (Greene, Columbia, Schoharie, Albany, Rensselaer, Washington, Saratoga, Schenectady, Montgomery, Herkimer, and Oneida counties); Mid Hudson (Rockland, Westchester, Putnam, Orange, Sullivan, Ulster, and Duchess counties); Nassau-Suffolk, and New York City.
[115]New York State Department of Mental Hygiene, 1975 Annual Report, 5.
[116]New York State Department of Mental Hygiene, Task Force on Mental Hygiene Service Delivery, Toward a New System of Service Delivery of Mental Hygiene Services for the State of New York (Albany: New York State Department of Mental Hygiene, Task Force on Mental Hygiene Service Delivery, [1976]), 25.
[117]Department of Mental Hygiene, 1975 Annual Report, 16, 22.

The task force found that localities were confused by the complex and multi-tiered funding provisions built into the act and intimidated by the prospect of having to coordinate the activities of many different (and sometimes uncooperative) agencies and programs. The permanency of unified services plans, which local authorities regarded as experimental and unprecedented, also gave them; once a locality had put forth an acceptable unified services plan, it did not have the choice of retreating and creating a local services plan if the unified plan proved unsuccessful. Most importantly, local governments were daunted by the prospect of having to increase expenditures for mental health care. Local officials who successfully waded through the Unified Services Act's complex funding formula often realized that a unified services plan would force them to spend more money than they would under a local services plan.[118] As it was, the New York City and Erie and Onondaga counties and other local authorities were reducing mental health expenditures as a result of the economy's downturn.[119] As a result of these problems, the Unified Services Act never produced the results desired by policymakers or the DMH.

Lawmakers, not satisfied with the DMH's efforts to remedy the problems associated with community-based mental health services and state hospital discharge policies, also enacted several pieces of legislation intended to remedy the DMH's shortcomings. From 1975 onward, the department was compelled to take into account the extent to which "consumers, consumer groups, voluntary agencies, and other providers of services" had participated in the development of a given unified services plan when judging whether to approve it.[120] In the following year, the state ordered the DMH to devise a comprehensive plan for the "consolidation [and] realignment of patient care functions" that would simultaneously ensure that patients were receiving adequate care and that resources were not being used inappropriately; the possibility of closing some state hospital facilities was specifically mentioned.[121] At the same time, New York State assumed greater responsibility for the care of the severely mentally ill. In 1974, it passed legislation mandating that all of the costs associated with furnishing aftercare to people who had been patients in state hospitals between 1 January 1969 and 31 December 1973 were to be paid by the state.[122] Another new law made New York State temporarily responsible for paying all public and medical assistance costs incurred by discharged patients who had been institutionalized for at least five years; however, the state's responsibility for costs incurred by a given patient ended after he or she had lived outside of state institutions for five years.[123]

The state's targeting of funds for community care, which was reinforced by the DMH's conscious decision to steer funds away from state hospitals and toward local programs in an effort to discourage use of state facilities, may have resulted in a decline in the quality of care found in state institutions. In 1975, the DMH endured the very public humiliation of having the Creedmoor and Pilgrim Psychiatric Centers stripped of their accreditation. The department was acutely aware that loss of accreditation meant that patients in these facilities were no longer eligible for Medicare and Medicaid reimbursements and publicly proclaimed the need for state facilities to meet accepted standards, but continued to divert funds toward outpatient care, which

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[118]Task Force on Mental Hygiene Service Delivery, Toward a New System of Service Delivery, 26-27.
[119]Task Force on Mental Hygiene Service Delivery, Toward a New System of Service Delivery, 42.
[120]Act of 29 July 1975, Laws of New York, ch. 515, § 1, § 2.
[121]Act of 23 June 1976, Laws of New York, ch. 437, § 1, § 2.
[122]Act of 30 May 1974, Laws of New York, ch. 620, §1, § 2.
[123]Act of 30 May 1974, Laws of New York, ch. 621, §1, § 3. Laws making the state responsible for one hundred percent of the costs associated with the outpatient care of the most acutely mentally ill further retarded the development of unified services plans. They led localities to believe that a dual system of care would continue to exist and tempted them to inflate the number of cases eligible for one hundred percent reimbursement; see Task Force on Mental Hygiene Services Delivery, Toward a New System of Service Delivery, 26-27.

was still widely regarded as less expensive and more humane than care furnished in state hospitals; the inpatient facilities that were best funded were recently constructed ones that were explicitly designed to fit into the community-centered treatment model.[124] In 1977, the DMH further proved that it was committed to moving patients out of state facilities: in response to the planning mandate of the previous year, it proposed closing the Marcy and Northeast Nassau Psychiatric Centers and merging the three facilities situated on New York City's Ward's Island. It also held out the possibility of closing other facilities, arguing that some should be closed because they were no longer housing significant numbers of patients and others because localities were overutilizing them.[125]

The DMH's efforts to direct more funds away from inpatient care and toward community-based outpatient programs sparked outright opposition from a number of quarters. The public and private organizations that furnished most community-based mental health care in many instances resisted accepting former state hospital patients, who were typically impoverished and unresponsive to psychotherapy. In addition, many providers of community-based care and treatment felt that the state had not adequately informed them of the impending return of large numbers of acutely ill people to society. In the New York City area, local mental health providers who felt that they had been taken by surprise formed the Coalition of Voluntary Mental Health, Mental Retardation, and Alcoholism Agencies in 1972 and lobbied city and state officials in an effort to avoid being saddled with what they saw as unanticipated and unwelcome responsibilities.[126] It is likely that providers of outpatient care working in other parts of New York State publicly resisted the state's efforts to force them to care for the seriously mentally ill or simply furnished just the bare minimum of care needed to remain eligible for state reimbursement. However, their ability to resist was soon reduced by the 1975 federal Mental Health Act, which sought to force community mental health centers receiving federal funds to screen and treat discharged state mental hospital patients.[127]

The DMH and state policymakers encountered even more resistance from the Civil Service Employees' Association (CSEA) and one of its offshoots, the Public Employees' Federation (PEF). The PEF, which represented most of those employed in state hospital facilities, and the CSEA reacted violently to the news that the DMH was contemplating the closure of hospital facilities and loudly protested the privatization of mental health jobs. The CSEA created a highly publicized task force that concluded that the state was "dumping" the acutely ill onto the streets and into substandard PPHA's and that community mental health care providers would never willingly care for the most seriously ill.[128] During the 1978 gubernatorial election, the union ran a brief but devastatingly effective radio and print advertising campaign that accused the state of sacrificing patient welfare in the name of cost-cutting. This campaign,

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[124]Department of Mental Hygiene, 1975 Annual Report, 10-11.

[125]New York State Department of Mental Hygiene, Proposals for Consolidation--Realignment of DMH Facilities (Albany: New York State Department of Mental Hygiene, 1977), 4.

[126]Johnson, "Unravelling of a Social Policy," 352, 549; The Coalition of Voluntary Mental Health Agencies, Inc., The Coalition of Voluntary Mental Health Agencies at 25: A Casual History of the First Quarter Century, available [online]: <www.cvmha.org/histoire.pdf> [29 May 1998]. The coalition is somewhat vague about the circumstances that led to its creation, asserting that it took shape because the New York City Department of Mental Health did not appreciate member agencies' commitment to "caring and nurturing of clients" and tried to limit their ability to determine how their clients' needs would best be met. The issue of being forced to care for an undesirable client population is never explicitly mentioned, but it is quite possible that the agencies that formed the coalition objected to being forced to assume responsibility for care of the seriously mentally ill.

[127]Grob, The Mad Among Us, 283.

[128]Civil Service Employees Association, Task Force on Mental Hygiene, Deinstitutionalization: State and County Policies and CSEA Response (New York: Civil Service Employee Association, 1977).

which did little to endear state hospital employees and community-based mental health workers to one another, apparently helped to produce a gubernatorial policy decision that thwarted state and DMH efforts to reduce the role of state facilities in mental health treatment. Shortly after the election, Governor Hugh Carey's chief policy advisor, Robert Morgado, drafted a memorandum that strongly recommended that the staff-patient ratio at state hospitals be increased to roughly 1.0, that hospital officials strive to ensure that all discharges were appropriate, and that employee retraining and transfer programs be implemented. In the wake of Morgado's memorandum, staffing levels apparently increased: an Accountants for the Public Interest study found that in 1981 the staff-patient ratio in state psychiatric facilities, which had been .25 in 1955, had increased to 1.38.[129]

Efforts to reduce the hospital population and create outpatient programs for the seriously mentally ill also provoked increasing opposition from private citizens. Advocates of community-based mental health care had since the 1950's been aware that the public could resist their initiatives, but citizen resistance to the depopulation of state mental hospitals became an increasing concern of policymakers during the 1970's.[130] In part, public resistance may have stemmed from economic conditions: voters who had readily approved local mental health levies in more affluent times were in all likelihood less willing to increase their tax burdens when inflation unemployment were on the rise. The discharge of large numbers of acutely mentally ill persons also aroused considerable fear about increases in crime and public disorder. Proposals for the creation of community-based residential programs for the mentally ill aroused increasing opposition from homeowners concerned about their physical safety and their property values. In 1976, the Assembly Joint Committee to Study the Department of Mental Hygiene faulted the past practices of the DMH for aggravating public resistance: in previous years, large numbers of poorly trained and inadequately socialized patients had been released into communities that were wholly unprepared for their return to society.[131] The combination of fear, anger, and ignorance that greeted community-based efforts to care for the seriously mentally ill remains a serious problem for the state, local and voluntary agencies that support community-based mental health care and treatment.

Mental Health in the Present Era, 1977-98

Frustrated by the slow development of community-based mental health programs, the high cost of furnishing inpatient care, and what it saw as the DMH's inefficiency and lack of clearly defined priorities, the state legislature took action in 1977. It completely recodified the Mental Hygiene Law and reorganized the DMH. In the process, New York State's mental health agency acquired the structure that it has to this day; some of its components have of course been

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[129]Accountants for the Public Interest, The Transfer of People Versus Dollars: Intergovernmental Financing for Mental Health Services in the State of New York (New York: Accountants for the Public Interest, 1983), 38-41. Part of the apparent rise in patient-staff ratio was due to the increase in outpatient and alcoholism services. Although those who conducted the study excluded hospital staffers who furnished outpatient care, they made no effort to disaggregate administrative and support staffers employed at state hospitals; some of these workers were responsible solely for outpatient programs. In addition, staffers responsible for inpatient treatment of alcoholism, a problem that was of increasing concern to policymakers, were included in calculation of staff-patient ratios. The figures put forth by Accountants for the Public Interest differ from those put forth by the Office of Mental Health, which stated in 1982 that its staff-patient ratio was .72; see New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1982 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1982), 2.

[130]See, e.g., Task Force on Service Delivery, Toward a New System of Service Delivery, 5, and New York State Assembly, Assembly Joint Committee to Study the Department of Mental Hygiene, Mental Health in New York State (Albany, New York State Assembly, Assembly Joint Committee to Study the Department of Mental Hygiene, 1976), 191-204.

[131] Joint Committee to Study the Department of Mental Hygiene, Mental Health in New York, 195-96.

created, merged, phased out, or renamed in subsequent years, but its administrative hierarchies generally resemble those established in 1977. The DMH's obligation to care for and treat the mentally ill, the developmentally disabled, and substance abusers was partitioned and invested in three autonomous offices: the Office of Mental Health (OMH), headed by the Commissioner of Mental Health, the Office of Mental Retardation and Developmental Disability (OMRDD), headed by the Commissioner of Mental Retardation and Developmental Disability, and the Office of Alcoholism and Substance Abuse (OASA), headed by the Director of the Division of Alcoholism and Alcohol Abuse and the Director of the Division of Substance Abuse. The three offices were to consult one another on a regular basis and to work together to care for people who had multiple mental disabilities, but the framers of the law clearly hoped that disaggregating the DMH's responsibilities would streamline the department's administration and reduce waste and inefficiency.[132]

In an effort to insure that the New Yorkers who needed the services provided by the OASA, the OMRDD, and the OMH were given appropriate care and treatment, legislators mandated that "each local government [had to] submit a five-year plan and annual implementation plans and budgets which . . . reflect[ed] local needs and resources" in order to remain eligible for state reimbursement.[133] These local or unified services plans had to conform to the state's long-term plans and had to win the approval of all three offices.[134] In order to facilitate these complex and long-range planning activities, the new Mental Hygiene Law established or reformed a host of councils and committees designed to assist the DMH's three offices. The OMH was aided by the Advisory Council on Mental Health, which consisted of the Commissioner of Mental Health and fourteen other members appointed by the governor; at least seven members had to be former patients or outpatient clients, relatives of current or former patients or clients, or other "consumer representatives." The Advisory Committee on Youth, which was similar in composition to the Advisory Council on Mental Health, aided the OMH in identifying the special mental health needs of children and adolescents.[135] The heads of the state's CMHB's (now called community services boards, or CSB's) were incorporated into the State Conference of Local Mental Hygiene Directors, which was to review proposals for changes in local and state provision of care.[136]
These advisory groups and similar bodies established within the OMRDD and the OASA reported to the Council for Mental Hygiene Planning, which consisted of the heads of the OMRDD, the OASA, and the OMH, and fifteen mental health, mental retardation, and alcohol substance abuse experts and advocacy group representatives appointed by the governor. The council was to supervise planning, devise effective evaluation mechanisms, and ensure that local and state programs were working toward common goals. Its ultimate task was to produce a comprehensive and detailed five-year plan and budget that drew upon local government plans and the work of the various councils and committees that reported to it.[137] In addition, these groups were to help the OMH devise new standards for admission to and discharge from all in- and outpatient mental health facilities, provisions for local review of admission and discharge

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[132]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 1. Records pertaining to the reorganization of the DMH are held by the New York State Archives.
[133]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 41.15, subd. b.
[134]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 41.16.
[135]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 7.05. In 1982, these two advisory bodies and the OMH's Advisory Committee on Minority Affairs were merged into the Mental Health Services Council, which was given greater influence in shaping OMH policy; see Act of 27 July 1982, Laws of New York (1982), Ch. 724, § 1.
[136]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 41.10.
[137]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 5.07.

decisions, a state-wide "assessment, evaluation, and reporting system," standard per-patient payment rates for facilities upkeep and programming, and new labor and employment policies governing mental health facilities.[138]

In keeping with its legislative mandate, the OMH devoted increasing attention to planning for future needs. It put forth its first five-year plan in 1978, issued updates in subsequent years, and to this day continues to devise plans in accordance with the 1977 Mental Hygiene Law. It also took other steps designed to increase its accountability to politicians and the public and its ability to perform its mandated tasks. In 1979, it standardized the planning forms and terminology used by localities in order to speed processing and increase the accountability of local officials. A year later, many state and local mental health personnel were using identical service categories in their reports and all local providers were required to employ standard planning, budgeting, and service reporting formats when working with the state.[139] It also sought to standardize patient case records.[140] In addition to reducing the potential for fraud and inefficiency, these changes made it possible for the OMH to compile more detailed statistics about the people it treated.[141]

The OMH also sought to mitigate some of the problems associated with the ad hoc policy of deinstitutionalization. Some of its efforts to do so were mandated by new legislation. Politicians and other policymakers were still convinced that community-based outpatient treatment was far more humane and far less expensive than state hospital care, and they had few alternative options; had they questioned the wisdom of depopulating state facilities, economic circumstances and the newly-established right to refuse treatment would almost certainly have led them to reject the possibility of dramatically expanding state-furnished inpatient care. However, they were displeased by the unplanned and often ill-considered manner in which state facilities had discharged patients. Dismayed that that the overwhelming majority of discharged state hospital patients had no further contact with state or voluntary mental health personnel, in 1977 the state legislature compelled the OMH to locate and contact former patients and to formulate individualized treatment programs for those who needed and desired outpatient care. By December 1979, the OMH had identified 11,000 former patients in need of follow-up care and had contacted ninety-eight percent of them.[142] This effort to insure that the seriously mentally ill were not left to fend for themselves developed into an ongoing intensive case management program that exists to this day.

Other OMH initiatives, most notably the Community Support System (CSS) took shape within the agency itself. The CSS, which was implemented in 1978 and which was in all likelihood propelled in part by the desire to make the state eligible for funds from the NIMH's new Community Support Program for the seriously mentally ill, was funded entirely by the state, supervised by the OMH's five regional offices, and maintained largely by local and private

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[138]Mental Hygiene Law, Laws of New York (1977), Ch. 978, § 41.17. The OMRDD and the OASA were to perform the same tasks.

[139]New York State Office of Mental Health, Annual Report 1979, 8, 20; New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1980 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1980), 4.

[140]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1981 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1981), 3.

[141]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1982 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1982), 3.

[142]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1979 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1979), 4. In all likelihood, OMH staff shortages and time constraints made it impossible for staffers to perform the lengthy follow-up visits and devise the highly individualized treatment plans that policymakers desired

agencies working under contract.[143] It was designed to furnish community-based outpatient treatment and other services needed by seriously ill people who had been patients in state, local, or private inpatient facilities. Almost eighty percent of the initial allocation of $15.1 million was targeted at the communities most profoundly affected by hospital discharges of the acutely mentally ill: Erie, Chemung, Niagara, Broome, Oneida, St. Lawrence, Dutchess, Rockland, Westchester, Sullivan, Nassau, and Suffolk counties, and nine areas within the New York City.[144] By 1984, the CSS, which received almost $50 million in funds, was treating some 20,000 former hospital patients on a regular basis and furnishing sporadic care to another 10,000.[145]

Aware of former patients' difficulties in finding suitable living arrangements, the OMH did as many other state mental health authorities were doing and began financing the establishment and operation of community-based residential facilities. Like its counterparts in other parts of the United States, the office did not become directly involved in the provision of such services; instead, it contracted out to voluntary and for-profit agencies.[146] It began working with a voluntary organization, the Association for Community Living Administrators in Mental Health, to build or subsidize appropriate facilities.[147] The number of beds supported by the OMH grew relatively rapidly but consistently lagged behind need: in 1987, there were only roughly 5, 500 such beds in existence.[148] Not surprisingly, the quality of these residences also varied considerably: a 1988 Commission on Quality of Care for the Mentally Disabled study of thirty-two OMH-sponsored residential facilities found that only one-third were completely "safe, nurturing, and rehabilitative," while half fell somewhat short of OMH goals and fifteen percent fell far short of meeting one or more of the OMH's standards concerning the safety, hygiene, health, recreational, and rehabilitative needs of residents. The commission also found that the OMH had failed to create programs for people who were ready to move out of these residences but were not yet capable of leading completely independent lives; as a result, residence administrators had to choose whether to continue housing people who were ready to assume

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[143]On the NIMH Community Support Program, which was intended to improve coordination of services for the mentally ill, see Grob, The Mad Among Us, 305. In 1982, the OMH received NIMH funding for ongoing analysis of the effectiveness of CSS programs, and it is likely that these funds were made available under the auspices of the Community Support Program; see Office of Mental Health, Annual Report (1982), 15. The 1977 reorganization created five new regional administrative units: Western New York (Chautauqua, Cattaraugus, Allegany, Erie, Niagara, Steuben, Chemeung, Schuyler, Seneca, Yates, Livingston, Wyoming, Genesee, Orleans, Monroe, Ontario, and Wayne counties); Central New York (Tioga, Broome, Delaware, Otsego, Chenango, Cortland, Cayuga, Onondaga, Madison, Lewis, Hamilton, Warren, Jefferson, St. Lawrence, Franklin, Clinton, and Essex counties); Hudson River (Greene, Columbia, Schoharie, Albany, Rensselaer, Washington, Saratoga, Schenectady, Montgomery, Herkimer, Oneida, Rockland, Westchester, Putnam, Orange, Sullivan, Ulster, and Duchess counties); Nassau-Suffolk; and New York City. It is probable that this change was an effort to improve services in the rural parts of the state. The annual reports that the DMH published during the 1970's suggest that rural areas were persistently underserved; in fact, the old North Country region, which contained the Adirondack State Park, was barely mentioned in the DMH's reports even though it contained the St. Lawrence Psychiatric Center.

[144]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1978 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1978), 14.

[145]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1984 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1984), 9.

[146]A 1986-87 NIMH study of state-supported residential programs found that the overwhelming majority of them began in the second half of the 1970's, when federal legislation compelled CMHC's receiving federal funds to furnish appropriate outpatient care for the seriously mentally ill, and mushroomed during the 1980's. The study also found that relatively few agencies were involved in creating and running such programs and that slightly more than half were not-for-profit organizations; see Frances L. Rudolph, Priscilla Ridgway, and Paul J. Carling, "Residential Programs for Persons with Severe Mental Illness: A Nationwide Survey of State-Affiliated Agencies," Hospital and Community Psychiatry 42 (November 1991): 1111-14.

[147]Office of Mental Health, Annual Report 1979, 9.

[148]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1987 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1987), 4.

greater responsibility for their own well-being or to cast them adrift and hope that they would be able to fend for themselves.[149]

The OMH also sought to improve standards of care in state inpatient facilities. Since the passage of the 1890 State Care Act, the DMH sought to insure that state facilities served clearly defined regional cachement areas, but the OMH increasingly felt that simply directing all patients from a given region to a single psychiatric center was wasteful and detrimental to patient well-being. From 1980 onward, it began grouping patients according to degree of treatment needed and level of functioning instead of geographic origin; in doing so, it was emulating the organization of other residential facilities that cared for the mentally ill.[150] The public embarrassment of having two state psychiatric centers denied reaccreditation was also a concern: in 1978 it created a Bureau of Accreditation that conducted preparatory reviews of all facilities awaiting accreditation inspections and in 1981 entered into an agreement with the Joint Commission on Accreditation of Hospitals that allowed it to direct most capital funds away from facilities that were being phased out of existence.[151] Efforts to insure that state psychiatric centers remained accredited also led the OMH to increase staffing levels; of course, continuing political pressure from the CSEA and other unions and the Morgado memorandum also guided its actions.[152] Increasing public concern about the abuse of patients, which culminated in a legislative inquiry into the problem, also goaded it into action. It began implementing reporting and investigative programs designed to uncover such problems, and sent employee representatives from state psychiatric centers to classes at Cornell University's School of Industrial and Labor Relations that detailed how to detect and respond to instances of abusive behavior.[153]

However, the OMH's efforts to improve inpatient care standards in large part grew out of its increasing awareness that serious mental illnesses such as schizophrenia could not be cured and that some patients simply could not function in community settings. During the late 1970's and the 1980's, the population of adult patients in state psychiatric centers declined only one to three percent each year, and the OMH acknowledged that the reduction in the inpatient census was due solely to the deaths of elderly patients; had it not been for these deaths, state hospital populations would have increased slightly during these years.[154] The OMH was also faced with the rapid growth of a new type of patient: the chronically ill young male adult. Men between the ages of eighteen and thirty-four made up an increasing percentage of the inpatient census, and the emergence of this patient cohort baffled OMH officials and other mental health professionals.[155] It is not at all surprising that the number of mentally ill young adults increased

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[149]New York State Commission on Quality of Care for the Mentally Disabled, A Review of 32 Office of Mental Health Supervised Community Residences (Albany: New York State Commission on Quality of Care for the Mentally Disabled, 1988), iii, 3-17. New York State was not atypical in this respect. The 1986-87 NIMH study found that only one-third of the agencies that furnished residential care "offered more than one type of program" and that the "continuum of residential services" needed to furnish effective care apparently did not exist; Randolph, Ridgway, and Carling, "Residential Programs for Persons with Severe Mental Illness," 1114.

[150]Office of Mental Health, Annual Report 1980, 6.

[151]Office of Mental Health, Annual Report 1979, 5, Office of Mental Health, Annual Report (1981), 3.

[152]Office of Mental Health, Annual Report 1982, 2.

[153]Office of Mental Health, Annual Report 1978, 7.

[154]Office of Mental Health, Annual Report 1984, 17.

[155]New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1983 (Albany: New York State Department of Mental Hygiene, Office of Mental Health, 1983), 18. The number of men who were between the ages of eighteen and thirty-four who were in state inpatient facilities increased by eighteen percent in 1983; in contrast, the percentage of those between the ages of thirty-five and forty-four declined by seven percent and those over by twenty-seven percent. Seriously ill young adults also constituted an increasing percentage of those treated at community mental health centers.

at this time: the number of adults between the ages of eighteen and thirty-four swelled as the baby-boom generation came of age. This increase in the absolute number of young adults, not a dramatic rise in the percentage of young adults afflicted by serious mental illness, was most likely responsible for the emergence of this patient cohort.[156] However, the characteristics of this group were in some respects unique: like others their age, acutely ill young adults were suspicious of authority, highly mobile, and unprecedentedly tolerant of illicit drug use. Many refused treatment, tried to run away from their problems (and sometimes ended up on the streets), and descended into alcohol or drug addiction.[157] Legal restrictions, funding shortages, and prevailing treatment philosophies militated against long-term institutionalization of this cohort of patients, but the OMH, other mental health agencies, and policymakers were increasingly forced to acknowledge that some forms of mental illness were hard to treat in outpatient settings and that some people who were capable of living outside of state facilities would never be capable of living independently of some sort of intensive support network.

The OMH also had to contend with a growing number of mentally ill people who were not eligible for any form of outpatient treatment: those who committed serious crimes. The state's prison population increased dramatically during the late 1970's and the 1980's, bringing increasing numbers of mentally ill people into contact with the criminal justice system. The office's increasing responsibility for caring for mentally ill criminals is evident in the rapid expansion of facilities designed specifically for them. In the mid-1970's, the DMH had taken over a reformatory established by the New York City and created the Mid-Hudson Psychiatric Center, which treated those who were deemed incompetent to stand trial or judged not guilty by reason of insanity. In 1977, the OMH established the Central New York Psychiatric Center, which was intended specifically for treatment of mentally ill prison inmates, and started outpatient programs in seven prisons around the state.[158] Between 1977 and 1985, the office also established regional forensic units at the Hutchings, Gowanda, Manhattan, Rochester, and Sullivan Psychiatric Centers.[159] From 1980 onward, the Insanity Defense Reform Act required that the criminally insane be institutionalized for lengthier periods of time and evaluated regularly, thus further increasing the demand for forensic services.[160] As a result, the OMH opened the Metropolitan New York Forensic Center in 1984 and the Kirby Forensic Psychiatric Center in 1985; both of these facilities were intended to relieve persistent overcrowding at the Mid-Hudson Psychiatric Center, which underwent expansion at roughly the same time.[161] Relying in part upon NIMH funding, the OMH also worked with local corrections officers, creating a demonstration program intended to identify and treat suicidal and potentially suicidal

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[156]It is difficult to tell from readily accessible OMH statistics whether the percentage of men being treated in inpatient facilities increased or remained constant; the question certainly bears investigation. The emergence of this patient cohort reflects a decline in the age of first hospitalization or onset of mental illness. In 1981, the OMH anticipated that the inpatient census might increase as the baby boom generation reached its thirties and forties, the age range that had historically produced high rates of hospital admission for schizophrenia and other serious mental disorders; see Office of Mental Health, Annual Report 1981, 21. In 1998, the National Alliance for the Mentally Ill noted that most people who have serious mental illnesses are diagnosed when in late adolescence or early adulthood; see National Alliance for the Mentally Ill, Things You Should Know: NAMI Facts, available [online]: <http://www.nami.org/about/thing.htm> [29 May 1998].

[157]Grob, The Mad Among Us, 296-300.

[158]Office of Mental Health, Annual Report 1978, 20. On the origins of the Mid-Hudson Psychiatric Center, see New York State Department of Parks, Recreation, and Historic Preservation, Bureau of Field Services, "A History of Mental Health Care Institutions in the United States and New York State," by Judith Botch, Albany, 1986, section II, part B, [ii], [iv]. (Photocopied.)

[159]Office of Mental Health, Annual Report 1983, 12; New York State Department of Mental Hygiene, Office of Mental Health, Annual Report 1985, 11.

[160]Insanity Defense Reform Act of 1980, Laws of New York,

[161]Office of Mental Health, Annual Report 1984, 8; Office of Mental Health, Annual Report 1985, 11.

county and city jail inmates.[162] This program soon became a full-fledged component of the OMH's forensic responsibilities and helped to spawn a joint OMH-Department of Correctional Services program that trains police officers how to recognize signs of mental illness and how to respond to mentally ill people they encounter while working.[163]

The OMH also implemented a number of new outpatient treatment initiatives that targeted specific groups of New Yorkers. Aware that African-Americans and Latinos were slightly overrepresented in the state's patient population, the OMH sponsored a number of research projects intended to identify the particular needs of mentally ill African-Americans and Latinos and demonstration programs that sought to provide culturally sensitive treatment; the need to furnish such treatment is to this day one of the office's hey concerns.[164] The OMH also devoted increasing attention to treating mentally ill senior citizens. Even though the state had since the mid-1960's sought to place patients over the age of sixty-five in nursing homes and other facilities, the elderly remained a substantial part of the inpatient population in state facilities and the OMH continued to it difficult to find appropriate placements for patients who no longer needed intensive inpatient care.[165] Increasing knowledge about some forms of mental illness that afflict older people and the concomitant formation of new advocacy groups also prodded the OMH into action. In the early 1980's, the degenerative phenomena that had formerly been attributed to arteriosclerosis or to the process of aging itself were increasingly recognized as symptoms of a distinct and progressive disorder known as Alzheimer's disease. The office sought to provide guidance to families caring for those who suffered the disease and to create day and respite care programs for elderly New Yorkers suffering from Alzheimer's disease and other forms of mental illness.[166] From the mid-1980's onward, it also paid increasing attention to the mental health needs of the growing number of people suffering from the newly-defined physicial illness known as Acquired Immune Deficiency Syndrome, or AIDS.[167]

With the probable exception of its new forensic programs, the OMH's efforts were guided not only by legislative mandates, public-relations considerations, and internal concerns about patient welfare but by pressure from a growing number of citizen advocacy groups. In 1979, the National Alliance for the Mentally Ill (NAMI), which is a support group for people with serious

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[162]Office of Mental Health, Annual Report 1984, 8.

[163]New York State Office of Mental Health, Local Correctional Suicide Prevention Crisis Service Program, available [online]: <http://www.omh.state.ny.us/suicide.htm> [29 May 1998]. New York State Office of Mental Health, Police/Mental Health Coordination Project, available [online]: <http://www.omh.state.ny.us/police.htm> [29 May 1998]. The OMH and the Department of Correctional Services were linked in another way: unneeded buildings at the Pilgrim, Gowanda, and Utica Psychiatric Centers and the Craig Developmental Center were in many instances taken over by the Department of Correctional Services and turned into prison facilities; see New York State Governor's Task Force to Identify Mental Health Facilities to be Adapted for Prison Use, A Proposal to Make Adaptive Use of the State's Capital Plant to Meet Prison Space Requirements (Albany: New York State Governor's Task Force to Identify Mental Health Facilities to be Adapted for Prison Use, 1982).

[164]Office of Mental Health, Annual Report 1981, 18; Office of Mental Health, Annual Report 1983, 24; Office of Mental Health, Annual Report 1985, 6. It is hard to determine the extent to which external political pressure led the OMH to assess whether African-Americans and Latinos were being treated appropriately. African-American and Latino advocacy groups demanding better care for the mentally ill members of their communities do not seem to have existed; it is possible that pressure for improved services emanated from chapters of advocacy groups and mental health professionals working in areas with high concentrations of African-American and Latino people. The OMH's current mission statement affirms the agency's responsibility to provide "individualized services which respect . . . cultural differences"; see New York State Office of Mental Health, OMH Strategic Framework, available [online]: <http://omh.state.ny.us/framewrk.htm.> [1 June 1998].

[165]Office of Mental Health, Annual Report 1980, 10. In 1980, roughly half of the state inpatient population was over the age of sixty-five. However, the percentage of elderly patients ranged from five percent in some new facilities to more than seventy percent in some older rural centers.

[166]Office of Mental Health, Annual Report 1981, 8.

[167]Office of Mental Health, Annual Report 1987, 5.

mental illness and their families, a lobbying organization that sought to increase funding for and levels of care, and a sponsor of research concerning the etiology of mental illness, was founded in Madison, Wisconsin. The NAMI grew rapidly, its membership swelling in large part due to the deep frustration felt by many people who had acutely ill relatives: the absence of appropriate treatment programs for relatives who had been discharged from state facilities or who had repeatedly been hospitalized for long periods of time led many family members to make great personal sacrifices and made many of them feel bewildered and isolated. In the early 1980's twelve New York State NAMI chapters formed the Alliance for the Mentally Ill in New York State, which currently has over seventy chapters and remains dedicated to helping mentally ill people and their families.[168]

Relations between these groups and the OMH and other mental health care providers have not always been ideal: like others who care for chronically ill relatives and lack adequate resources or support, many of those drawn to them were (and are) profoundly dissatisfied with the status quo. Searching for effective alternatives to institutionalization and in many instances convinced that outpatient care was simply not suitable for their relatives, they have often been convinced that state mental health agencies, the state and federal courts, and mental health professionals had failed them; some have openly yearned for a return to long-term institutionalization.[169] As a result, these organizations were at times impatient with and publicly critical of the OMH. However, these groups also sought to work with the OMH and other state agencies, which in the long term probably benefited from their involvement. The OMH's programs for people suffering from Alzheimer's disease were developed in tandem with a new voluntary organization, the Alzheimer Disease and Related Disease Foundation, and in subsequent years the office worked with other citizen advocacy groups when developing new mental health programs.[170] Cooperative efforts such as these may have initially magnified frustrations, but they may also have served to create lasting working relationships between the OMH and the new advocacy groups. In addition, these organizations performed much-needed educational and support functions at little cost to the OMH or other state agencies and pressed legislators to increase funding for mental health treatment and research.

The emergence of this growing citizen constituency was in part propelled by the mounting fiscal difficulties faced by the OMH and social welfare and mental health agencies across the nation. From the late 1970's onward, the OMH shouldered an increasing share of the cost for the care of the mentally ill. The goal of making county and city governments assume a greater share of the burden was increasingly recognized as unworkable, and federal monies earmarked for mental health research and treatment declined substantially. The federal government's intent to decrease funding for mental health care first became evident during the administration of Jimmy Carter. State policymakers, mental health professionals, and advocacy groups had hoped that the Carter administration would produce significant advances in federal support for mental health: First Lady Rosalyn Carter was a prominent advocate of better care for

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[168]Alliance for the Mentally Ill of New York State, About AMI-NYS, available [online]: <http//:www.crisny.org/not-for-profit/aminys/About.html [29 May 1998]; Alliance for the Mentally Ill of New York State, Affiliate List, available [online]: <http//:www.crisny.org/not-for-profit/aminys/affilate.html> [29 May 1998].

[169]Families' anger at not being able to have mentally ill relatives placed in state facilities for lengthy periods of time stemmed from a number of sources. A few probably wanted to be rid of troublesome kin. However, others caring for deinstitutionalized family members had good reason to fear violence from their mentally ill loved ones or watched helplessly as family members repeatedly improved as a result of drug therapy administered in inpatient programs and then declined after they were discharged and refused to take their medicines. See Issac and Armat, Madness in the Streets, 272-76, and Johnson, "Unravelling of a Social Policy," 373-75, 433-34, 486.

[170]Office of Mental Health, Annual Report 1981, 8.

the mentally ill, and the creation in 1977 of the highly publicized President's Commission on Mental Health seemed to portend an expansion of federal support for mental health initiatives. However, the federal government's ability to do so was limited by spiraling inflation, the escalating cost of Medicare, Medicaid and other federal entitlement programs, the absence of vocal champions at the NIMH and other government agencies, and the lack of consensus about priorities; the community mental health centers' many responsibilities and the increasing prominence of psychologists and social workers in the mental health field virtually guaranteed that there would be no agreement as to which forms of mental illness or treatment were to be emphasized. These contradictions were reflected in the 1980 National Mental Health Systems Act, which stressed the need for improving linkages between mental health and other forms of health care, increasing provider accountability, improving care for the acutely ill, and safeguarding patients' civil rights but did not detail how these aims were to be accomplished. In addition, the act stressed that the federal government would continue to help shape mental health policy even as federal funding for community mental health centers would eventually cease.[171]

From 1981 onward, the federal government's reluctant disengagement from mental health policy quickly gave way to a determined retreat. Seeking to cut federal taxes and expenditures, President Ronald Reagan sought to dismantle or shrink many social welfare programs. One of the aims of aims of his first administration was to take apart federal mental health and substance abuse programs, cut federal support for them by twenty-five percent, and forward federal monies to the states in the form of block grants that would allow each state to devise its own mental health and substance abuse treatment policies policies. With the passage of the 1981 Omnibus Budget Reconciliation Act of 1981, which revoked the Mental Health Systems Act, this goal was made into policy.[172] Gerald Grob argues that the Omnibus Budget Reconciliation Act constituted a dramatic rejection of the federal mental health policy that had taken shape during the 1960's. In its wake, American mental health policy was once again the responsibility of the states and of localities. However, the federal government's abdication of responsibility occurred "at precisely the same time that states [and local governments] were confronted with monumental social and economic problems that increased their fiscal burdens" and was as a result particularly disastrous for the mentally ill.[173]

Part of the states' fiscal difficulties stemmed from other federal policy changes. During the Reagan years, the executive and legislative branches of the federal government sought to curb Social Security expenditures. Rejecting the call of the President's Commission on Mental Health, which issued its final report in December 1980, to integrate federal entitlement programs and mental health treatment, both the president and Congress sought to shrink the SSI and SSDI rolls and curb abuse of these programs. Under the provisions of the 1980 Disability Amendments Act, each SSI and SSDI recipient was to undergo a benefits review every three years. Under pressure from the Reagan administration, the Social Security Administration used these reviews to cut large numbers of mentally ill and other disabled recipients from these programs. It created definitions of mental disability that differed considerably from those it had employed in the past and from prevailing professional definitions of acute mental disorder, and its actions resulted in a dramatic decline in the number of mentally ill people receiving SSI and SSDI. Mentally ill people, who constituted roughly eleven percent of recipients, made up some

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[171]Grob, The Mad Among Us, 284-86.
[172]Richard Frank and Thomas MacGuire, "Health Care Financing and State Mental Health Systems," in Health Policy, Federalism, and the American States, ed. Robert F. Rich and William D. White (Washington, D.C.: Urban Institute Press, 1996), 129.
[173]Grob, The Mad Among Us, 286-87.

thirty percent of those dropped from the SSI and SSDI rolls. The vast cuts in SSI and SSDI expenditures, which produced savings far greater than that anticipated by the Reagan administration, ultimately produced a public uproar that compelled the Reagan administration to reverse course.[174] However, the hardships and dislocations that grew out of this policy were no doubt substantial; at least some of those who were denied benefits became homeless and severed all contact with mental health and social service agencies.[175] Decreases in federal support for low-income housing and other social-welfare programs made it even more difficult for mentally ill people to adjust to being removed from the SSI and SSDI rolls.[176]

Federal funding cuts and the state cuts that followed them clearly affected mental health care in New York State. The OMH noted in 1982 that fourteen of the twenty-six community mental health centers that had constructed and staffed under the provisions of the CMHCCA and other federal laws had "graduated from federal funding" and were being supported largely by the state.[177] The state's fiscal difficulties were also noted by the Governor's Select Commission on the Future of the State-Local Mental Health System, which predicted that New York State would eventually face a fiscal nightmare if it did not integrate state and community-based programs more effectively and that it could no longer expect substantial assistance from the federal government.[178] By 1983, funding for a number of OMH programs had been slashed, and the office laid off some personnel and transferred responsibility for the office's Long Island Research Institute to another state agency in hopes of saving money.[179] The office, goaded perhaps by a report from the New York State Division of Audits and Accounts that charged that slipshod OMH managerial practices denied the state some $4.5 million in Medicaid and Medicare reimbursements every year, also automated its billing procedures and took over responsibility for setting Medicaid reimbursement rates in order to insure that it got as much money as possible from remaining federal sources.[180]

In the wake of federal cutbacks, policymakers in New York State and other states were more firmly committed than ever to community-based provision of mental health. Some still hoped that community programs would be much cheaper than inpatient care at state psychiatric centers, but most were guided by the realization that the current fiscal and legal climate militated against any dramatic expansion of inpatient care and remained convinced that inappropriate institutionalization remained a problem. As a result, the OMH sought improve community-based care for the acutely ill. The office created a program designed to support voluntary agencies' efforts to acquire real property and create residences for mentally ill people and sought to boost funding of community-based service programs.[181] In addition, the OMH used the federal block

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[174]Grob, The Mad Among Us, 300-02. The administration had hoped for a savings of $218 million by 1985, but the Social Security Administration projected that some $3.5 billion would be saved by that time.

[175]New York State Governor's Select Commission on the Future of the State-Local Mental Health System, Final Report of the New York State Governor's Select Commission on the Future of the State-Local Mental Health System (Albany: New York State Governor's Select Commission on the Future of the State-Local Mental Health System, 1984), 6. For a complete list of commission members, subcommittee members, and others involved in the Select Commission's work, see pp. i and 45-48.

[176]Frank and MacGuire, "Health Care Financing and State Mental Health Systems," 129.

[177]Office of Mental Health, Annual Report 1982, 2.

[178]Governor's Select Commission on the Future of the State-Local Mental Health System, Final Report, 6.

[179]Office of Mental Health, Annual Report 1983, 5.

[180]New York State Division of Audits and Accounts, Department of Audit and Control, "Re: Audit Report AL-Misc-3-83, Medicare Recovery of Outpatient Service Costs" (20 September 1982); Office of Mental Health, Annual Report 1982, 12, and Office of Mental Health, Annual Report 1983, 22.

[181]Office of Mental Health, Annual Report 1987, 7. The OMH's share of block-grant monies was relatively small: the House Committee on Energy and Commerce concluded that by the early 1990's New York State was directing only ten percent of its block-grant funds to mental health programs. See U.S. Congress, House, Committee on Energy and Commerce, Community

grant funds it received to expand the CSS, and in 1987 streamlined funding for the program by inducing the legislature to merge monies allocated for the CSS with those earmarked to fulfil the state's legal obligation to pay for the aftercare of former state psychiatric center patients.[182]

The OMH also undertook a number highly-publicized efforts to address the problem of homelessness, which grew in part as a result of federal and state cuts in social welfare spending and was particularly pronounced in New York City. The office's drive to furnish care to the homeless was in large part the result of mounting public criticism of past mental health policy: many citizens and politicians had become convinced that almost all former state hospital patients ended up on the streets, that all but a few of them were belligerent, socially disruptive, and potentially dangerous, and that deinstitutionalization was solely to blame for the phenomenon of homelessness and the urban decay associated with it. In reality, only a highly visible subgroup of mentally ill people became homeless and the problem had multiple roots: the shortage of aftercare, the inability of the OMH and other agencies to compel the acutely ill to undergo treatment, the reductions in the SSI and SSDI rolls, alcohol and drug addiction, and New York City real-estate tax and abatement codes that encouraged ruthless (and often illegal) evictions from and demolition of SRO's and other residences inhabited by low-income people.[183]

Aware of the complexity of the problem, the OMH sought to defuse public criticism by addressing the existence of mental illness among the homeless population of the New York City. It cooperated with the Governor's Task Force on the Homeless and, in conjunction with the State Department of Social Services and the New York City Human Resources Administration, created short- and long-term programs for the homeless at the Creedmoor Psychiatric Center.[184] In addition, the OMH, acting in tandem with the Human Resources Administration, placed mental health screening teams in a number of municipal shelters for the homeless; after the Creedmoor facility for the homeless opened in 1985, the OMH screening teams directed those in need of immediate and intensive inpatient care to the city-operated Bellevue Hospital and those requiring less intensive care to Creedmoor.[185] The OMH's efforts did not hold back the swelling tide of public criticism; however, given the multiple causes of homelessness and the simple fact that not all homeless people are mentally ill, no amount of action taken by the OMH would have completely resolved public concern about (and fear of) homeless people.[186]

The financial hardships that the OMH and other mental health authorities endured during the early 1980's became less acute during the second Reagan administration and the administration of George Bush. Advocacy groups and mental health professionals supportive of the reforms outlined by the President's Commission on Mental Health were galvanized into action by dramatic federal funding cuts, and they increasingly made common cause with advocacy groups representing people with other forms of disability. The resulting alliances made it easier for supporters of mental health care expansion and reform to influence the

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Mental Health and Substance Abuse Services Improvement Act of 1992, H. Rept 102-464 to Accompany H.R. 3698, 102d Congress, 2d sess., 1992 (Washington, D.C.: Government Printing Office, 1992), 53

[182]Office of Mental Health, Annual Report 1984, 4-5; New York State Office of Mental Health, Annual Report 1987, 4;

[183]On the roots of the problem of homelessness in New York City, see Johnson, "Unravelling of a Social Policy," 399-410, and Governor's Select Commission on the Future of the State-Local Mental Health System, Final Report, 6.

[184]Office of Mental Health, Annual Report 1983, 4-5.

[185]Office of Mental Health, Annual Report 1985, 32; Office of Mental Health, Annual Report 1987, 27.

[186]The prevalence of mental illness among homeless people has been the subject of protracted debate. Estimates have ranged from twenty to more than fifty percent, and funding considerations may have colored efforts to equate homelessness and mental illness. One New York City mental health worker subsequently recalled that the state labeled homeless people mentally ill because it could use the existing CSS program to finance their care and thus avoided having to pass legislation that would furnish funds through the Department of Social Services; see Johnson, "Unravelling of a Social Policy, 407-09.

formation of policy. In addition, the Social Security Administration implemented a number of desirable changes after it was forced to stop purging mentally ill persons from program rolls. It altered the requirements of SSI (but not SSDI) to allow mentally ill people to remain eligible for partial benefits after they found paid work and expanded Medicaid support for mental health care. These reforms may have stemmed partly from the involvement of the agency's fiscal experts in the work of the President's Commission: as a result, key Social Security personnel became aware that some SSI provisions did not meet the needs of mentally ill recipients.[187]

These changes were accompanied by modest increases in federal spending for mental health research and treatment. These increases were typically implemented with little fanfare: high-profile initiatives such as the 1992 Community Mental Health and Substance Abuse Services Improvement Bill, which sought to make federal funding more equitable and expand community programs, did not become law.[188] Mental health advocacy groups and their friends in the Democratic-controlled Congress soon learned that the most effective way to increase federal mental health expenditures was to bury funding mandates in mammoth budget reconciliation bills that retarded close scrutiny.[189] However, some federal measures explicitly dedicated to improving mental health care did become law. In 1984, Congress succeeded in overcoming the objections of the Reagan administration and bestowed full legal status upon the NIMH's Community Support Program, which for the next five years continued to induce the states to improve services for people with serious and chronic mental illness.[190] In 1986, the State Comprehensive Mental Health Services Plan Act (SCMHSPA), which compelled the states to devise detailed service plans that emphasized improving outpatient-based care for the chronically mentally ill in order to receive federal mental health monies, became law.[191] The planning provisions of the SCMHSPA, which mark a low-profile return to direct federal involvement in the shaping of mental health policy, bear more than a passing resemblance to those contained within the 1977 recodification of the New York State Mental Hygiene Law.

During the presidency of Bill Clinton, the executive and the legislative branches of the federal government have cooperated in increasing both the amount of and the strings attached to the block- grant funds disbursed by the Center for Mental Health Services (CMHS), which is a component of the Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA).[192] In addition to controlling block-grant monies, the CMHS also administers grant funds targeted for demonstration projects involving mentally ill children, programs for the homeless and people with HIV disease, legal advocacy and information groups serving the mentally ill, and training of mental health personnel. The center is also responsible for compiling statistics concerning mental illness, treatment, and research, and furnishing assistance to those devising programs for select populations (e.g., women, African-Americans, Asian-Americans, Latinos, prison inmates, those living in rural areas) or working with disaster survivors. Most recently, the CMHS has begun the National Mental Health

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[187]Chris Koyanagi and Howard H. Goldman, "The Quiet Success of the National Plan for the Chronically Mentally Ill," Hospital and Community Psychiatry 42 (September 1991), 903.

[188]U.S. Congress, House, Committee on Energy and Commerce, Community Mental Health and Substance Abuse Services Improvement Act of 1992, H. Rept 102-464 to Accompany H.R. 3698, pp. 2-8, 57-58.

[189]Koyanagi and Goldman, "The Quiet Success of the National Plan for the Chronically Mentally Ill," 903.

[190]Grob, The Mad Among Us, 305. In 1989, the NIMH dedicated the Community Support Program solely to measuring the effectiveness of state programs.

[191]State Comprehensive Mental Health Services Plan Act of 1986, Statutes at Large 100, sec. 501-03, 3794-97.

[192]See note 19 for discussion of the creation of the SAMHSA.

Services Knowledge Exchange Network, an information clearinghouse for mentally ill people, their family members, and others interested in mental-health issues.[193]

Apart from these incremental increases in federal responsibility and funding for treatment, research, and public education, federal mental health policy has undergone little change during the Clinton years. The first Clinton administration's highly publicized national health insurance plan was notable for its relatively generous provisions for mental health treatment. However, in the wake of the plan's rejection by Republicans and many Democrats in Congress and the 1994 elections that gave control of both houses of Congress to the Republican Party, the Clinton administration has been loath to press for dramatic expansions of social welfare programs. Instead, the administration and Congress have sought modest improvements in third-party insurance coverage of mental health treatment. The Mental Health Parity Act (MHPA) of 1996, which went into effect upon 1 January 1998, compelled corporations that offered mental health benefits to their employees to increase annual and lifetime caps to match more closely those set for physical disorders.[194] These changes have at best meant a modest improvement in the insurance benefits of some seriously or moderately mentally ill people, but mental-health professionals and advocacy groups heralded the MHPA as a first step toward equal coverage of mental and physical disorders.[195] The MHPA did not prohibit the states from enacting more stringent parity legislation, and in its wake a number of states did so.[196] However, New York State was among neither the pioneers that had acted in advance of federal legislation nor among those propelled into action by it. At the present time, state lawmakers apparently believe that the MHPA's provisions are sufficient; apart from a bill improving insurance coverage of treatment for serious mental illness, which is at the time of this writing being studied by the New York State Insurance Department, politicians have been loath to press private insurance companies to offer more comprehensive mental health benefits.[197]

New York State legislators have been much more eager to adopt some of the cost-containment strategies devised by commercial and not-for-profit health insurers. In 1991, they compelled counties to devise managed care programs for Medicaid recipients, including those who are mentally ill, and in 1996 subsequent legislation mandated the creation of Special Needs Plans (SNP's) for mentally ill adults and children who receive Medicaid benefits; pending federal approval, the 1996 legislation also gives the state the power to force the mentally ill into these managed care programs.[198] As of late 1997, the OMH, which has played a substantial role in

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[193]Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, The Center for Mental Health Services Information Page, available [online]: <http://www.samhsa.gov/cmhs/cmhs.cmhs.htm> [29 May 1998].

[194]Mental Health Parity Act of 1996, Statutes at Large 110, sec. 701-03, 2944-50. The MHPA, which expires on 30 September 2001, does not compel companies to offer mental-health coverage, apply to those that have fewer than fifty employees, or extend to treatment for substance abuse and chemical dependency. In addition, corporations that could prove that parity implementation would raise their insurance costs by at least one percent could apply for exemptions. The passage of the MHPA also brings to the fore a subject of particular interest to those seeking to document the development of mental health policy and programs: the history of private insurance coverage of mental illness. Information on this aspect of mental health policy is hard to come by, but it seems that mental health benefits began to develop in the 1960's and became more common in subsequent decades.

[195]See, e.g., National Alliance for the Mentally Ill, The Mental Health Parity Act of 1996, available [online]: <http/nami.org/update/parity96.htm> [1 June 1998].

[196]See National Alliance for the Mentally Ill, State Mental Illness Parity Laws, available [online]: <http://www.nami.org/pressroom/statelaws.html> [1 June 1998].

[197]At present, the only bill that would mandate improved coverage of mental illness is Assembly Bill 1379, which would compel insurers to cover serious mental illness. The bill was sent to the Insurance Department for study in January 1998; see New York State Legislature, Legislative Bill Drafting Commission, Legislative Digest 1998: January 7 to May 22, vol. 2, Assembly Introduction Record, 81.

[198]Act of 12 June 1991, Laws of New York, Ch. 165, § 8;New York State Office of Mental Health, OMH Quarterly 2 (March 1996), available [online]: <http://www.omh.state.ny.us/qvol2no2htm#anchor1348229> [9 June 1998].

determining the provisions of the SNP's, anticipated that the plans designed for adults would be implemented in the summer of fall of 1998 and that those for children and adolescents six months to a year later.[199]

The drive to cut costs also spurred the OMH to close a number of its psychiatric centers. However, declining inpatient populations also drove the closures: the inpatient census declined from 22,724 in 1980-81 to 10,500 in late 1993 and that admissions rates, which had remained constant throughout the 1980's, dropped substantially in 1991-92. In response to this rapid drop in population, the Harlem Valley, Gowanda, Central Islip, Willard, and King's Park Psychiatric Centers all ceased operations during the mid- to late 1990's.[200] The closure of these facilities, coupled with sustained efforts by Mario Cuomo and George Pataki to reduce the number of state employees, produced a dramatic decrease in the number of people employed by the OMH: between 1988 and 1997, transfer programs, retirement incentives, and attrition contributed to a forty-seven percent drop in the agency's workforce. As of late, the OMH anticipates that community-based outpatient programs and the growing number of inpatient psychiatric beds in general hospitals (which are eligible for Medicaid reimbursement) will in the future produce a further decline in the state's inpatient population.[201]

The OMH's closure of facilities and declining workforce gave rise to concern that the welfare of the seriously mentally ill would be sacrificed in the name of cost-effectiveness. In an effort to insure that psychiatric-center closures do not produce the problems associated with deinstitutionalization in the 1970's and that efforts to pare the OMH workforce and close facilities that it operates are not propelled solely by the desire to reduce mental-health spending, the Community Mental Health Reinvestment Act (CMHRA) of 1993 mandates that the savings realized from the closure of Harlem Valley, Gowanda, Central Islip, Willard, King's Park, and any other state psychiatric centers be directed to community-based treatment, residential, and support programs for people with severe mental illnesses.[202] Although Governor Mario Cuomo initially objected to the CMHRA on the grounds that it would tie the hands of his successors and the CSEA was opposed to any facility closures, the Mental Health Action Network, an informal coalition of politicians, mental health professionals and advocacy groups that pressed for the law's passage and shaped its provisions, successfully overcame this opposition and secured its passage. Despite Governor Pataki's efforts to undercut it, the CMHRA remains in effect.[203]

Conclusion

In some respects, the course of mental health treatment and policy in New York State and in the United States from the late nineteenth to the late twentieth century has been circular. Psychiatrists and advocacy groups representing families of the mentally ill now concur that serious mental illnesses are biologically rooted. In the future, the mountain of studies into the neurochemical dimensions of mental illness may alter the very manner in which it is conceptualized: the New York City chapter of the NAMI asserts that "mental illness" is a

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[199]New York State Office of Mental Health, OMH Quarterly 3 (December 1997), available [online]: <http://www.omh.state.ny.us/qvol3no3.htm.#anchor1482785> [9 June 1998].

[200]New York State Office of Mental Health, Statewide Comprehensive Plan for Mental Health Services 1994-1998 (Albany: New York State Office of Mental Health, 1993), 1-2.

[201]New York State Office of Mental Health, OMH Quarterly 3 (June 1997). Available [online]: <http://www.omh.state.ny.us/qvol3no2.htm.> [9 June 1998].

[202]Community Mental Health Reinvestment Act of 1993, Laws of New York, ch. 723, § 2, § 12, subd. a-i, § 24. The relevant provisions of the act expire on 31 March 2000.

[203]For the circumstances leading to the creation and passage of the CMHRA, see Robert N. Swidler and John V. Tauriello, "New York State's Community Mental Health Reinvestment Act," Psychiatric Services 46 (May 1995): 496-500.

misnomer and that "neurobiological disorder" is a more appropriate and precise way of classifying disorders such as schizophrenia, and the term seems to be gaining favor.[204] Although the OMH continues to assert that its actions should be guided by "the expectation that each person can recover from mental illness," advocacy groups such as the NAMI and most members of the psychiatric profession have become markedly pessimistic about curing serious mental disorders.[205] The federal government's retreat from extensive involvement in the shaping of mental health policy and the increasing latitude given the state also calls to mind the decades before the Second World War.

However, these apparent similarities obscure as much as they reveal about the trajectory of mental health policy. The federal government has since the mid-1980's resumed some responsibility for mental health policy and compels states seeking federal funds to adhere to certain requirements concerning care of the seriously mentally ill and development of community-based programs. The OMH and its counterparts in many other states preside over a decentralized system of care and treatment that consists of both local and state agencies and which is supported by a combination of state, local and federal monies. The office also strives to meet the needs of a much broader client population: the expansion of mental health treatment to cover those suffering less serious forms of mental illness or having difficulty coping with difficult life circumstances that began during the Progressive era and blossomed from the 1960's onward has compelled it to develop its programs accordingly. In devising these programs, the OMH continues to rely upon psychiatrists, the traditional providers of care and treatment of the mentally ill, but it also works with psychologists, social workers, and other mental health professionals who no longer defer to psychiatric expertise. State inpatient institutions, which once housed most of the mentally ill, have become but one of several kinds of facilities providing care and treatment, and it is highly unlikely that they will once again predominate: even if the state had the money needed to reconstruct the extensive network of hospitals that once existed, the numerous court cases that established patients' right to refuse treatment would militate against the recreation of the old mental health system.

Changing attitudes toward treatment also work against the reestablishment of the old state hospital-centered system. The hope of finding easy and permanent cures for serious mental illness has been discarded, but few mental health professionals and advocacy groups believe that simple custodial care such as that formerly furnished on the back wards of state hospitals is desirable. Recognizing that serious mental illness is chronic and that those who suffer from it are likely to suffer relapses from time to time, they have instead focused upon trying to ensure that mentally ill people can function to their fullest potential and to reduce the dislocations that the illness produces. Of course, these hopes do not always coincide with reality: in many instances, the quality of life in PPHA's and other institutions that developed as state hospital systems were being dismantled is little better than that found in the back wards of the old state facilities, and community-based programs in many areas remain fragmented and ill-equipped to prevent those with serious mental illness from falling through the gaps in the safety net.

The mental health system of New York State resembles the integrated network envisioned by the drafters of the 1954 Community Mental Health Services Act much more closely than it does the centralized hospital system created by the 1890 State Care Act. However, it continues to exhibit many of the problems highlighted by its critics from the mid-

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[204]National Alliance for the Mentally Ill/ New York City, NAMI/NYC, available [online]: <http://www.schizophrenia.com/ami/> [1 June 1998].
[205]Office of Mental Health, OMH Strategic Framework.

1950's onward: lack of cooperation between state and local providers, gaps in provision stemming from the state's efforts to tailor policy to maximize reimbursements from the federal government, and an unfortunate tendency to lose track of the most acutely ill. Recent policy initiatives spearheaded by the OMH, state lawmakers, and federal authorities have sought, with varying degrees of success, to address these problems, and it seems that this relatively modest goal will in the immediate future continue to animate state and federal policy reforms: given the immense difficulty of radically restructuring such a complex system and the seeming absence of the political will needed to do so, it seems likely that most efforts at changing the mental health system will focus upon correcting its more readily identifiable and (apparently) remediable flaws.

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Timeline

Mental Health Policy in New York State, 1900-1998

1890's-1930's: Psychiatrists, who over the course of the nineteenth century become distant from the medical profession, seek to reestablish their medical credentials. No longer content to see themselves as providers of humane custodial care, they adopt an aggressive therapeutic stance.

1909: The National Committee for Mental Hygiene (NMCH) is founded and headquarters in Manhattan. The NCMH spearheaded the mental hygiene movement, which was pessimistic about curing mental illness but convinced that it could be prevented. The aims of the movement fit well with psychiatrists' efforts to broaden their influence, but by the 1930's the movement's efforts to involve psychologists and social workers in mental health treatment make many psychiatrists feel that their status and authority is under attack. Psychiatrists attracted to the mental hygiene movement refrained from embracing the demands for compulsory sterilization of the mentally ill and developmentally disabled and harsh immigration restrictions put forth by some active in the movement.

1920's: Fever therapy is introduced in mental hospitals. Many psychiatrists are ambivalent about its use.

1920's-1940's: The mental hygiene movement's preventative activities focus upon schools. After the Second World War, concepts of personality development and child guidance become so deeply ingrained in American pedagogical theory that the movement as a result of own success.

1926: The New York State Department of Mental Hygiene (DMH) is created in wake of 1925 constitutional reorganization of state government. The DMH's sole responsibility is to inspect state and private institutions caring for the mentally ill, the developmentally disabled, and epileptics.

1927: The New York State Mental Hygiene Law is enacted. The DMH is given almost all responsibility for the care and treatment of the mentally ill, the developmentally disabled, and epileptics. The Mental Hygiene Law also underscores the influence of the mental hygiene movement upon state policymakers: it mandates the creation of a DMH Division of Prevention.

1930's: Insulin shock and metrazol shock therapies and surgical technique of prefrontal lobotomy are developed. As was the case with fever therapy, many psychiatrists are hesitant to embrace them.

1930's- 1945: Conditions in state mental institutions deteriorate as a result of Depression-era financial hardships and the resource and personnel demands of the war. Physical plants deteriorate and overcrowding is common.

Late 1930's-Early 1940's: Electroconvulsive therapy, which replaces insulin and metrazol shock therapies, is introduced into the United States. Psychologists are of two minds about its value.

1941-1945: The experience of treating military personnel suffering from combat-related mental illness leads many psychiatrists to emphasize the social dimensions of mental disorder. The recognition that patients suffering from war-related disorders respond best when given immediate care in outpatient-based settings leads the profession to hypothesize that mentally ill civilians might best be treated outside of traditional mental institutions.

Late 1940's--Early 1950's: Exposés of hospital conditions produce a widespread public and professional demand first for reform and then for dismantling of state hospitals.

Mid-1940's: Fountain House, a Manhattan-based support group, is started by a group of former patients of the Rockland State Hospital. In 1948, the organization purchases a Midtown brownstone that serves as a residence for program members.

1946: The federal Hill-Burton Act, which allocates monies for state hospital renovation and construction, is enacted.

1949: The National Institute of Mental Health (NIMH), a new component of the Public Health Service's National Institute of Health, comes into existence.

1949: The New York State Mental Health Commission is formed. The commission is charged with meeting annually to determine the outlines of a new state mental health policy designed to reduce the state's inpatient census, which is the largest in the nation.

1954: The New York State Community Mental Health Services Act is passed. The act encourages localities to establish community-based mental health programs and to apply for state reimbursement of up to fifty percent of the cost of these programs.

Mid-1950's: The development of psychiatric drugs such as Thorazine and new tranquilizers reinforce psychiatric confidence in the effectiveness of outpatient treatment and their ability to cure mental illness. Even die-hard champions of environmental models of mental illness are enthusiastic.

Mid-1950's: The open-hospital movement, which developed in Great Britain and emphasizes patients' need to govern their own movements, comes to the United States. In 1957, DMH commissioner Paul Hoch becomes interested and sends seven state hospital

administrators to Britain to study the movement. All seven return adherents of the principle of allowing patients the greatest freedom of movement.

1955: The Federal Mental Health Study Act funds the activities of the Joint Commission on Mental Illness and Health, a study group established by the American Medical Association and the American Psychiatric Association.

1956: The DMH creates the Association of Community Mental Health Boards in order to foster communication between and innovation among community mental health boards (CMHB's), the local authorities responsible for creation and administration of community-based mental health programs.

1959: The DMH creates ten Regional Mental Health Advisory Committees in an effort to assist CMHB efforts to devise suitable programs.

1961: The Joint Commission on Mental Illness and Health issues its final report, Action for Mental Health. The lack of consensus and focus within the commission, which is dominated by social and behavioral psychiatrists, is evident, and APA is divided about its recommendations.

1963: The Federal Community Mental Health Centers Construction Act makes available federal funds for construction of community centers; between one- and two-thirds of the cost of each center is paid for by the federal government. States have to submit plans, designate an agency responsible for executing them, appoint a broad advisory council and develop a construction program. In subsequent years, the federal government allocates some funds for staffing centers and training necessary personnel.

1963: The New York State Mental Hygiene Facilities Improvement Corporation is established and given control of disbursing all local, state, and federal funds targeted for facility construction. The state's Housing Finance Authority, the agency responsible for issuing loans for health facility, public housing, and state university construction projects, is empowered to issue loans for construction of mental health facilities.

1965: Medicare, a federally-supported health insurance program for senior citizens, and Medicaid, a health insurance program for the needy funded jointly by local and federal government, are established. Both contain provisions for mental health treatment, but care furnished in state hospitals is explicitly not covered and mentally ill people under the age of sixty-five are ineligible for Medicaid benefits. These provisions result in the transfer of large numbers of the elderly mentally ill from state hospitals to nursing homes, a shift that increases mortality rates among mentally ill senior citizens.

1967: The NIMH is given full bureau status.

Late 1960's-1970's: Academic attacks on mental health and psychiatry, including some launched from within, proliferate:

-- R.D. Laing, a left-wing Scottish psychiatrist and Thomas Szasz, a libertarian professor of psychiatry at the SUNY Upstate Medical Center at Syracuse University, launch concerted and highly influential assaults upon psychiatry.
-- French philosopher Michel Foucault's studies of insane asylums, penal institutions, and other modern Western phenomena stress that psychiatry and other developments commonly seen as "enlightened" are in fact tools of the modern Western state, which induces people to internalize its codes of thought and behavior.
-- Sociologists such as Earving Goffman assert that psychiatrists are concerned above all else with preserving their own professional identity.

Late 1960's-1970's: The mass political movements of the era are often hostile to the concept of mental health.
-- The New Left sees it as a tool of "the Establishment" and embraces the arguments of Laing, Szasz, and Goffman; however, a few drawn to the New Left attempt to create more responsive alternatives to traditional mental health treatment.
-- Feminists assert that psychiatrists wittingly or unwittingly seek to compel women to accept their subordination.
-- Gay-rights activists, who in 1973 successfully force the American Psychiatric Association to assert that homosexuality is not a mental disorder, denounce the suffering that psychiatrists have caused lesbians and gay men.
--A nascent patient-liberation movement denounces psychiatry and mental institutions as instruments of oppression.
-- Conservatives angered by the pronouncements of the minority of psychiatrists who are active in the civil rights and anti-war movements denounce mental health as a covert means of advancing a liberal or radical political agenda.

Late 1960's-1970's: The definition of mental illness, which has gradually broadened as a result of the mental hygiene movement and psychiatric efforts to expand the scope of their influence, expands to include minor mental disorders and difficulty in coping with life crises. This expansion is in part propelled and reinforced by the increasing involvement of psychologists, social workers and other non-psychiatric personnel in treating mental illness. During the 1960's, these professionals successfully challenge the hegemonic position of the psychiatric profession.

Late 1960's-1970's: The problems associated with the policy of mass discharges from state hospitals, which is increasingly referred to as deinstitutionalization, become increasingly evident: lack of continuity of care and failure to meet the needs of the seriously mentally ill.

Late 1960's-1970's: State and federal courts rule that the mentally ill have the legal right to refuse treatment and cannot be involuntarily committed to mental institutions unless they

pose a clear and present danger to themselves or others. Other court rulings force New York State and other states to improve the quality of care in the institutions they operate.

1970's: Economic difficulties affect the DMH and hamper its ability to maintain and expand programs.

1972: Two new federal Social Security programs, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), dramatically alter care for the mentally ill. Designed to preserve recipients' dignity, they do not mandate that mentally ill recipients seek treatment. These benefits enable those who might otherwise have no place to go other than a state hospital to live independently, sometimes at the cost of ensuring that they are housed, fed, and clad decently.

1973: New York State Unified Services Act seeks to improve coordination between state and local agencies by encouraging localities to devise service plans that harmonize state and local efforts. Owing to the complexity of its funding provisions, local lawmakers' reluctance to embrace untried reform measures or increase spending on mental health programs, the act does not produce desired results: only five counties put forth acceptable unified services plans.

1973: The NIMH is made part of the Department of Health and Human Services' newly created Alcohol, Drug Abuse and Mental Health Administration(ADAMHA). Its research functions are transferred to the National Institute of Health.

1974: The New York State Legislature enacts laws mandating that the state furnish appropriate care for those discharged from state hospitals.

1975: The Creedmoor and Pilgrim Psychiatric Centers are stripped of their accreditation. Although deeply embarrassed, the DMH continues to channel resources away from the state's psychiatric centers.

1975: The Federal Mental Health Act, which Congress passes over the veto of President Gerald Ford, compels federally funded community mental health centers to care for the seriously mentally ill.

1977: The New York State Mental Hygiene Law is recodified and the DMH's responsibilities broken down and assigned to three autonomous offices: the Office of Alcohol and Substance Abuse, the Office of Mental Retardation and Developmental Disability, and the Office of Mental Health (OMH). The recodification also compels local mental health authorities and the three successor offices of the DMH to draw up five-year service plans and to issue annual progress reports.

1977: Jimmy Carter forms the President's Commission on Mental Health.

1978: The OMH creates the Community Support System, a program designed to furnish treatment and support services to the seriously mentally ill. This program may be an effort to secure funds from the NIMH's newly-created Community Support Program for the seriously ill.

1978: The Civil Service Employees Association, the labor union representing many state hospital employees, sponsors a radio and print advertising campaign that accuses the state of "dumping" the mentally ill onto the streets or into substandard custodial facilities. The highly effective campaign, which runs during the gubernatorial election, results in an executive-office policy directive that instructs the OMH to increase staffing levels in state psychiatric centers.

1979: The National Alliance for the Mentally Ill (NAMI), a new advocacy group for people with serious mental illness and their families, is formed in Madison, WI. Branches quickly take shape in New York State. The NAMI is but one of several new advocacy groups that shape the direction of mental health policy.

1980's: The OMH creates new initiatives designed to meet the specific needs of mentally ill African-Americans and Latinos. In response to the emergence of Alzheimer's disease as a distinct mental illness, it increases outpatient programs for the elderly. Escalating prison populations lead it to create new facilities for the treatment of mentally ill criminals, outpatient programs in several state correctional facilities, and training programs for state and local law enforcement officers. From the mid-1980's onward, it also devotes increasing attention to the mental health needs of people with AIDS.

1980: The New York State Insanity Defense Reform Act increases the OMH's responsibility for caring for and evaluating criminals deemed not responsible by reason of insanity.

1980: The National Mental Health Systems Act, which asserts that the federal government will continue to shape mental health policy but will assume less of the burden of paying for treatment, is passed during the last months of Jimmy Carter's presidency.

1981: The President's Commission on Mental Health issues its final report, albeit without fanfare.

1981: The administration of Ronald Reagan abdicates responsibility for setting federal mental health policy. The 1981 Omnibus Budget Reconciliation Act repeals the provisions of the National Mental Health Systems Act, cuts federal mental health and substance abuse allocations by twenty-five percent, and converts them to block grants disbursed with few strings attached. New York State, which uses block-grant monies to fund community-based programs, and other states have to cut mental health programs.

Early 1980's: Seeking to cut federal expenditures, the Reagan administration directs the Social Security Administration to pare the SSI and SSDI rolls. Social Security administrators respond by developing definitions of mental illness that diverge from

those used in the past and those employed by mental health professionals. They also project a savings of $3.5 billion dollars, a figure far larger than that predicted by the administration's budget personnel, who had anticipated a $218 million savings. The mentally ill were disproportionately affected by program cuts: they constituted eleven percent of SSI and SSDI recipients and roughly thirty percent of those purged from the rolls. The resulting dislocations ultimately produce a public outcry that compels the administration and Social Security to back down.

Mid-1980's: Federal support for mental health treatment increases as advocacy groups protest against funding cuts and Democrats in Congress bury funding allocations in omnibus budget bills.

1986: The federal State Comprehensive Mental Health Plan Act compels states to devise detailed service plans that emphasize the needs of the seriously mentally ill in order to remain eligible for federal block grant funds. In its emphasis upon planning, it closely resembles New York State's efforts to insure that seriously ill people receive adequate care.

1992: The federal Alcohol, Drug Abuse, and Mental Health Administration Reorganization Act abolishes the ADAMHA and replaces it with the Substance Abuse and Mental Health Services Administration (SAMHSA). During the Bush and Clinton adminstrations, the SAMHSA emphasizes information provision and administration of block grants, which have more restrictions than they had in the past.

1993: The New York State Community Mental Health Reinvestment Act mandates that all savings realized from the closure of unneeded state psychiatric centers be funneled to community mental health programs. The act is propelled in part by the OMH's intention to close several facilities.

1993: The Clinton administration's efforts to create a national health insurance program are notable for their relatively generous provisions for mental health care. However, the plan is rejected by Republicans and many Democrats in Congress and the administration shies away from advancing any other bold policy initiatives.

1996: The federal Mental Health Parity Act compels companies that offer mental health insurance benefits to their employees to insure that coverage of mental and physical illness is reasonably equitable.

New York State's Community Mental Health Reinvestment Act

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In an era of scarce resources, public mental health systems have been struggling to develop comprehensive community-based treatment and rehabilitation systems for persons with mental illnesses. In New York State the Community Mental Health Reinvestment Act, signed into law in December 1993, establishes the state government's commitment over a five-year period to provide substantial new resources to fund the development of community services. The basic principle behind the legislation, the most significant reform in the state's mental health care financing in decades, is that funds saved from downsizing the state hospital system through closures and census reductions must be "reinvested" to create more community-based services. The authors describe the political processes leading to the act's passage, the obstacles overcome by legislative negotiators, the act's provisions, and some implementation issues. Although the act has received some criticism, it appears to be favorably regarded by mental health advocates, recipients, providers, and administrators. (Psychiatric Services 46:496–500, 1995)

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On December 20, 1993, New York State Governor Mario M. Cuomo signed into law the Community Mental Health Reinvestment Act (1). In several ways, the act dramatically reformed the state's funding of community-based mental health services.

At its core is a basic principle: funds saved from downsizing of the state-operated psychiatric hospital system must be "reinvested" to create more community-based services for persons with severe mental illnesses. The act implements the demand of mental health advocates and the longstanding promise of public officials: dollars should follow persons discharged into the community.

Background

The political impetus for the reinvestment legislation arose from persistent factors that were ignited by recent developments. Mental health activists and others have long advocated a shift in the locus of mental health services from large institutions to smaller, community-based settings.

When this shift began to occur in the 1960s, it reflected changes in treatment philosophy, the advent of new medications, and a preference, from a civil liberties and quality-of-life standpoint, for treatment in less restrictive settings. The shift also coincided with the state's interest in reducing the financial burden of serving an enormous inpatient population, which had reached a peak of 93,000 patients in 1959. As a result of the shift, the census of state-operated psychiatric hospitals in New York fell rapidly and steeply. Between 1983 and 1993 the adult inpatient census declined from 21,800 to about 10,000 patients.

At the same time, mental health advocates contended that the state had failed to match its reduction in inpatient services with the development of community-based services. From a balance-sheet perspective, the contention is debatable. New York State's spending for community-based mental health services has risen significantly over the past decade, from $273 million in 1983–1984 to $560 million in 1993–1994. However, advocates have pointed out that community-based services have received a disproportionately low share of state mental health funding: although 90 percent of persons receiving mental health care are served in community-based programs, such programs have received only about 40 percent of the public mental health system's dollars.

Statistics aside, the most forceful argument that the state was not meeting its responsibility to fund community-based services was the evidence on the streets of New York's major cities: the high visibility of persons with severe mental illness, who were struggling not only with their mental disorders but with homelessness, unemployment, drug and alcohol problems, and poor general health.

The immediate factor that ignited the demand for the reinvestment legislation was the state's budget crisis of 1990–1992. In the mental health arena, the budget crisis increased the pressure on the state both to acceler-

ate downsizing of state psychiatric hospitals and to contain new local mental health spending. Specifically, in conjunction with the 1992 executive budget, the state proposed both the closure of five psychiatric hospitals and an 8 percent cut in community-based mental health spending.

At this juncture, mental health advocates faced not only a steep reduction in community-based funding but a loss of the resource base—funding for psychiatric hospitals, which was the potential source for further community-based funding. The advocates' political goal became clear: further hospital downsizing must be matched by increased community spending.

A coalition of interested organizations began to meet on this issue, calling itself the Mental Health Action Network. Membership in the network was broad and included groups representing patients, families, providers, local governments, and others. Although these organizations clearly shared a broad objective—to push for more spending on community-based mental health services—forging a consensus was no easy matter. They differed in matters ranging from their vision of a community-based system to questions of tactics and how much to compromise.

Despite these differences, by the spring of 1992 the network succeeded in developing a consensus proposal and securing its introduction in the state legislature. The Mental Health Resources Bill (as it was called at that time) attracted some attention but was not acted on during that session. In the spring of 1993 a revised bill was introduced, and the Mental Health Action Network began promoting the bill in earnest through a combination of personal lobbying, demonstrations, media coverage, and other activities.

The politics surrounding the bill at this stage were complex. The state's fiscal crisis still cast a shadow over all proposals for new spending. Nonetheless, legislators shared a growing sense that the mental health system had borne more than its fair share of the brunt of budget cuts in recent years. The bill was also boosted by the rhetoric that it did not seek new spending, only the reallocation of current spending for inpatient services.

Governor Cuomo, however, found the bill highly problematic. Above all, he opposed, as a matter of principle, legislation that would bind him and possibly a future governor to fund a particular budget category according to a formula. He forcefully argued that he had a constitutional responsibility to evaluate the state's projected revenues and projected needs each year and develop a budget accordingly.

In developing the legislation, efforts were made to direct funds toward New York State's most severely mentally ill adults and children and to ensure that funds would be used to purchase an effective array of services.

The governor also lodged other criticisms against the bill. He noted that real savings in inpatient costs came not simply from census decreases but from the closure of facilities, and he criticized the bill for doing nothing to help secure the closure of underutilized state-operated psychiatric hospitals. He also maintained that the bill did not guarantee that funds would go where the need was greatest, such as for care of homeless mentally ill persons, and that the bill did not adequately ensure the cost-effective use of funds.

However, Governor Cuomo increasingly appreciated the principle of reinvestment, as well as the growing political support for the principle. Accordingly, his staff and staff of the State Office of Mental Health began to explore ways to address his specific concerns.

Meanwhile, the bill was promoted by sponsors, advocates, and newspaper editorial boards throughout the state and gathered considerable political momentum. On July 5, 1993, the state senate passed the bill, and at 7 a.m. on July 7, after an all-night session, the state assembly passed it—the last bill passed on the last day of the session.

The governor's signature was required before the bill would become law, and he reiterated his concerns about the bill in its current form. However, he authorized his executive staff, along with OMH staff, to meet with senate and assembly staff to try to work out a compromise bill. Meetings occurred throughout the summer and fall.

In general, the governor's staff pushed for a reinvestment formula linked to actual state savings, an agreement to close five facilities, the targeting of funds for homeless or chemically dependent mentally ill persons, and provisions to make it easier to provide capital financing for community-based services. The legislature generally sought to keep the formula as generous as possible, to restrict the conditions under which closures could occur, and to maintain a politically acceptable geographic distribution of reinvestment funds.

Agreements were reached in the fall of 1993. At a special December legislative session called to address a variety of unfinished business, the legislature passed the revised bill. The governor signed the Community Mental Health Reinvestment Act into law on December 20, 1993.

Provisions of the act

Amount of funds made available. The new legislation establishes a five-year commitment by the legislature and the governor of New York State to shift resources from a shrinking state hospital system into an expanded community-based mental health service system. The act reallocates an estimated $210 million over five state fiscal years, 1994–1995 through 1998–1999.

The funds are derived from three sources. The largest source, amounting to $143 million, is savings asso-

ciated with anticipated declines in the census of patients who are the financial responsibility of the state (that is, adults between the ages of 22 and 64). The second largest source of funds, about $47 million, is savings associated with the closure of at least five state-operated psychiatric hospitals identified in the law. Third, a separate five-year appropriation of $30 million is provided for services to mentally ill persons who are also homeless or substance dependent.

The act requires up to $27 million to be set aside to enhance the number of staff on inpatient wards of state psychiatric hospitals to ensure the health and safety of patients and staff. Therefore, the amount actually "reinvested" into community-based mental health services over the five-year period is expected to total $183 million, or an average annual allocation of $36.6 million. This represents an annual growth rate of approximately 6 percent, a significant improvement over rates in recent, recession-hit years.

The funding made available under the Reinvestment Act is largely contingent on the decline in the psychiatric hospital census. For example, in the first year the act provides for reinvestment of no less than $57,500 per bed closed. Thus the actual amount of reinvestment funding in any fiscal year may vary from the estimates because of the uncertainty of census projections. If census declines exceed projections, more funds will be available for community-based services; if projected declines do not materialize, funding for new services will be less than anticipated.

If the statutory formula described above appears inadequate or excessive in any year, the legislature and the governor retain the authority to modify the funding through the budget process. Indeed, each year's allocations are subject to appropriations.

Geographic allocation of funds. The distribution of funds throughout the state will be accomplished primarily through state grants of aid to each of the state's 58 local governmental units. New York State is diverse in terms of demography, wealth, and needs for services. For political purposes and reasons of fairness, the negotiators of this new law had to ensure that each locality would receive an equitable share of reinvestment funding. However, it was also necessary to make certain that some portion of the funds would be used to redress historic inequities in the distribution of funds and services to meet unmet needs, particularly in inner-city and rural areas. In addition, it was recognized that the promise of additional funding could be used to encourage the development of new services, such as innovative service models, recipient-run programs, and more cost-effective multicounty programs, that would further reduce the need for state-operated inpatient services.

To accomplish these goals, the bill established a four-part allocation formula. First, 50 percent of the funds are distributed on a pro rata basis according to the number of county residents who have serious mental illness. (The City of New York, with roughly half of the state's population, can receive no more than half of this portion of the funding.) Second, 25 percent of the funds are distributed based on each county's relative need for new community mental health services.

Third, 5 percent of funds in any fiscal year are granted to counties served by each state psychiatric hospital that is scheduled to close during that year. Finally, the remainder of such funds—up to 25 percent, depending on the number of hospital closures that year—is distributed at the discretion of the state commissioner of mental health.

Statutory priorities for the discretionary monies (the last category described above) are county proposals designed to deliver needed community-based services to persons who are discharged from state hospitals. The remainder of these discretionary funds is allocated based on the commissioner's determination of priority needs.

The legislation establishes a minimum amount of funding that each county must receive each year, $75,000. This provision ensures that even the most sparsely populated counties will receive funds to provide a meaningful level of services.

Targeted population and services. In the development of the Reinvestment Act, efforts were made to direct funds toward New York State's most severely mentally ill adults and children and to ensure that the funds would be used to purchase an effective array of services. Recipients of the new mental health services are required to have a designated diagnosis of mental illness, with a severity and duration of illness resulting in "substantial functional disability" (2). Particular emphasis is placed on the need to serve "special populations," including mentally ill homeless persons, persons with both mental illness and substance abuse problems, and other "hard-to-serve populations" (3). Hard-to-serve populations are defined to include persons with frequent hospitalizations and persons who have a history of being noncompliant with necessary mental health treatment (4).

Services to be developed are those needed by persons with the most severe mental illnesses. They include emergency and crisis services, intensive case management services, residential services, outpatient services that provide "an adequate level of treatment and rehabilitation," and other support services such as psychiatric rehabilitation, supported work programs, consumer self-help programs, and vocational training (5). The state mental health commissioner is given statutory powers to ensure that reinvestment funds are used to serve persons with severe mental illness and other hard-to-serve populations in a cost-efficient and effective manner.

Counties will use a revised version of the state's existing planning process for community mental health services to determine which services are to be funded and which providers are to receive reinvestment funds. The revised planning process is a locally conducted evaluation, which provides authority to counties to

plan where, when, and how to spend the new funds based on local determinations of need. To assist local governments in this effort, the legislation amends the local planning process to require significant involvement by recipients of mental health services and their families.

Mental health subcommittees, which are appointed by counties to assist in the development and evaluation of local plans for the new services, must include among their membership at least two current or former recipients of services and at least two family members (effective December 20, 1994). These subcommittees are given enhanced authority to review the use of reinvestment funds and report on the consistency of local plans with the needs of residents with serious mental illnesses. Despite the revitalized role of government, recipients, and families in the planning process, the state mental health commissioner retains authority to "modify" any local plan (6).

Funds annually set aside for reinvestment in community mental health services "are intended to pay for the development, expansion, and operation" of new community-based services (7). These funds cannot be used to "supplant or replace" funding of identical community mental health services that had previously been paid for through other sources. Because community-based mental health services in New York are a shared state and local responsibility, the state commissioner of mental health is also authorized to reduce state assistance in future fiscal years to any county that fails to maintain at least the same annual level of financial contributions for local community mental health services.

Recognizing that a handful of newly constructed buildings could devour the bulk of the available funds, the legislation provides that traditional "capital costs" cannot be paid with reinvestment funds. However, counties may use reinvestment funds to pay for initial "program development costs" of community programs and operating costs of these programs, including debt service incurred as a result of building construction or renovation.

Hospital closures and alternate uses of hospital campuses. A significant portion of the money to be reinvested in community services will come from closure over the next five years of five state psychiatric hospitals that the State Office of Mental Health had previously proposed to close. Each of these hospitals is a significant employer and economic resource in its area, and powerful coalitions of local business leaders, labor unions, and state and locally elected officials had presented formidable obstacles to previous attempts to close these facilities. In addition, relatives and friends of patients, and patients themselves, had asserted that closures would impair access to and quality of mental health services.

The legislation requires that plans for reuse and development of state hospital campuses vacated by hospital closures must consider alternative uses that will minimize displacement of the hospital workforce.

The negotiators of the Reinvestment Act were able to forge a political consensus to overcome these obstacles and authorize the closure of five facilities. Several factors accounted for their success. First and foremost, the legislation explicitly links closures to funding and authorization to develop additional community-based services. The act provides that all savings resulting from hospital closures will be reinvested in new or expanded services in areas of the state where persons with serious mental illnesses reside and where the relative need for services is greatest. Furthermore, the new law specifically dedicates a significant infusion of funding for new services—5 percent of that year's new funding—to localities in which a hospital is closed.

Second, by establishing state and local task forces with specific planning responsibilities, the law ensures the involvement of state and local government representatives in developing alternate uses for closed state hospital campuses. In addition, involvement of local community business leaders and the public is ensured through the requirement that at least one public hearing be held before plans are developed for reuse of any closing hospital. To assist in the implementation of plans for alternative uses, the act also expands the authority of the state to convey, lease, or sublease these properties for new public or private uses (8).

Finally, the law includes specific provisions to address several issues unique to a particular hospital or issues considered to be particularly vital by those who negotiated the Reinvestment Act. For example, one hospital, which serves a largely geriatric population, is prohibited from closing until a "co-located, gero-psychiatric" facility is established at a nearby state psychiatric hospital (9). Another hospital, which is located in a rural area of the state that has been particularly hard hit by a federal military base closing and other adverse economic conditions, is prohibited from closing until the aforementioned state task force certifies "that a significant alternative use . . . has been established" (9).

State workforce issues. State labor representatives were concerned that any law encouraging state hospital closures and the reduction of state inpatient resources was certain to have a significant adverse impact on the state workforce, including layoffs. Concern was also expressed that as the hospital census declined, remaining patients were likely to be younger and more seriously mentally ill and would thus require more staff-intensive services to ensure health and safety within the hospital.

Drafters of the Reinvestment Act

attempted to address these workforce issues in several ways. First, labor received statutory assurances that a significant amount of reinvestment dollars (up to 15 percent of each year's funding) would be made available to improve staff-to-patient ratios on state hospital inpatient wards (10). The act also provides that at least 7 percent of all newly developed community services will be state operated and, therefore, will be staffed by state employees. Plans for reuse and development of state hospital campuses vacated by hospital closures must consider alternative uses that will minimize displacement of the hospital workforce. In addition, the state commissioner of mental health, in consultation with commissioners of other relevant state agencies, is required to develop specific proposals to provide continuity of employment, to ease the transition of state employees to other jobs, and to provide alternatives to layoffs.

Implementation issues

As of late 1994, implementation of the Reinvestment Act was well under way—some $38.6 million in first-year projected savings from downsizing and closures was being distributed to counties for new community-based services developed pursuant to local plans. By most accounts, the act is highly regarded, both for the new resources it has made available and for the process by which the funds are allocated. Nonetheless, criticisms have emerged from various quarters.

For example, local reinvestment plans have tended to apply reinvestment dollars toward non-Medicaid programs, such as consumer-run initiatives and nonresidential community support programs. This tendency is partly due to local ideas about desirable programs and partly due to the fact that in New York State, local governments are required to match the state share of most Medicaid expenditures. (The Reinvestment Act provides only the state, not the local, share of Medicaid expenditures.) Consequently, providers and others who had hoped for expansion of Medicaid-funded programs such as outpatient clinics have been disappointed.

Moreover, by promoting the development of community-based services, the Reinvestment Act has become the focus of complaints from some local activists who oppose siting residential programs and other services for persons with mental illness in their neighborhoods. Actually, the Reinvestment Act does not change siting practices in New York State; negotiators on all sides avoided this highly volatile issue. However, the act has been characterized by some as a scheme to expedite deinstitutionalization to the detriment of communities. The fallacy of that critique is that rapid downsizing of state psychiatric hospitals had been occurring for some time; the Reinvestment Act finally attaches funding to that process and thus actually relieves the burden on communities.

Further, many mental health advocates have argued that distribution of new funds for residential services has been far less than need would dictate. In fact, local plans for reinvestment services have devoted only 10 percent of funds to new residential services. Critics argue that this level of funding is inadequate and has resulted from local siting concerns and neighborhood opposition to residential development.

Other concerns have been expressed about such matters as the overall level of funding, whether provisions for including families and recipients in the planning process have "enough teeth" to ensure their meaningful participation, the process for distributing funds for homeless and substance-abusing persons with mental illness, and the dearth of new funding for services for persons not seriously and persistently mentally ill. Such tensions are inevitable in response to a new and complex bill that strives to balance different interests and to set new priorities in an era of scarce resources.

Conclusions

The principle behind the Reinvestment Act is simple and compelling: as state psychiatric hospitals become smaller or close, dollars should follow the patients into the community. Efforts to embody that principle into statute encountered a thicket of legal, political, and fiscal issues, from the governor's institutional concerns about the intrusion on the budget-making authority of the executive to the fear of unions that the bill would expedite layoffs in hospitals and the suspicion of some legislators that it would excessively shift mental health funds from upstate New York to New York City.

Nonetheless, empowered and propelled by pressure from advocates and other lobbying groups, negotiators were able in a relatively short period of time to find viable compromises or other solutions to the myriad problems presented. The result is a bill that if it lives up to its stated goals, will bring about a significant increase in community-based services for persons with mental illness in New York State.

Shortly before publication of this article, newly elected New York Governor George E. Pataki proposed a state budget containing a broad range of spending cuts, including a reduction in funding under the Community Mental Health Reinvestment Act. At this time, it cannot be determined whether the state legislature will adopt those proposals.

References

1. NY Session Laws, chp 723, 1993
2. NY Mental Hygiene Law, sec 1.03(52) (1995)
3. NY Mental Hygiene Law, sec 1.03(51) (1995)
4. NY Mental Hygiene Law, sec 41.16(3)(2) (1995)
5. NY Mental Hygiene Law, sec 1.03(51)(c) (1995)
6. NY Mental Hygiene Law, sec 41.16(e)(2) (1995)
7. NY Session Laws, chp 723, sec 21, 1993
8. NY Session Laws, chp 723, sec 13–18, 1993
9. NY Session Laws, chp 723, sec 24, 1993
10. NY Session Laws, chp 723, sec 19, 1993

November 7, 2022

The President
The White House
1600 Pennsylvania Avenue NW
Washington, D.C. 20500

Mr. President:

There is no question that Americans have suffered great loss of life and endured financial hardships, across all sectors, over the past 32 months due to the COVID-19 pandemic. Frontline healthcare workers risked their lives, provided care during physically and emotionally demanding situations, and bore witness to their patients' goodbyes to loved ones from afar.

Yet, in recent months, hospital emergency departments (EDs) have been brought to a breaking point. Not from a novel problem – rather, from a decades-long,[1] unresolved problem known as patient "boarding," where admitted patients are held in the ED when there are no inpatient beds available. While the causes of ED boarding are multifactorial, unprecedented and rising staffing shortages throughout the health care system have recently brought this issue to a crisis point, further spiraling the stress and burnout driving the current exodus of excellent physicians, nurses and other health care professionals.

Boarding has become its own public health emergency. Our nation's safety net is on the verge of breaking beyond repair; EDs are gridlocked and overwhelmed with patients waiting – waiting to be seen; waiting for admission to an inpatient bed in the hospital; waiting to be transferred to psychiatric, skilled nursing, or other specialized facilities; or, waiting simply to return to their nursing home. And this breaking point is entirely outside the control of the highly skilled emergency physicians, nurses, and other ED staff doing their best to keep everyone attended to and alive.

Any emergency patient can find themselves boarded, regardless of their condition, age, insurance coverage, income, or geographic area. Patients in need of intensive care may board for hours in ED beds not set up for the extra monitoring they need. Those in mental health crises, often children or adolescents, board for *months* in chaotic EDs while waiting for a psychiatric inpatient bed to open anywhere. Boarding doesn't just impact those waiting to receive care elsewhere. When ED beds are already filled with boarded patients, other patients are decompensating and, in some cases, dying while in ED waiting rooms during their tenth, eleventh, or even twelfth hour of waiting to be seen by a physician. The story recently reported[2] about a nurse in Washington who called 911 as her ED became completely overwhelmed with waiting patients and boarders is not unique – it is happening right now in EDs across the country, every day.

> *"At peak times which occur up to 5 days per week we have more patients boarding than we have staffed beds. High numbers have included last week when our 22 bed emergency department had 35 boarders and an additional 20 patients in the waiting room…In addition, we have patients who unfortunately have died in our waiting room while awaiting treatment. These deaths were entirely due to boarding. Our boarding numbers have unfortunately skyrocketed in the wake of covid as a consequence of increasing surgical volumes and decreasing inpatient nurse staffing."* --anonymous emergency physician

To illustrate the stark reality of this crisis, the American College of Emergency Physicians (ACEP) recently asked its members to share examples of the life-threatening impact the recent uptick in boarding has brought to their emergency departments. Excerpts of the responses received, as well as key findings from a qualitative analysis of the submissions, are included in this letter to summarize aspects of the problem. The full compilation of anonymized stories, attached as an appendix, paint a picture of an emergency care system already near collapse. As we face this winter's "triple threat" of flu, COVID-19 surges, and pediatric respiratory illnesses that are on a sudden rise, **ACEP and the undersigned organizations hereby urge the Administration to convene a summit of stakeholders from across the health care system to identify immediate and long-term solutions to this urgent problem.** If the system is already this strained during our "new normal," how will emergency departments be able to cope with a sudden surge of patients from a natural disaster, school shooting, mass casualty traffic event, or disease outbreak?

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[1] Andrulis DP, Kellermann A, Hintz EA, Hackman BB, Weslowski VB. Emergency departments and crowding in United States teaching hospitals. Ann Emerg Med. 1991 Sep;20(9):980-6. doi: 10.1016/s0196-0644(05)82976-2. PMID: 1877784.

[2] "Silverdale hospital short on staff calls 911 for help after being overwhelmed with patients"

Background

Imagine a short-staffed restaurant with seating for 40, with a long line of starving customers that cannot be turned away. The chef and line cooks are desperately trying to keep up to provide safely prepared and high-quality meals. They create space for an extra 15 diners in a back hallway and assign one server to attend to them all. But there are 50 more customers waiting to come into the dining room to eat. They serve as many as possible in chairs in the lobby with a much more limited menu. Now imagine that those who are fed never leave and stay there until they need food again. Meanwhile, Uber Eats and other delivery service orders are also coming in, and the delivery drivers crowd the room further, waiting to pick up orders.

In this simplified analogy, the restaurant is the emergency department; the chef, line cooks, hosts, and waitstaff all comprise the emergency care team; the meals are the emergency care itself; and the Uber Eats drivers are emergency medical service (EMS) crews bringing in more patients. Customarily, patients who arrive to the ED via walk-in are checked in and either directed to a treatment area or the waiting room to wait until space is available, depending on the severity of illness. Once space becomes available, they are taken back into the treatment area for a completion of the clinical assessment and any needed treatment. A decision is then made that the patient is either well enough to go home or requires admission to the hospital for continued treatment. Inpatient beds traditionally require both a physical bed space (patient room) and nurses to care for that patient. Unlike in the ED, most hospitals have ratios of nurses to patients for inpatient beds to promote quality of care and patient safety that are set by state laws, regulatory agencies, and accrediting bodies. If there are no available (staffed) beds within the specific unit to which the patient needs transferring, the patient must wait, or be "boarded" in the ED, often for hours, sometimes days or even weeks. The same issue of required staffing ratios holds true for transfer outside the facility, such as to an inpatient psychiatric facility or a skilled nursing facility. As well, patients that arrive in an ambulance via EMS must be appropriately screened by ED staff before the EMS crew can release the patient and return their ambulance to service. So once the hospital's available inpatient beds are full, more ED patients are boarded and must be accommodated in the ED, filling up valuable ED beds and even hallways. Unless the ED can go on diversion status (which is becoming increasingly difficult), more patients continue to show up via EMS. Needed ambulances must be taken out of service as the EMS crews must often wait hours with their patient in the ED before they can safely hand them over to ED staff. And through this all, walk-in patients continue to arrive to the ED and cannot be turned away under the federal Emergency Medical Treatment and Labor Act, or EMTALA, requirements.

Boarding and ED crowding are not caused by ED operational issues or inefficiency; rather, they stem from misaligned economic drivers and broader health system dysfunction.[3] Boarding and ED crowding lead to increased cases of mortality related to downstream delays of treatment for both high and low acuity patients. Boarding can also lead to ambulance diversion, increased adverse events, preventable medical errors, lower patient satisfaction, violent episodes in the ED, and higher overall health care costs. Much has been written on causes of and potential solutions to boarding, but the issue persists, due in part to its many derivative factors, the disparate stakeholders involved, and misaligned economic incentives.

Preventable Patient Harm

There is ample evidence that boarding harms patients and leads to worse outcomes, compromises to patient privacy, increases in medical errors, detrimental delays in care, and increased mortality.[4] The Joint Commission identifies boarding as a patient safety risk that should not exceed 4 hours,[5] yet many of the responses to the ACEP's call for stories cite boarding times much longer than that as an almost routine occurrence; 97 percent of stories with times provided cited boarding times of more than 24 hours, 33 percent over one week, and 28 percent over 2 weeks.

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[3] Kelen GD, Wolfe R, D'Onofrio G, et al. Emergency Department Crowding: The Canary in the Health Care System. NEJM Catalyst. Epub 2021 Sep 28.

[4] Boudi Z, Lauque D, Alsabri M, et al. Association between boarding in the emergency department and in-hospital mortality: a systematic review. PLoS One. 2020;15(4):e0231253. doi:10.1371/journal.pone.0231253

[5] The Joint Commission. R3 report: requirement, rationale, reference. Accessed March 13, 2022.

Descriptions of the negative impact on patient outcomes, including potentially avoidable deaths, follow:

> *"We are a very rural hospital with only family practice and emergency physicians - there are no specialists within 90 miles…Recently I had a woman with abdominal pain in the ER. When she arrived she had normal vital signs and was not really very sick. Testing showed that she had an infected gallbladder - a simple problem for any surgeon to treat. We called 27 hospitals before one in a different state called us back when a bed finally opened up. She spent thirty six hours in our ER, and was in shock being treated with maximum doses of drugs to keep her alive when she was transferred. She didn't survive."*

> *"…The physician finally was able to see her in a side waiting room, he stepped out of the room for several minutes and on return she was face down and blue. They immediately began trying to resuscitate her, brought her back to our trauma bay in which they were unable to intubate her and then performed an emergent cricothyrotomy on her. She had anoxic brain injury and died. While this sounds like a random occurrence, I am frequently asked to come to the waiting rooms to help carry people out of their cars or off the floor because they have passed out or gone into cardiac arrest in the waiting rooms on multiple occasions. I have since reached out to nearly all my close friends and family and have begged them under no circumstances to go to the ED without reaching out to me first. I have begun doing house calls in my neighborhood as well as Zoom calls with family to keep them out of the ED's because they are so dangerous. In fact, I've gone as far as begun sending people home from the ED whom I would normally admit because the hospitals have become that dangerous. It's safer for many of these people to be discharged home and taken care of by family than run the risk of the multitude of mistakes that are taking place in the hospitals because there is no staff."*

> *"In the past six months, 3 people have died in our er waiting room. One only noticed when he had been sitting for > 6 hours and slumped to the floor. When he was found had been dead "awhile". The patient had been triaged by a nurse, but in a very busy urban where the waiting room is always packed and people regularly wait > 8 hours to be seen regularly the er physicians were never aware of this patient. We can only see new patients all day rotating through 3- chairs as all other beds are full. We physicians want desperately to see patients but there is a huge stop gap as we cannot pull back patients efficiently because there are no nurses for new patients. All ER nurses are now functioning floor nurses for all the boarding patients."*

Waiting Room Care

Many emergency physicians who submitted stories reported daily numbers of boarders close to or even exceeding 100 percent of the total number of beds in their EDs, while the number of patients in the waiting room comprised up to 20 times the number of free treatment beds in which they could even be seen. In the past, that often left only hallway stretchers within the ED to care for incoming patients. But now, those too are increasingly over capacity, and so the emergency department waiting room has become the latest ad-hoc location for receiving patient care.

> *"We've had lobby nurses responsible for 15-20 patients each. We've pushed diltiazem, hung amiodarone, cared for septic shock, and are now admitting patients regularly directly from the lobby. Care is being provided in chairs with little privacy and the hope of a portable monitor. Meanwhile 40 boarders are being cared for in an ED with overhead pages, lights on all the time and a total of 5 bathrooms and no showers. One night we had a septic patient waiting two hours for triage code and die in our triage room."*

> *"My shop is 34 bed rural tertiary care center that serves an area greater than 20,000 square miles. Month after month our boarding issues continue to exacerbate and have surpassed critical levels many months ago. We are frequently the largest in-patient ward in the hospital. Currently we average 28 boarding patients in our department and this has been as high as 41 boarded inpatients and 31 patients in the waiting room less than a week ago…Due to these challenges we have fully implemented "waiting room medicine", closed down our Provider in Triage, instead all providers pickup patients in the waiting room. Nearly 50% of our patient encounters now result in discharge from the waiting room. Finally, it is not at all uncommon to have patients in*

the waiting room with SarsCoV-2, pending orders for heparin, diltazem, or other vasoactive medications. In the past month we have had SAH [subarachnoid hemorrhage, or brain bleed], Fournier gangrene, hip fractures, Septic shock all being treated in the waiting room with no available beds to move them into."

"...our 40 bed ED was boarding a large number of patients up to several days awaiting an inpatient hospital bed with a waiting room of >30 people. We had someone in the lobby who was not being appropriately monitored and began having large bloody vomiting. Vitals were only available from when he initially presented to triage almost 8 hrs ago. He lost pulses in the waiting room in front of others including children. As the resuscitation began in the lobby, this posted high risk for other patients in the lobby as we began CPR while blood ejected from his mouth with every compression. It wasn't until he was in a proper room that we were able to obtain IV access and suction the blood. This was not only scarring for the others and hospital workers, but may have been avoided if our emergency department was decompressed and an appropriate history/exam/workup had been done by me or another physician much earlier in order to initiate treatments that have been shown to improve outcomes related to his presenting complaint and known risk factors."

Patients don't just arrive in the ED through the waiting room—they are also brought in by EMS via ambulance. Many hospitals are unable to go on diversion status, even when the emergency department is completely backed up with patients, which means EMS crews must wait with the patient until they can be seen. This means the ambulances are stuck at hospitals and unable to respond to new emergencies:

"We have 26 beds in the emergency department but often over 50 total patients. We are not allowed to go on divert as [County] does not allow us to. It is often very unsafe in the emergency department when there are too many patients without any physical space or enough nurses to care for them. It puts physicians in a bad place as we have to continue to accept ambulance traffic without being able to care for them or the 20+ patients in the lobby."

"Our County's Emergency Medical Services reduced our ability to go on diversion down to 200 hours max for the month of October. Diversion is when paramedics bypass our hospital to take patients with heart attacks and strokes to other hospitals and is the only mechanism we have to offset ED overcrowding due to inpatient boarding. Removing this ability means patients will continue to arrive despite all beds being occupied with admitted patients thereby forcing us to care for these patients in areas such as ambulance ramps and public hallway spaces. Therefore we are essentially disrobing patients in public spaces in order to care for them. All this because of inpatients boarding in the ED. Basically the ED is the largest inpatient unit in the hospital. Patients are receiving bills for 2 or 3 days of inpatient care but never actually arrive upstairs to an inpatient space."

Pediatric Care

Unfortunately, the pediatric population is not immune to the serious ED boarding issue we are facing—particularly those with mental health conditions. During the last decade, pediatric ED visits for mental health conditions have risen dramatically.[6] The COVID-19 pandemic led to a greater acceleration of these visits, causing several pediatric health organizations to issue a national emergency for children's mental health in 2021 and the U.S. Surgeon General to release an advisory on mental health among youth. According to the Centers for Disease Control and Prevention (CDC), during March–October 2020, among all ED visits, the proportion of mental health-related visits increased by 24 percent among U.S. children aged 5–11 years and 31 percent among adolescents aged 12–17 years, compared with 2019. Further, a metanalysis conducted in 2020 illustrates the detrimental effects of boarding among the pediatric population. Multiple studies show that pediatric patients with mental health conditions who are boarded are more likely to leave without being treated, and less likely to receive counseling or psychiatric medications. Beyond mental health, children with other health care conditions are experiencing similar ED wait

[6] Cutler GJ, Rodean J, Zima BT, et al. Trends in Pediatric Emergency Department visits for mental health conditions and disposition by presence of a psychiatric unit. Acad Pediatr. 2019;19:948–955.

times as adults; even children's hospitals that only serve the pediatric population are already over capacity[7] as cold and flu season is only getting started. The stories below illustrate how boarding is particularly impacting those children in the greatest need of immediate medical attention:

> *"We are a 28 bed pediatric ED, with a catchment area of 2.5 million children. I came onto shift yesterday morning. We had 15 children on psych holds, many of them waiting in the lobby for their 24-72 hours stays so we could use our beds to see medical patients. One of those patients had been in the ED for >150 hours, as their parents had relinquished their rights and DFS was refusing to take the patient back, even though our psychiatry team had cleared them as no longer a danger to self or others. We had 10 admissions boarding, 7 on high-flow oxygen, 4 of which were Peds ICU level. There are no open Peds ICU beds in our 4 closest counties, including our own. We had 35 patients in the waiting room in addition to the 20 medical patients being managed by the ED. We had 7 transfers pending from outside facilities to the ED, plus more awaiting direct admissions from an outside ED to an inpatient bed whenever a bed became available. One that left another hospital's ED against medical advice and came to our ED had been waiting 3 days for transfer. They had an AVM in their brain that needed urgent surgery."*

> *"We had a 12 month old patient who presented in respiratory distress and low oxygenation who was found to have pneumonia and required a high amount of oxygen (Opitflo) to maintain his oxygen saturations. After stabilizing him for the interim, we attempted to transfer to a Pediatric ICU (PICU). We were met with not a single open PICU bed in the state, as well as no hospitals with capability to accept transfer in every major city in the surrounding states. The critically ill child stayed in our emergency department for over 24 hours awaiting acceptance at one of our state's Children's Hospitals and still had an over 8 hour wait for EMS once a bed was available. Luckily, this child started to improve with antibiotics and treatment over those 24 hours though if they had progressed, we may have had to be boarding a child on life support (ventilator) without access to a Pediatric ICU."*

> *"My wife is a Pediatric Emergency Physician. She works at the [redacted] Children's Hospital in the world, with all available services at the hospital and patients from all over the world who come for care. She walked into her shift the other day with over 50 patients in the waiting room of a 60+ bed ER, with all hospital and ER beds already full with sick patients and others holding to be admitted. 27 ER beds were being held up with actively psychotic or suicidal children with nowhere else to go. A young child had to sit in the waiting room for 8+ hours with their lower lip lacerated and nearly completely hanging off of their face, because there weren't any beds available to properly evaluate and treat the patient."*

Psychiatric

Boarding of psychiatric patients in EDs is particularly prevalent, disproportionately affecting patients with behavioral health needs who wait on average three times longer than medical patients because of significant gaps in our health care system. While the ED is the critical frontline safety net, it is not ideal for long-term treatment of mental and behavioral health needs. Research has shown that 75 percent of psychiatric emergency patients, if promptly evaluated and treated in an appropriate location – away from the active and disruptive ED setting – have their symptoms resolve to the point they can be discharged in less than 24 hours. However, far too many Americans have limited options for accessing outpatient mental health care. This can exacerbate ED boarding from two directions: on one end, as patients who can't access outpatient treatment may then enter into a crisis that requires an ED visit, and from the other end, a lack of available outpatient follow-up care prevents patients from being discharged from inpatient psychiatric care and freeing up a bed for the next admission waiting in the ED.

> *"We have ~ 70 beds, this AM we had 42 admitted patients (admitted up to 38 hours earlier), 10 boarding Behavioral Health Patients, and 5 social boarders/group home patients. Our group home patients all have*

[7] https://www.cnn.com/2022/10/25/health/childrens-hospital-beds-delayed-care-long-waits/index.html

chronic, lifelong behavioral issues, and were inappropriately 'dumped' in ED by the group home and guardian (whether LME or DSS, after not following state guidelines related to appropriate group home discharge). Our group home patients have been here from 1200 - 3520 hours. Considering average ED visit being 3-4 hours, those 6 group home patients boarding hours = loss of ability to see upwards of 2500 other ED patients."

"Our system has failed our most vulnerable patients. We held a 14 yr old girl in a tiny ED room for 42 days (!!!) awaiting transfer/placement for inpatient psychiatric care. In our ED we routinely board patients due to the hospital at capacity, but it's particularly bad with mental health patients who need inpatient psychiatric treatment. Our hospital is not a licensed psychiatric facility, and by law we may only hold for 72 hours under a 5150 application. That said, just because there are no facilities able and/or willing to take the patients doesn't mean their psychiatric emergencies have resolved. Can you imagine being confined to a small room, without actually getting psychiatric care, for 42 days??? This could have been the subject of a Stephen King novel. Horrific."

"I'm working in a 9-bed ED with an additional 3-beds dedicated to psychiatric patients. We now have a patient who has been boarding with us for over 5 MONTHS with no end in sight. She is unfortunately a disruptive person as well, interrupting patient care elsewhere in the ED as she wanders the hallways (we do have to allow her out of her 10x10 room on occasion and tying up our security resources. She has injured herself on occasion, and has refused medications until she is so psychotic that she can't refuse them any longer."

Burnout

Overcrowding and boarding in the emergency department is a significant and ever-growing contributor to physician and nurse burnout, as they must watch patients unnecessarily decompensate or die despite their best efforts to keep up with the growing flood of sicker and sicker patients coming in. Health care professionals experiencing burnout have a much higher tendency to retire early or stop practicing all together. This increases the loss of skilled health care professionals in the workforce and adds more strain to those still practicing, which continues the cycle of burnout within the profession.

Though stress is a given in emergency medicine, the rate of burnout is of tremendous concern and causing additional strain to an already crippled healthcare system. Shift work, scheduling, risk of exposure to infectious disease, and violence in the emergency department can all affect the mental health and wellbeing of the physicians and nurses. Coupled with overcrowding and boarding in the ED, health care professionals are now facing stresses and moral injury that go well beyond everyday practice. The danger of the cycle of burnout is further demonstrated with the American Medical Association (AMA)'s recently released study that shows that **62.8 percent of physicians felt burned out in 2021.** Additionally, according to another recent study[8] in Mayo Clinic Proceedings, the burnout rate among physicians in the United States spiked dramatically during the first two years of the COVID-19 pandemic. As the winter's "triple threat" of flu, COVID- 19 surges, and pediatric respiratory illnesses approaches, it is critical that we end the burnout cycle in EDs to ensure our nation's health care workforce can meet the needs of its patient population.

"We are a large-volume ED, seeing 350-400 patients per day. When we have over 50% of our ED beds full of admitted patients (which happens frequently) we have a plan in place to move our physicians out to see patients in the waiting room. We also, at the same time, fill the hallways with stretchers, where patients are interviewed, examined and often given discharge instructions after their workup is complete. As you can imagine, this is not ideal as it is hard to ensure privacy, and patient comfort in either of these settings. Patient experience is impossible to improve for these patients (would you be happy if this was you or your family member???). Physicians are unhappy as it feels like we can't provide the care we want to, the care we went into medicine for...

[8] Tait D. Shanafelt, Colin P. West, Lotte N. Dyrbye, Mickey Trockel, Michael Tutty, Hanhan Wang, Lindsey E. Carlasare, Christine Sinsky, Changes in Burnout and Satisfaction With Work-Life Integration in Physicians During the First 2 Years of the COVID-19 Pandemic, Mayo Clinic Proceedings, 2022, https://doi.org/10.1016/j.mayocp.2022.09.002.

we are drowning, stressed and we need help - desperately."

"Evening shift with 55 boarding admitted patients, waiting room backs up to 45-50 patients. A 70 year old woman presents with abdominal and back pain but relatively normal vital signs. She is in a chair in the waiting room. Due to the # of people in the waiting room her husband is sent up to another waiting area. She waits for over 3 hours. Her husband tries communicating with his wife via text messages, but no response. He comes down to ED to find his wife slumped over in the chair and yells to the triage nurses. The patient is in cardiac arrest. She is brought back to the resuscitation bay but is not able to be resuscitated and dies. The ED team, attending physicians, residents, nurses, techs, when finding out that she had been in the waiting room that long, are devastated, many in tears, highly frustrated by the failure of our institution and US healthcare in general to be able to provide adequate access for patients, adequate staffing for our hospitals and ED's, enough options for longer term care, and a safe environment for patients and providers. Our level of burnout in physicians and nurses is at an all time high. A tragic case like this, a consequence of boarding, is another wound in this long battle which shows no signs of letting up. It even seems to be worsening."

"By the time I saw her she had been there for 6 hours, stuck on a stretcher inches from an intoxicated man who was vomiting on himself and another patient screaming obscenities. She had not gotten any pain medication and was having severe right hip pain. She also had to urinate badly but had been unable to get anyone to help her. There are 2 triage nurses who are there to watch the 15+people who were in ambulance triage that night while also receiving the new EMS patients. Orthopedic surgery saw my patient and admitted her from ambulance triage. For the rest of my 8 hour shift she remained in ambulance triage waiting for a bed upstairs or to go to the or, whichever happened first. She is only 1 of many patients with broken bones that I have seen wait for hours before being seen because of how boarded our ED is…It is demoralizing to start every patient encounter with profuse apologies for the wait and difficulty they have had to endure just being in our emergency department. It is heartbreaking to find someone who could be my grandmother languishing in pain for hours before we are finally able to see and evaluate her. We are in a crisis and although we do everything we can to MacGyver solutions to the problem while we are on shift, there is only so much we can do from the ground. We cannot fix this problem in the ED, we need help."

Staffing Shortages

Nursing shortages have exacerbated the deficiency of the health care workforce and stretched care teams to take on extra hours, care for more patients, and shoulder additional clinical and nonclinical duties. Adding to this challenge is the fact that EDs are also not subject to the same staffing ratio requirements as other parts of the hospital often are, and as a result, the ED too often becomes the only place in which to keep many patients. Prior to the pandemic, the American Association of Colleges of Nursing already projected a nursing shortage. That trend has accelerated due to COVID-19, confirmed by a recent American Nurses Foundation survey[9] which found that 21 percent of nurses surveyed intended to leave their position, with another 29 percent considering leaving. Almost half of all respondents cited insufficient staffing as a factor in their resignation, and their departures will only increase the insufficiency, forcing their fellow nurses to an even more severe condition and impeding the ability to provide high-quality patient care.

"I work in a 34 bed ED in [redacted]. At night we normally staff enough nurses a PA or NP and myself for 20 patients. We calculate one RN to 4 patients. Unfortunately over the past year or more we have nights we hold 20 or more patients in the ED waiting for beds. Some are ICU patients. In the unit they would have one nurse to 1-2 patients. Ours nurses will have one or more sick patient that takes lots of work and at least 3 other patients. Some nights 7 patients to one nurse. This is not safe. We cannot turn people away when over whelmed. That means many people sit in the waiting room uncared for 8-9 or up to 12 hours waiting to be seen."

[9] Mental Health and Wellness Survey Report. American Nurses Foundation 2021.

"While previously we were able to adapt, utilizing float pool to care for these patients and creating "care spaces" in every nook and cranny, the current boarding and staffing crisis leaves us at the breaking point. ED nurses, with less than 50% staffing sometimes at night, are left to care for boarders in the ED as well as acute patients. Inpatients rooms are closed due to staffing with ratios upstairs barely budging from 1:4."

"We are a 70 bed tertiary emergency department as part of a health system and we continually have holding of 10-30 patients in our emergency department for 7-72 hours. This holding may be a result due to volume, a lack of movement upstairs on the inpatient floors (having 'clean' beds available so the nurse doesn't get another patient), holding 'dead beds' for theoretical postoperative patients and trauma victims, nursing ratios of how many patients an inpatient nurse can see (1:4,6 vs and emergency nurse 1:6,8,10,12,18). I've seen elderly patients that cannot fend for themselves in the hallway under cared for and dwindling for hours. I've seen pediatric psychiatric patients held with no free bed to transfer to for two to three days. I've see adult psychiatric patients locked away on a constant observation order in a 4x6' room for 48-80 hours with only the freedom to walk to the bathroom and back (no sunlight, no exercise)."

Misaligned Incentives

Despite years of advocacy and research to draw attention to the harmful impacts of boarding, it continues, largely due to misaligned incentives in how health care is financed. As hospitals continue to bring in and dedicate beds to elective admissions while boarding the backlog of non-elective patients in the ED, the financial benefits of ED boarding exceed the cost.[10] This was reflected in numerous anecdotes collected in the ACEP poll:

"We are a top nationally ranked hospital that, due to budget issues, has now prioritized transfers and surgery admissions over ED admissions. We typically board 120-200 hrs/day and LBTC rates have climbed from 3-4% to 15-20%."

"Since July boarding has become the new norm. In our 15 bed ER we are utilizing space in an adjacent unit to house holds. We have had a steady uptick from 5 in July to 5-10 in august, to now consistently 8-15 boarders/holds per day. Last week the AM doc came in to 15 holds and 2 spaces available to see patients. A nursing leader came down and he told them he was tired of this and admin answer was "we will get through it like we have the last few weeks". We didn't get through it, our patients suffered extensive delays and suboptimal care boarding. Admin doesn't want to pay agency rates, so the ER is bearing the brunt of shortages…We are treating things like acute appendicitis out of the waiting room with IV fluids and antibiotics, fluids while awaiting OR. We have not cancelled any elective surgeries and until last week they were getting inpatient beds before people holding in ED >24 hours right after PACU."

"We are a 38 bed ED, usually with 30-40 pts in the waiting room and many EMS patients waiting for rooms in the hallway. Patients come in agitated, acutely psychotic occasionally violent. We cannot provide these patients with high-quality medical care when they are waiting for a bed for hours/sometimes days. We also have critically ill patients requiring higher level of care who have to wait in hallways. It's not unheard of for these patients to decompensate before we are able to get them into a ED room. This is not sustainable. Saving beds for elective surgical patients while truly ill, critically ill patients waiting hallways in the emergency department is disheartening. It's unsustainable, morally, wrong, and dangerous for staff and for patients. How did we go from being healthcare heroes to an afterthought of the medical system?"

All of these stories paint a stark picture of boarding's impacts on every aspect of the health care system. Yet it is clear a disproportionate share of that burden is being carried by two key stakeholders – the emergency care team and their patients. At any time, any of our loved ones are just a moment away from becoming one of these

[10]"Despite CMS Reporting Policies, Emergency Department Boarding Is Still A Big Problem—The Right Quality Measures Can Help Fix It", Health Affairs Forefront, March 29, 2022. DOI: 10.1377/forefront.20220325.151088

patients, and their health and safety will depend on your immediate action to address a system that is heading towards collapse.

We greatly appreciate the commitment and attention your Administration has given to the health and safety of those in our nation over the last two years, and we implore you to now make the growing crisis of boarding a major priority. We stand ready to collaborate with you and other impacted stakeholders to identify near- and long-term solutions. If you have any questions, please contact Laura Wooster, MPH, ACEP's Senior Vice President of Advocacy & Practice Affairs, at lwooster@acep.org.

Sincerely,

American College of Emergency Physicians
Academy of General Dentistry
Allergy & Asthma Network
American Academy of Child and Adolescent Psychiatry
American Academy of Emergency Medicine (AAEM)
American Academy of Family Physicians
American Academy of Physical Medicine and Rehabilitation
American Academy of Physician Associates
American Association of Oral and Maxillofacial Surgeons
American College of Allergy, Asthma & Immunology (ACAAI)
American College of Osteopathic Emergency Physicians (ACOEP)
American College of Radiology
American Foundation for Suicide Prevention
American Medical Association
American Nurses Association
American Osteopathic Association
American Psychiatric Association
American Society of Anesthesiologists
Association of Academic Chairs of Emergency Medicine
Association of State and Territorial Health Officials (ASTHO)
Brain Injury Association of America
Council of Medical Specialty Societies
Council of Residency Directors in Emergency Medicine (CORD)
Emergency Medicine Residents' Association
Emergency Nurses Association
Family Voices
Infectious Diseases Society of America
International Association of Fire Chiefs
National Alliance on Mental Illness
National Association of EMS Physicians
National Health Care for the Homeless Council
National Partnership for Women & Families
Society for Academic Emergency Medicine
Society of Emergency Medicine Physician Assistants (SEMPA)
The National Alliance to Advance Adolescent Health

cc: The Honorable Xavier Becerra, Secretary, U.S. Department of Health and Human Services
The Honorable Alejandro Mayorkas, Secretary, U.S. Department of Homeland Security

February 7, 2023

The Civil Rights Community Urges Prioritization of Alternative Response in EO Implementation

Dear Deputy Assistant Attorney General Mathis, Deputy Associate Attorney General Mody, and Senior Advisor Fisher,

Thank you for meeting with our groups on January 11, 2023, regarding implementation of Section 14 of Executive Order 14074, Executive Order on Advancing Effective, Accountable Policing and Criminal Justice Practices to Enhance Public Trust and Public Safety (hereafter "EO"). It was an informative and productive meeting, and we look forward to continuing to work together on this important issue.

We would like to emphasize again our commitment to alternative unarmed responders for calls involving people with mental health conditions or other disabilities or who are experiencing a crisis episode — and our continuing serious concerns about co-responder models. Such models lead to continued uses of force and criminalization of people with disabilities, especially when they are Black. We urge you to support alternative responders rather than co-responders in your implementation of the EO, including in any studies, funding, or investments associated with the EO or other activities or programs. Alternative response is an important step towards reducing the harm faced by those experiencing problems with mental health and represents our best chance to respect the civil and human rights of people with disabilities in a safe and just manner.

As you know, encounters with law enforcement can create lasting harm. Black people experience heightened surveillance; higher rates of stops, searches, and arrests by law enforcement; and are grossly overrepresented among those incarcerated in the United States.[1] Police encounters also have a deleterious effect on the mental health of Black people.[2] Vulnerable populations — including people with mental health conditions, deaf people, autistic people, and people with intellectual and developmental disabilities

[1] *See* Legal Defense Fund & Bazelon Center for Mental Health Law. "Advancing An Alternative to Police: Community-Based Services for Black People with Mental Illness." Pg. 2. July 6, 2022. https://www.naacpldf.org/wp-content/uploads/2023-LDF-Bazelon-brief-Community-Based-Services-for-MH48.pdf (hereafter "LDF-Bazelon").

[2] *See, e.g.*, Jindal, Monique, et al. "Police Exposures and the Health and Well-being of Black Youth in the US: A Systematic Review." *JAMA Pediatrics*. Sept. 7, 2021. https://jamanetwork.com/journals/jamapediatrics/article-abstract/2783637.

— are at heightened risk for harm from police encounters, which can often turn deadly, especially when the person involved is Black.[3]

People with mental health conditions and cognitive disabilities are grossly overrepresented among those in jail and prison: Although people with serious mental health conditions comprise only 4 to 5 percent of the U.S. population, they make up about 15 and 20 percent of the prison and jail populations, respectively.[4] The Bureau of Justice Statistics identifies cognitive disability as the number one reported disability in state and federal populations.[5] Law enforcement encounters especially threaten the health of Black people with mental health conditions: A recent study shows that Black men with mental health conditions are shot and killed by law enforcement officers at significantly higher rates than White men who exhibit similar behaviors.[6]

There is a heightened risk that police will harm or kill those with mental health conditions or other disabilities, particularly if the individual at risk is Black, and yet law enforcement is generally the default and sometimes only response to calls from or involving those with mental health conditions. This risk would be mitigated if trained mental health workers, including people with lived experience, responded to these calls instead.[7] Since the risk of harm to the individual is so great, and the actual threat to public safety is usually small, mental health advocates stress that law enforcement response to people with mental health conditions should be avoided whenever possible. Contact between law enforcement and people experiencing mental health crises should be limited to only the rarest exceptions because of the potentially dire consequences. While some advocate for co-responder models, in which law enforcement respond to situations alongside mental health workers, there is not enough evidence to suggest that these models have a positive impact. In fact, law enforcement officer involvement can *increase* trauma to individuals in crisis, and a co-responder model falsely assumes that most mental health-related 911 calls pose a high safety risk that requires police involvement.[8] Police responses present an inherent threat of involvement in the criminal-legal system, including incarceration, and that threat cannot be mitigated by better training or the accompanying presence of a mental health professional. The risk posed by law enforcement involvement to those with mental health conditions is simply too great.

Just as the health care system responds to physical health emergencies, be it with an ambulance, a medic, or other services, so too should the mental health system and peer support lead on responding to mental health crises. Instead of relying on law enforcement, the federal government should help cities, states, and other localities invest in community-based alternative response models and mental health services.

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[3] *See* LDF-Bazelon, *supra* note 1, at 3-6.
[4] *Ibid* at 3.
[5] Maruschak, Laura M., et al. "Survey of Prison Inmates, 2016: Disabilities Reported by Prisoners." *U.S. Dep't of Justice.* March 2021.
[6] M.D. Thomas, N.P. Jewell, & A.M. Allen. "Black and Unarmed: Statistical Interaction between Age, Perceived Mental Illness, and Geographic Region among Males Fatally Shot by Police Using Case-Only Design." 53 Annals of Epidemiology. Pg. 42. 2021.
[7] *See, e.g.*, Espinosa, Carlos Rios. "Canada Program Leads the Way in Addressing Mental Health Crises." Human Rights Watch. Dec. 2, 2021. https://www.hrw.org/news/2021/12/02/canada-program-leads-way-addressing-mental-health-crises.
[8] El-Sabawi, Taleed & Carroll, Jennifer J. "A Model for Defunding: An Evidence-Based Statute for Behavioral Health Crisis Response." 94 Temple Law Review. Pg. 17. 2021. *See also* Bromberg, Rachel. "Busting Myths About Safety and Community Responder Teams." *The Council of State Governments Justice Center*. Oct. 7, 2021. https://csgjusticecenter.org/2021/10/07/busting-myths-about-safety-and-community-responder-teams/.

Providers of all these services must take steps to ensure that staff understand the cultural norms and socio-economic challenges of the communities they serve and the traumas experienced by members of those communities. These steps should include training received from and the involvement of community members themselves, especially those with lived experience.[9] Peers with lived experience and from communities that have borne the brunt of harmful police involvement are key to any response and should be actively involved in developing alternative response models.[10]

Communities across America, in both urban and rural settings, are investing in mental health care crisis teams or other alternative response models with positive results.[11] For example, since 2015, as required by its settlement agreement with the department, Georgia has provided mobile crisis services within all 159 of the state's counties, with an average annual response time of one hour or less.[12] The state has a central call center, the Georgia Crisis and Access Line (GCAL), which deploys community-based crisis response teams (historically, on a disbursed staffing model, with clinicians dispatching from their own homes) to individuals in active crisis.[13] Critically, an increasing number of jurisdictions — including St. Petersburg, Florida; Durham, North Carolina; and Albany County, New York, among many others — have specifically designed their programs so that unarmed teams are answering 911 calls that would otherwise receive a police response by default.[14] Other jurisdictions have trained community members, including but not limited to individuals with background in providing medical care, to work as mobile responders.[15]

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[9] Beck, Jackson, et al. "Civilian Crisis Response: A Toolkit for Equitable Alternatives to Police." *The Vera Institute*. April 2022. https://www.vera.org/civilian-crisis-response-toolkit.

[10] The federal Substance Abuse and Mental Health Services Administration (SAMHSA) has said that to be aligned with best practice guidelines, behavioral health mobile crisis teams should include people with lived experience working as peers. SAMHSA. "National Guidelines for Behavioral Health Crisis Care: Best Practice Toolkit." Pg. 18. 2020. https://www.samhsa.gov/sites/default/files/national-guidelines-for-behavioral-health-crisis-care-02242020.pdf. San Francisco has launched a Street Crisis Response Team (SCRT) program that dispatches teams including a clinician, a community paramedic, and a peer worker to calls for help involving people experiencing mental health crises. City & County of San Francisco. "Street Crisis Response Team." https://sf.gov/street-crisis-response-team (last visited Jan. 23, 2023). As part of its response to a Consent Decree with the Department of Justice, the city of Baltimore is implementing two-person teams including a clinician and a peer worker across the city and three neighboring counties. Behavioral Health System Baltimore. "GBRICS Partnership." https://www.bhsbaltimore.org/learn/gbrics-partnership/#1609274555958-4a845e25-3003 (last visited Jan. 23, 2023).

[11] *See, e.g.*, Congressional Research Serv. "Issues in Law Enforcement Reform: Responding to Mental Health Crises." Pgs. 25-31. Oct. 17, 2022. (appendix describing behavioral health alternative response teams operating in, among others, Albuquerque, New Mexico; Minneapolis, Minnesota; Denver, Colorado; Anchorage, Alaska; Olympia, Washington; and Stockton, California).

[12] Settlement Agreement, Doc. No. 112, Sec. III.B.2.b.v(B)(3), *United States v. Georgia* (N.D. Ga. Oct. 19, 2010).

[13] Georgia Dep't of Behavioral Health & Developmental Disabilities. "The Crisis System of Georgia." https://dbhdd.georgia.gov/be-dbhdd/crisis-system-georgia (last visited Jan. 23, 2023). Among others, Colorado and Washington State are also implementing mobile crisis alternative response teams statewide. *See, e.g.*, Washington State Health Care Auth. "Mobile Crisis Response Program Guide." Oct. 5, 2022. https://www.hca.wa.gov/assets/program/mobile-crisis-response-program-guide.pdf.

[14] *See* "Community Assistance and Life Liaison." *City of St. Petersburg*. https://police.stpete.org/call/index.html#gsc.tab=0 (last visited Jan. 31, 2023). "Community Safety." *City of Durham.* https://www.durhamnc.gov/4576/Community-Safety (last visited Jan. 31, 2023); "Albany County Crisis Officials Responding and Diverting (ACCORD)." *University of Albany*. Aug. 2022. https://www.albanycounty.com/home/showpublisheddocument/22105/637983135518570000.

[15] *See, e.g.*, National Ass'n of State Mental Health Program Directors. "Strategies for the Delivery of Behavioral Health Crisis Servs. In Rural and Frontier Areas of the U.S." Pgs. 5-6. Aug. 2020. (describing Alaska's community-based Behavioral Health Aide program, established in 2008 and following a similar program providing medical services in rural communities: BHAs are often the first to identify when someone is experiencing a crisis, and are the first to respond to traumatic events in the communities they serve. Alaska has found the BHA program to be

Some programs pair workers like these with emergency medical technicians as part of an alternative response.[16] Following the embrace of telehealth services during the COVID-19 pandemic, and with increased federal support available through the American Rescue Plan, other models pair onsite in-person crisis response with virtual support from clinicians and/or prescribers.[17]

A significant benefit from the use of alternative response is the increased likelihood that individuals with mental health conditions will be effectively linked to voluntary, longer-term community-based services that have been shown to help them live successfully in their own homes and communities.[18] Voluntary engagement in assertive community treatment (ACT), housing support programs, supported employment, peer support services, and outpatient medication assisted treatment (MAT) have been shown to help people with mental health conditions avoid involvement with law enforcement and subsequent incarceration.[19] In particular, ACT and other multidisciplinary team approaches are functioning in both urban and rural areas and should be the first responders for individuals enrolled in such programs.[20]

We ask that, as you implement the executive order, you and your colleagues at the Department of Justice and at the Department of Health and Human Services keep these considerations in mind and work to prioritize alternative response as much as possible over law enforcement involvement in incidents involving those with mental health conditions. If you have any questions, please feel free to contact Chloé White, senior policy counsel for justice at The Leadership Conference, at white@civilrights.org.

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effective at utilizing available human resources in communities that may otherwise not have an adequate supply, or any supply, of licensed behavioral health providers.") [hereinafter Strategies for Rural Areas], https://nri-inc.org/media/1679/2020paper10.pdf. Colorado's efforts to implement a similar program in its rural areas have been delayed by the COVID-19 pandemic. *Id.* at 7.

[16] *See, e.g.*, #CrisisTalk. "How a 911-EMS Crisis Intervention Diverts People in Mental Health Crisis." (describing Atlanta's Upstream Crisis Intervention mobile team program) (last visited Jan. 23,2023); Rockland Paramedic Servs. "EMS Mobile Crisis Team" (describing EMT-clinician mobile response teams deployed in Rockland County, New York). http://www.dsriplearning.com/2018/library/presentations/breakout-sessions/C5_Success%20in%20Mobile%20Crisis%20Service%20Delivery%20(1).pdf (last visited Jan. 23, 2023).

[17] *See, e.g.*, Strategies for Rural Areas, *supra* note 15, at 10 (describing Charleston County, South Carolina, program under which ambulance workers use tablet to connect individual in crisis with mobile crisis team for triage: "Service is immediate and allows for more appropriate use of EMS time and resources, and reduces the number of referrals to emergency departments in the county. It reduces the need for mobile crisis teams to travel long distances to reach a crisis, and allows individuals in crisis to receive services quickly.").

[18] *See, e.g.*, Watson, Amy C., et al., "Crisis Response Services for People with Mental Illness or Intellectual or Developmental Disabilities: A Review of the Literature on Police-Based and Other First Response Models." *The Vera Institute.* Pg. 44. 2019. (following literature review, concluding that mobile crisis services "have high rates of consumer and provider satisfaction and can effectively increase community-based service use, reduce reliance on psychiatric ED [emergency departments], and link people to community-based care once discharged from an ED"), https://www.vera.org/downloads/publications/crisis-response-services-for-people-with-mental-illnesses-or-intellectual-and-developmental-disabilities.pdf.

[19] *See, e.g.*, Bazelon Center for Mental Health Law. "Diversion to What? Evidence-Based Services That Prevent Needless Incarceration." 2019. https://www.bazelon.org/wp-content/uploads/2019/09/Bazelon-Diversion-to-What-Essential-Services-Publication_September-2019.pdf.

[20] *See, e.g.*, Swanson, CL & Trestman, RL. "Rural Assertive Community Treatment and Telepsychiatry." J Psychiatry Pract. 24(4). Pgs. 269-273. July 2018. https://pubmed.ncbi.nlm.nih.gov/30427810/; RI Int'l. "Assertive Community Treatment (ACT) Team" (describing ACT service in Greenville, North Carolina: "Assertive Community Treatment (ACT) is a multidisciplinary team that provides intensive, community-based services to adults with Severe Persistent Mental Illness (i.e., Schizophrenia, Schizoaffective, Bipolar, etc.). The services provided by ACT include: housing supports, medication management, independent living skills, therapy, vocational skills training, and 24/7 crisis response."). https://riinternational.com/listing/assertive-community-treatment-act-team/ (last visited Jan. 23, 2023).

Sincerely,

The Arc of the United States
Bazelon Center for Mental Health Law
Human Rights Watch
The Leadership Conference on Civil and Human Rights
NAACP
NAACP Legal Defense and Educational Fund, Inc. (LDF)
National Urban League
Vera Institute

Cc: Tiffany Russell, SAMHSA

Advancing An Alternative to Police: Community-Based Services for Black People with Mental Illness

July 2022

I. Background

Natasha McKenna was a 37-year-old Black mother of a seven-year-old daughter in Alexandria, Virginia.[1] On February 3, 2015, law enforcement officers began to transfer Natasha from her cell in Fairfax County Jail, where Natasha was being detained on suspicion of attacking a police officer, to a facility in Alexandria, where Natasha would have access to the mental health services that she needed.[2] Natasha was diagnosed with schizophrenia, bipolar disorder, and depression at a young age and clearly displayed signs of her mental illness leading up to and during the week she was detained in Fairfax County jail before her death.[3] In fact, officers at the jail initiated Natasha's transfer because of rising concerns over the rapid deterioration of her mental health while she was detained.[4] After officers handcuffed Natasha in preparation for her transfer, Natasha grew increasingly anxious. Although she was only 5'3" and weighed about 130 pounds,[5] the Fairfax County Sheriff's Office deployed its emergency response team of five officers dressed in biohazard suits and gas masks to restrain her.[6] Video footage shows officers forcibly removing Natasha, seemingly nude, out of her cell, wrestling her to the ground, and using a taser on her four times as she sat in a restraint chair.[7] After withstanding over 100,000 volts of electricity, Natasha's heart stopped beating.[8] A nearby hospital put Natasha on life support for five days, until hospital staff removed the support and pronounced her dead on February 8, 2015. Among Natasha's last words to the law enforcement officials who tackled, restrained, and ultimately killed her were, "You promised you wouldn't kill me. I didn't do anything."[9]

On April 4, 2018, Saheed Vassell, a 34-year-old Black man, was walking up and down the block, as he always did, in his neighborhood of Crown Heights in Brooklyn, New York.[10] Saheed had developed and was diagnosed with bipolar disorder following the tragic killing of his best friend at the hands of the NYPD.[11] Before his mental illness worsened, Saheed worked as a welder.[12] His bipolar diagnosis inhibited him from maintaining work, but Saheed nonetheless continued to find fascination in collecting and carrying around metal objects reminiscent of his welding days.[13] On the day of his murder, Saheed was carrying part of a welding torch[14] in the shape of a curved silver pipe.[15] Three 911 calls, however, described a black man pointing something that "looked like a gun."[16] The calls reporting Saheed's "erratic behavior" were likely made by new arrivals in the neighborhood, unfamiliar with Saheed's "frequent, harmless presence on the streets."[17] Three plainclothes officers saw an alert about these calls in their unmarked car and, even though they were not explicitly assigned to the incident, decided to respond.[18] They reached Saheed within two minutes of seeing the alert,[19] followed closely by a marked police car.[20] Although all the local police officers knew of Saheed, his idiosyncrasies, and his history of mental illness, the officers who responded to the scene were part of a specialty anti-crime unit detached from the community.[21] The responding officers claimed they saw Saheed assume a "shooting stance" and rapidly shot him ten times[22] within less than ten seconds of their arrival.[23] Saheed was pronounced dead after arriving at a nearby medical center.[24] Several witnesses recount that the officers did not say anything before opening fire.[25]

In the early hours of March 23, 2020, Daniel Prude, a 41-year-old Black man, experienced a mental health crisis during his visit to his brother in Rochester, New York.[26] During this episode, Daniel ran out of his brother's home shirtless and shoeless.[27] Daniel had experienced a crisis episode the night before, in response to which he was taken to a nearby hospital for evaluation and released a few hours later.[28] This time, several law enforcement officers arrived on the scene to find Daniel completely nude and wandering the streets as snow began to fall.[29] The first officer who approached Daniel pointed a taser directly towards him, demanding Daniel lie face first on

the street with his hands behind his back.[30] Daniel immediately complied.[31] After several minutes of sitting handcuffed on the cold, wet street with four officers standing at varying distances, Daniel began to verbally express his increasing agitation.[32] Video footage shows Daniel spitting something out of his mouth, in the opposite direction from where the officers stood around him.[33] From behind Daniel's back and without any advance warning, the officers placed a "spit sock" over Daniel's face,[34] purportedly to decrease the potential spread of the ongoing Coronavirus,[35] which Daniel had earlier said he had.[36] The mesh hood visibly exacerbated Daniel's distress and he started to move around on the pavement and speak up even more.[37] When Daniel attempted to stand up, three officers pinned him to the ground, with one pressing his knee on Daniel's back and another pushing his face into the pavement using the weight of his body.[38] After two minutes, Daniel stopped breathing.[39] He was pronounced brain dead upon arrival to the hospital shortly after.[40] Daniel's last words in between gasps of air and prayers were "You're trying to kill me."[41]

The killings of Natasha McKenna, Saheed Vassell, and Daniel Prude illustrate the all-too-common experiences of Black people with mental illness[42] who encounter law enforcement officers.[43] To protect Black people with mental illness and help them thrive, states and local governments must invest in comprehensive mental health systems to prevent emergencies from occurring, and to respond when emergencies occur.

II. Black People are More Likely to Encounter Law Enforcement and Be Harmed During the Encounter

Black people experience heightened surveillance,[44] higher rates of stops,[45] searches,[46] and arrests by law enforcement,[47] and are grossly overrepresented amongst those incarcerated in the U.S.[48] Additionally, Black people are over three times as likely as white Americans to be killed by law enforcement.[49] In fact, use of force by law enforcement is among the leading causes of death for Black men and boys, making them 2.5 times more likely to be killed by law enforcement officers than white men and boys.[50] "Over the life course, about 1 in every 1,000 black men can expect to be killed by police;" a "nontrivial lifetime risk of being killed by police."[51] Similarly, Black women are 1.4 times more likely to be killed by law enforcement than white women.[52]

Anti-Black racial bias—whether unconscious, conscious, or structural—from law enforcement officers and agencies contributes to increased stops and violence for Black people when they encounter law enforcement.[53] A false association of Blackness with criminality[54] has historically been used to control Black bodies and movement.[55] This dangerous association persists even today, often influencing perceptions by people regardless of race, gender, class, or occupation, including law enforcement. Research has demonstrated that Black people are also perceived to be more "hostile" than white people with the same facial expressions.[56] These misperceptions likely contribute to aggressive responses from law enforcement officers during encounters with Black people.[57]

Despite decades-long patterns of racial discrimination and law enforcement violence against Black communities, efforts to promote public safety in these communities often rely upon continuing or expanding the use of law enforcement without accounting for the threats and harm law enforcement themselves pose to the communities.[58] Increased law enforcement presence within Black communities leads to increased exposure and contact with officers. This increased contact with law enforcement can harm Black people not only physically, but also psychologically, through lasting trauma and anxiety even in those they do not arrest.[59] Studies show that beginning from a young age, men who reported more frequent contact with law enforcement also reported

more symptoms of psychological distress, the severity of which positively correlated with the intrusiveness of the encounter and the perceived unfairness of law enforcement in general.[60] Even those who experience less intrusive kinds of encounters—e.g., being stopped but not physically searched—are at heightened risk of psychological distress.[61]

Inundating predominantly Black communities with law enforcement officers[62] creates a dangerous self-fulfilling prophecy. High concentrations of law enforcement officers result in overexposure for Black residents to encounters with law enforcement,[63] during which officers may be primed to see suspicious activity or criminal conduct where there is none.[64] Even without a subsequent arrest, law enforcement stops of Black youth have led to a greater likelihood that they engage in criminal activity in the future.[65] Rather than promoting public safety, an increased law enforcement presence is often counterproductive.[66]

III. People with Mental Illness Are Harmed by Law Enforcement

People with mental illness are also at risk from encounters with law enforcement. The results of such encounters are often deadly,[67] especially when the person with mental illness is Black, as discussed in Section IV. Nationwide, law enforcement officers are generally the first and only responders to be dispatched when people with mental illness experience a crisis or otherwise need help—or are reported for disturbing or annoying others. The same is true for autistic people, individuals with substance use issues, and individuals with intellectual or developmental disabilities. And far too often, as in the cases of Natasha McKenna, Saheed Vassell, and Daniel Prude, tragic consequences follow.

People with mental illness are grossly overrepresented among those in jail and prison.[68] Their interactions with law enforcement officers often end in arrest and incarceration, even when they do not engage in actual criminal behavior. Although people with a serious mental illness comprise only 4-5% of the U.S. population,[69] they make up about 15 and 20% of the prison and jail population, respectively.[70] Contrary to a misguided and unfortunate public perception, people with mental illness, or serious mental illness, are not more violent than the population at large.[71] Moreover, people with mental illness do not engage in criminal behavior more than people without mental illness.[72] Nonetheless, two million people with a serious mental illness are booked into jails each year,[73] and the risk of confinement is particularly high for Black people with mental illness.[74] Indeed, one study found that Black people with mental illness were more likely to be incarcerated than any other racial group.[75]

As the stories of Natasha McKenna, Saheed Vassell, and Daniel Prude illustrate, there is a real risk that police will use deadly force when they interact with individuals with mental illness. Of the over 7,500 people shot and killed by law enforcement officers since 2015, one in five fatalities were of people who were experiencing a mental health crisis.[76] The risk of death at the hands of law enforcement is even higher when the individual is Black.[77] Black people account for less than 13 percent of the population, yet police officers fatally shoot Black people at more than twice the rate as they do White Americans.[78] A recent study shows that Black men with mental illness are shot and killed by law enforcement officers at significantly higher rates than white men who exhibit similar behaviors.[79]

Despite this risk, law enforcement is generally the default and only response to calls from or involving people with mental illness.[80] The vast majority of these calls, however, would be much safer and more effectively handled if trained mental health workers—including people with lived experience with mental illness working as "peers"—responded to the crisis instead of law

enforcement or, only in the rarest exceptions, with law enforcement as a backup. About ten percent of calls to 911 involve people with mental illness,[81] yet few of these situations actually threaten public safety. Such calls may involve situations where families are concerned for a loved one experiencing a mental health crisis, but who is not posing any kind of threat.[82] Other calls may involve situations when individuals with mental illness display behavior considered "erratic" in public, or when a person's unusual but nonthreatening behavior is induced by alcohol or drug use.[83] Law enforcement officials also respond to situations when individuals with a mental illness are suicidal or otherwise experiencing a crisis, when unhoused individuals with mental illness linger in public spaces, and when individuals with mental illness fail to obey staff in facilities or schools. Law enforcement officers are also used to transport people to hospitals, typically in handcuffs, when a doctor or judge directs that they be institutionalized.

Since the risk of harm to the individual is so great, and the actual threat to public safety is usually small, mental health advocates stress that law enforcement response to people with mental illness should be avoided whenever possible.[84] Contact between law enforcement and people experiencing mental health crises—even when officers respond alongside mental health workers in the "co-responder" model[85]—should be limited to only the rarest exceptions because of the potentially dire consequences.[86] Even when co-responder models dispatch officers who have undergone crisis intervention training (CIT),[87] completing such training should not exempt officers from this limitation. Studies have shown that equipping officers with CIT has produced no net effect on outcomes of arrest or officer use of force.[88] One study of the Chicago Police Department, however, showed a marginal *increase* in use of force by CIT-trained officers over their non-CIT counterparts.[89] While co-responder models have had some success in increasing access to behavioral health services more than traditional police responses, there is not enough evidence to conclude that overall, co-responder programs positively impact encounters for people experiencing mental health crises.[90] One factor, studies have suggested, is that officer involvement may retraumatize individuals due to their previous traumatic interactions with law enforcement.[91]

The overall failure of our public mental health systems largely explains why law enforcement continues to be the first responder to people experiencing mental health crises, and often the only responder. Publicly funded mental health service agencies have limited funding, and what services exist are inequitably distributed across communities.[92] The services that work best for people with serious conditions are in very short supply.[93] Programs created or funded through federal and state legislation, intended to provide community-based services and avoid the harmful and unnecessary placement of people with mental illness in institutions to receive care, have never been sufficiently funded to meet the needs of people with mental illness, especially those with the most serious conditions.[94] The dearth of appropriate care, combined with the rise of mass incarceration and the lack of adequate federal support for affordable housing (and the concurrent increase in homelessness), has exposed people with mental illness to disproportionately high rates of arrest and incarceration. The lack of community services also results in many people with mental illness being unnecessarily institutionalized, in violation of the Americans with Disabilities Act and the U.S. Supreme Court's *Olmstead* decision.[95]

When law enforcement officers respond, this not only fails to protect people with mental illness, but also exacerbates the crisis they are experiencing. Law enforcement officers are not adequately equipped to respond to people going through mental health crises. Experiencing a mental health crisis can significantly compromise a person's ability to think and behave rationally, making it much more difficult for even close family and friends, let alone law enforcement officers,

to calm the person down. The threat of force inherent in police encounters, especially when weapons are drawn, aggravates an already-sensitive situation and distresses the person in crisis even further. This unhealthy dynamic contributes to the disproportionate incarceration, institutionalization, and trauma experienced by people with mental illness at the hands of law enforcement, and is counterproductive to promoting the wellness and safety of people with mental illness.[96]

IV. Black People with Mental Illness Face Discrimination in the Mental Health System

Black people with mental illness are not only at great risk of arrest, incarceration, and fatal harm by law enforcement,[97] but also of racially biased and discriminatory treatment by mental health professionals.[98] This process begins for Black people in their youth and continues through adulthood. For example, when Black youth show indications of attention deficit/hyperactivity disorder (ADHD), medical professionals, perhaps due to unconscious biases, are more likely to misdiagnose them with disruptive behavior disorders (e.g., oppositional defiant disorder (ODD) or conduct disorder (CD)) rather than with ADHD.[99] The over-diagnosis of disruptive behavior disorders deprives Black youth of the proper behavioral interventions, educational accommodations, and medication provided to children with an ADHD diagnosis. Moreover, medical professionals are less supportive of children with ODD or CD, who are seen as less treatable or even untreatable.[100] The bias in diagnosis may perpetuate other biases by, for example, influencing how educators and school administrators perceive Black children and contributing to disparities in disciplinary practices and involvement in the juvenile corrections system.[101]

Beyond the education system, Black people face the challenges of cross-cultural communication and language differences in the healthcare system,[102] which leads to fear and mistrust of the system itself.[103] One study found that physicians were more verbally dominant and less patient-centered when communicating with Black patients than with white patients, two factors that contribute to poorer health outcomes.[104] Nurses, too, have demonstrated implicit biases against Black people by recommending significantly less pain medication for Black patients than white patients, upon viewing pictures of both patients exhibiting genuine expressions of pain.[105] Only 3% of American Psychological Association members are Black,[106] leading some mental health advocates to worry that the majority of mental health care practitioners lack the cultural competency to adequately treat Black patients.[107] When Black patients do receive care, they often receive inadequate services and experience worse outcomes.[108] For example, Black people are less likely to receive appropriate care for depression, leading to longer and more severe episodes.[109] They may also be more likely to experience coerced treatment, in the form of involuntary commitment.[110] In Alameda County, California, where Black people make up 11 percent of the population,[111] a lawsuit alleged that "[d]uring a recent two-year period, over 2,300 people were detained at the County's psychiatric facilities more than three times, the majority of whom were Black" and "some individuals were detained more than 100 times";[112] 36% of people detained at one facility—"more than three times their overall representation in Alameda County"—were Black;[113] and "[f]rom January 2018 to June 2020, more than 45% of individuals institutionalized in County psychiatric facilities three or more times were Black."[114] And yet, two-thirds of Black people in need of mental health services do not receive any care at all.[115]

The existence of bias in the responses of both the police and medical professionals to Black people with mental illness is supported by research regarding how Black people are perceived in general.[116] Decades of research demonstrate that most people have implicit biases against Black people.[117] People have a tendency to unconsciously associate Black people with criminality[118] and

often perceive identical ambiguous behaviors as more "aggressive" when committed by Black people as compared to white people.[119] Further, law enforcement officers have a view of acceptable behavior—of what is obedient or compliant—that often leads them to react harshly to people they think are not according them the level of deference they believe they deserve.[120] Black men and people with mental illness are at greater risk of being perceived as noncompliant, and thus, disrespectful, to officers.[121] Taken together, these two biases help explain how contact with the police for minor behavior can become fatal for so many Black people with a mental illness.[122]

Walter Wallace Jr.'s experience with Philadelphia police officers illustrates the risk that Black people with mental illness face when encountering law enforcement. In the midst of a mental health crisis on October 26, 2020, Walter Wallace Jr., a 27-year-old Black man, walked outside of his parents' front door in Philadelphia, Pennsylvania holding a kitchen knife by his side.[123] Walter did not make any threatening motions or actions towards anyone,[124] even when two police officers pointed their guns at Walter and yelled for him to drop the kitchen knife.[125] A number of factors signaled that Walter was experiencing a mental health episode: several calls to 911 from Walter's family earlier that day seeking emergency medical assistance for Walter's condition;[126] shouts from bystanders familiar with Walter's history with bipolar disorder, warning officers that Walter was "mental;"[127] and Walter's almost trance-like state as he casually walked away from and around the officers, ignoring their repeated commands.[128] But Walter's seeming indifference towards the two white police officers and nonthreatening grasp of a kitchen knife resulted in both officers quickly shooting Walter seven times each,[129] hitting him in the shoulder and chest.[130] Walter's mother, who just seconds before was pleading for the officers not to shoot her son,[131] ran towards his bleeding body, screaming, "You killed my son."[132] Walter was pronounced dead shortly after arriving at a nearby hospital.[133] It was only three weeks after his wedding day.[134]

Walter Wallace Jr. did not attack, threaten, nor engage with the police officers who shot and killed him. The officers were not even the emergency responders Walter's family requested in their calls to 911—Walter's brother, who made the last of several calls that day, specifically requested medical assistance and an ambulance for Walter because of his history of mental illness.[135] Tragically, police arrived at the Wallace family home before the ambulance.[136] The Wallaces knew that Walter needed help from medical professionals who would be better equipped to de-escalate their loved one. Had medical assistance intervened instead of law enforcement, Walter could still be alive today.

V. New Solutions are Needed to Better Support Black People with Mental Illness, and All People with Mental Illness

As demonstrated above, the practice of law enforcement responding to calls involving people with mental illness does not provide people with mental illness the needed support and often results in physical harm, sometimes fatal. We must therefore develop better solutions to serve those with mental illness, and protect their rights.[137] To do so, we must expand the capacity of states, counties, and cities to deliver culturally competent community-based mental health services, including Assertive Community Treatment (ACT), housing, assistance securing and maintaining employment, and substance use treatment.[138] Schools must take a similar approach, ending their reliance on law enforcement and school resource officers, and increasing their investment in professional staff and improved services.[139] Providers of all these services must take steps to ensure that staff understand the cultural norms and socio-economic challenges of the communities they serve, and the traumas experienced by members of those communities. These steps should include training received from community members themselves.

When there is a physical health emergency, typically the health care system responds, with a medic, ambulance, or both. When people experience a mental health crisis, there should also be a healthcare-centered response, with the mental health system taking the lead.

As we develop alternatives to a police response, we must look at the historic and current harmful impact of police involvement, and heed the voices of those communities that have borne the brunt of such harms—Black people, people with mental illness, and those at the intersection. Far too often, their voices have been excluded or ignored. Peers with lived experience, including those with lived experience with mental illness, should play a major role in planning and implementing the alternatives developed. Peers with lived experience are a valuable resource. They have a keen understanding of the needs and concerns of people receiving services, and they are able to develop relationships of trust, help individuals see the benefits of treatment, and help prevent and respond to crises.[140]

Some communities have already taken steps to reduce the role of the police in responding to people with mental illness. In the Eugene, Oregon CAHOOTS[141] program, a medic and social worker, both unarmed, are dispatched to most situations involving people with mental illness, instead of the police. Police join them in rare situations, including if someone is in immediate danger or presents a clear threat to others.[142] The program reports that each year it saves the city $8.5 million in public safety costs and $14 million in ambulance and emergency room costs.[143] Other communities are implementing similar programs.[144] For example, San Francisco has adapted the CAHOOTS model so that it includes a peer responder on the team.[145]

An even greater number of communities are investing in mental health crisis teams.[146] New federal funding is available for such teams,[147] which can be dispatched by 911 or law enforcement as well as by the mental health system. Mental health crisis teams include a clinician and often a peer.[148]

The alternative programs that communities have implemented to better support people with mental illness and to address the disproportionate harm people with mental illness experience at the hands of law enforcement have common elements: they are implemented by skilled unarmed personnel from a variety of backgrounds able to address the needs of people with mental illness, including – clinical training in mental health or social work, nursing, peers with lived experience with mental illness, and specially-trained emergency medical technicians (EMTs). Psychiatrists are available “on call” through telehealth as virtual back-up to responders. Mobile crisis teams are trained to successfully de-escalate situations, diverting people from arrest and incarceration, or hospitalization. When the crisis is resolved, they strive to connect people with the services they need for long term stability.[149]

These types of alternative responses should be supplemented by a sufficient array of facilities that are available for crisis care, including short-stay apartments staffed by mental health professionals and peers,[150] walk-in urgent care centers and “drop-off” centers (in urban areas, scattered so that they are readily accessible to people in all neighborhoods),[151] and hospital beds for those who need inpatient care.[152] Short-term detox facilities should be available as well, with offers of treatment for substance use disorders upon and following discharge.[153]

Some proponents of changing responses to people with mental illness have focused on improving law enforcement encounters through training or pairing police with mental health professionals[154] (frequently called "co-responder models"). These are not solutions to the problems caused by unnecessary police contact with people with mental illness. Meta-analyses of currently

implemented training programs and co-responder models across the country have not found either reform to have significant positive impacts on police encounters with people with mental illness.[155] These programs will not remedy the trauma and safety issues experienced during even the best-intentioned law enforcement interactions. Better police training will not provide the expert medical and peer support that people with mental illness or in crisis need. Police responses by their very nature present a threat of violence or incarceration.[156] And a police response is unnecessary in the vast majority of calls involving people with mental illness.[157] Moreover, as noted in Section III above, research on the effects of CIT programs across the country demonstrates no significant effect on officer use of force in encounters of people with mental illness.[158] Mental health systems should provide services to prevent people from experiencing crises, and when crises occur, they should provide the services needed to stabilize the situation, and connect people to long-term services. Not only is this safer and more effective, but it also advances civil rights and avoids incarceration, institutionalization, and coercion.

A. Specific Steps to Implement Alternatives to Harmful Police Response

Developing alternatives to a law enforcement response requires action in three areas.

1. Re-direct requests for police intervention.

Calls to 911 and the police should be screened to determine whether the person about whom the call is made is known to or appears to have a mental illness or is experiencing a mental health crisis. Such calls should be redirected to experts and peers in the mental health system and handled by a unit within the mental health system that operates much like 911, making urgent responses when required.

The mental health system should have policies identifying the small number of cases where it may be appropriate for the mental health system to respond jointly with the police or have the police on the scene as backup.[159] Communities should collect and analyze data and provide training to call-takers and police staff, identifying those situations that can and should be handled entirely by the mental health system.[160] The police should not respond, jointly or as backup, when the call involves an individual who is suicidal and presents no risk to others.

2. Develop the services needed for a non-police response.

Each community should have the services needed to respond to calls involving an individual with mental illness or experiencing a mental health crisis. Such calls, including calls to 911, should be routed to the mental health system, where trained call-takers can resolve many calls by providing advice, making referrals, and/or providing transportation to a community-based provider. Other calls will require dispatching a mobile support team that can quickly respond and resolve the situation—like the CAHOOTS team (discussed above) or a mental health crisis team.[161] There should also be an array of walk-in, drop-off, and other facilities for crisis resolution and stabilization, scattered throughout the community. Many of these activities, including mobile crisis teams, can be funded through Medicaid, with the federal government picking up a sizeable share of the cost.[162]

3. On-going community-based services.

After the immediate issue is resolved, the mental health system should follow up to ensure the individuals gain access to voluntary community-based services on an on-going basis. Many people with serious mental illness will need access to long-term housing, intensive case

management, peer support services, ACT, and supported employment.[163] People with lived experience working as peers can be involved in—and lead—the delivery of all of these services.

If the person was regularly receiving services before the episode, the mental health system should review and improve the services it is providing, in order to help the person avoid similar issues in the future.

B. Advocating for Solutions

To protect Black people and others with mental illness, it is critical that we expand culturally competent community-based mental health services. The services needed include clinical services, such as ACT and mental health crisis services, but also non-clinical services, such as supportive housing, peer support, and supported employment.

Below is a list of actions that government authorities should take to better support Black people and others with mental illness.

Actions that Congress, the U.S. Department of Health and Human Services, and State and Local Governments Should Take

Congress should:

- Enact legislation to fund community-based mental health services including supportive housing. Congress should pass, and the President should sign, legislation that provides states and localities with the resources they need to provide these critical services and supports and require that they be culturally competent.[164]
- Permanently authorize flexibilities in Medicaid funding for tele-mental health services as permitted related to COVID-19,[165] while also requiring that in-person services and hybrid in-person and virtual services are available for people who want them. This will ensure that services are accessible by whatever means people with mental illness find most effective.[166]
- Fund call centers within the mental health system to which calls for help involving people with mental illness can be routed.[167]
- Provide strong financial incentives, including through federal grant programs, for communities to use the mental health system, rather than law enforcement, to respond to calls involving people with mental illness.[168]
- Invest in programs that help expand the behavioral health workforce, including peer support/services, and provide incentives to individuals from Black and Brown communities to join the behavioral health workforce.[169]

The U.S. Department of Health and Human Services (HHS) should:

- Robustly promote and fund services that prevent encounters with law enforcement, including ACT, mobile crisis services, peer services, supported housing, and supported employment.[170]
- Support programs that address underlying problems—sometimes called "social determinants of health"—that may prompt mental health crises for people with mental illness, such as supportive housing and supported employment programs.[171]

- Provide significant funding to efforts that ensure mental health services are culturally competent, including the efforts of the National Network to Eliminate Disparities In Behavioral Health (NNED).[172]
- Allow federal Medicaid dollars to be used to support housing for people with mental illness.[173]
- Improve Medicaid rules regarding reimbursement for peer services, including removing the requirement that peer services be delivered under the supervision of a clinician.[174]
- Clarify Medicaid rules regarding reimbursement for mental health services provided to students at school, which could help build significant additional service capacity in school districts that enroll large numbers of Medicaid and Children's Health Insurance Program (CHIP) beneficiaries.[175]

States and local governments should:

- Ensure that there is a robust array of voluntary, community-based services that reduce the occurrence of mental health crises, provide an effective response when they occur, and provide on-going treatment and support after the crisis is resolved.[176] The services should be culturally competent and acknowledge the trauma Black people have experienced, and incorporate a trauma-informed approach.[177]
- Ensure that every community has each of the necessary components of a community-based behavioral health crisis response system, and that this system is a meaningful alternative to a law enforcement response. This includes call centers (reachable through 911, 988, or other hotline or warmline numbers) that can resolve most calls for help,[178] mobile crisis teams to respond quickly when needed, de-escalate situations, and connect people to services,[179] and an array of facilities when people need somewhere to go for crisis resolution and stabilization.[180]
- Create a continuum of alternative responders to calls for help, from street outreach teams,[181] to CAHOOTS-type teams, to mental health crisis teams to handle the wide variety of calls involving people with mental illness.[182]
- Conduct public education campaigns to inform people about the availability of alternatives to calling 911 and law enforcement, and of community-based mental health services. Such campaigns should effectively reach Black communities—including by acknowledging trauma, featuring Black service providers, and reducing stigma about mental health services.[183]
- Collect and analyze data, adopt policies, and provide training to 911, 988, and police staff about situations involving people with mental illness that can and should be handled entirely by the behavioral health system, and situations to which the police should also respond.[184]
- Ensure that law enforcement officers refer people with mental illness whom they encounter while on duty to appropriate community-based resources, and arrange for safe transportation if needed.[185]
- Ensure that affected communities are involved in the design, implementation, and evaluation of all alternatives to a law enforcement response to people with mental illness, such as advisory councils and working groups.[186]

- Expand the mental health workforce, including peer services, by among other things, taking advantage of federal Community Mental Health Services and Substance Abuse Prevention and Treatment block grants and Certified Community Behavioral Health Center (CCBHC) funds,[187] investing in professional development, and identifying and removing barriers to entry for Black people and others.[188]
- Invest in peer-led services such as peer crisis respite centers,[189] peer "bridger" services that help people transition from hospitals, jails, and prisons to the community,[190] and peer-run hotlines and warmlines for people who need help.[191]
- Expand supported employment services using the Individual Placement and Support (IPS) model.[192] Peer specialists should be part of the IPS teams.
- Take steps to diversify the mental health workforce to reflect the racial, ethnic, cultural, sexual orientation, and gender identity diversity of the communities served. Peer workers should reflect the lived experiences of people in the communities they serve, including Black communities.[193]
- Take advantage of COVID-19-related flexibilities in Medicaid to suspend premiums, co-pays, and other cost sharing; suspend the need for prior authorizations or re-authorizations for mental health services; make advanced and/or incentive payments to community mental health providers; and increase payment rates for services.[194]
- Address the social determinants of health, which helps prevent mental health crises.[195] States and local governments should invest in programs that, among other things, help people secure and maintain housing and find and maintain employment.
- Use federal COVID-19 relief funds to support mental health services in schools.[196] Schools can use these funds to recruit, retain, and train more school-based mental health professionals, such as social workers and counselors; provide more individualized and small group instruction and tutoring; provide high-quality afterschool and summer programs; and invest in other strategies for supporting student mental health.[197]

VI. Conclusion

It is past time that we address the incarceration, institutionalization, and police violence that Black people with mental illness, and all people with mental illness, face in law enforcement encounters when community-based mental health services are not available to respond to their needs. It is too late to avoid the tragic deaths of Natasha McKenna, Saheed Vassell, Daniel Prude, Walter Wallace, Jr., and the other Black people with mental illness who have lost their lives during encounters with law enforcement. But it is not too late for stakeholders to demand action and for our policymakers to respond with effective solutions.

We urgently call upon national and local stakeholders to center community-based, trauma informed approaches that integrate peers, language diversity, cultural competency, and cross disability accessibility. Effective alternative responses to crises are needed. Robust longer-term services, including peer services, Assertive Community Treatment (ACT), supported employment, and supported housing, delivered equitably and without bias, are also critical. Black communities must be centered and participate in decision-making about the systems that will serve them. These systems must be a meaningful alternative to a police response.

Implementing a comprehensive community-based mental health system can and will stop violence against Black people with mental illness. We urgently call on our cities, states, and the federal government to implement these systems now.

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[21] *Locals Knew*, *supra* note 10.

[22] *Id.*

[23] Mueller, *supra* note 14.

[24] Mueller & Schweber, *supra* note 12.
[25] *Locals Knew*, *supra* note 10.
[26] Michael Gold & Troy Closson, *What We Know About Daniel Prude's Case and Death*, N.Y. TIMES (Apr. 16, 2021), https://www.nytimes.com/article/what-happened-daniel-prude.html.
[27] *Id.*
[28] Sarah Maslin Nir, *Rochester Officers Will Not Be Charged in Killing of Daniel Prude*, N.Y. TIMES (Mar. 6, 2021), https://www.nytimes.com/2021/02/23/nyregion/daniel-prude-rochester-police.html.
[29] Gold & Closson, *supra* note 26.
[30] Taylor Romine, Benjamin Norbitz, & Madeline Holcombe, *7 Rochester police officers suspended over Daniel Prude's death, mayor says*, CNN (Sept. 4, 2020, 3:21 AM ET), https://www.cnn.com/2020/09/03/us/rochester-police-daniel-prude-death/index.html.
[31] *Id.*
[32] *Id.*
[33] Michael V. Pettigano, *Daniel Prude video: Rochester police body cam footage (10-min. version)*, DEMOCRAT & CHRON. (Sept. 5, 2020, 12:49 PM), https://www.democratandchronicle.com/videos/news/2020/09/04/daniel-prude-death-rochester-police-body-cam-video-10-minute-version/5710351002/ (showing spitting at 2:56).
[34] *Id.*
[35] Ali Watkins, *What Are 'Spit Hoods,' and Why Do the Police Use Them?*, N.Y. TIMES (Sept. 8, 2020), https://www.nytimes.com/2020/09/03/nyregion/spit-hoods-police.html.
[36] Gold & Closson, *supra* note 26.
[37] Romine et al., *supra* note 30.
[38] *Id.*
[39] Gold & Closson, *supra* note 26.
[40] Romine et al., *supra* note 30.
[41] *Id.*
[42] This paper uses the term "mental illness" to describe people who have "health conditions involving changes in emotion, thinking or behavior (or a combination of these)." *What is Mental Illness?*, AM. PSYCH. ASS'N (Aug. 2018), https://psychiatry.org/patients-families/what-is-mental-illness. "Mental illnesses are associated with distress and/or problems functioning in social, work or family activities." *Id.* There are other terms that people use to describe these conditions. For example, most people with mental illness are protected by the Americans with Disabilities Act (ADA); for that reason, this paper sometimes uses the term "mental health disabilities." *See infra* notes 95, 110. However, many people with mental illness do not use either of these labels to describe themselves. Some people refer to having "lived experience" with mental health conditions. Others use different terms to describe themselves and others with such issues. *See, e.g.*, u/MadQueerResearcher, *Queer MMIND (Mad, Mentally Ill, Neurodivergent, and Disabled) College Student Experiences*, REDDIT (Oct. 15, 2021), https://www.reddit.com/r/SampleSize/comments/q8ouhg/academic_queer_mmind_mad_mentally_ill/.
[43] This paper uses the terms "law enforcement" and "police" interchangeably to represent the array of law enforcement officers and agencies that disproportionately harm black people and people with mental illness, and especially those at the intersection of both identities.
[44] Devon W. Carbado & Patrick Rock, *What Exposes African Americans to Police Violence?*, 51 HARV. C.R.-C.L. L. REV. 159, 166 (2016) (noting that Black people are disproportionately exposed to law enforcement); Rashida Richardson et al., *Dirty Data, Bad Predictions: How Civil Rights Violations Impact Police Data, Predictive Policing Systems, and Justice*, 94 N.Y.U. L. REV. 192, 209 n.68 (2019) ("The areas that are subject to heightened [Chicago Police Department] presence…are concentrated in the South and West sides of Chicago, which are predominantly non-white and heavily low income neighborhoods.").
[45] Drew DeSilver et al., *10 things we know about race and policing in the U.S.*, PEW RSCH. CTR. (June 3, 2020), https://www.pewresearch.org/fact-tank/2020/06/03/10-things-we-know-about-race-and-policing-in-the-u-s/ ("Black adults are about five times as likely as whites to say they've been unfairly stopped by police because of their race or ethnicity.").
[46] Data from the Los Angeles Police Department shows that a "black person in a vehicle was more than four times as likely to be searched by police as a white person," even though white people were more likely to be found with illegal items. Ben Poston & Cindy Chang, *LAPD searches blacks and Latinos more. But they're less likely to have contraband than whites*, L.A. TIMES (Oct. 8, 2019, 3:52 PM PT), https://www.latimes.com/local/lanow/la-me-lapd-searches-20190605-story.html. The DOJ's investigation of the Ferguson Police Department revealed that "African Americans are more than twice as likely as white drivers to be searched during vehicle stops," but "are found in possession of contraband 26% less often than white drivers." C.R. DIV., U.S. DEP'T OF JUST., INVESTIGATION OF THE

FERGUSON POLICE DEPARTMENT 4 (Mar. 4, 2015), https://www.justice.gov/sites/default/files/opa/press-releases/attachments/2015/03/04/ferguson_police_department_report.pdf.

[47] *See* Emma Pierson et al., *A Large-Scale Analysis of Racial Disparities in Police Stops Across the United States*, 4 NATURE HUM. BEHAV. 736, 737 (2020), https://www.nature.com/articles/s41562-020-0858-1.pdf ("...[A]mong state patrol stops, the annual per-capita stop rate for black drivers was 0.10 compared to 0.07 for white drivers; and among municipal police stops, the annual per-capita stop rate for black drivers was 0.20 compared to 0.14 for white drivers."); s*ee also Table of Arrest rates by offense and race in 2019 (all ages)*, U.S. DEP'T OF JUST., OFF. OF JUV. JUST. & DELINQ. PREVENTION, https://www.ojjdp.gov/ojstatbb/crime/ucr.asp?table_in=2&selYrs=2019&rdoGroups=1&rdoData=r (last visited June 21, 2022) (reporting that the arrest rate for Black people and white people is 5,723.3 and 2,750.4 per 100,000, respectively); *U.S. Incarceration Rates by Race and Ethnicity, 2010*, PRISON POL'Y INITIATIVE, https://www.prisonpolicy.org/research/race_and_ethnicity/ (last visited June 21, 2022) (noting that the incarceration rate for Black people and white people is 2,306 and 450 per 100,000, respectively).

[48] Peter Wagner & Wendy Sawyer, *States of Incarceration: The Global Context 2018*, PRISON POL'Y INITIATIVE (June 2018), https://www.prisonpolicy.org/global/2018.html.

[49] Gabriel L. Schwartz & Jacqueline L. Jahn, *Mapping fatal police violence across U.S. metropolitan areas: Overall rates and racial/ethnic inequities, 2013-2017*, PLOS ONE 15(6): e0229686 (2020), https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0229686&type=printable (finding that Black people are 3.23 time more likely to be killed by police than white people); JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH L., "DEFUNDING THE POLICE" AND PEOPLE WITH MENTAL ILLNESS (Aug. 2020), http://www.bazelon.org/wp-content/uploads/2020/08/Defunding-the-Police-and-People-with-MI-81020.pdf.

[50] Morgan Sherburne, *Police: Sixth-leading cause of death for young black men*, UNIV. OF MICH. INST. FOR SOC. RSCH. (June 1, 2020), https://isr.umich.edu/news-events/news-releases/police-sixth-leading-cause-of-death-for-young-black-men-2/ (noting that police killings are the sixth leading cause of death in Black men; 100 Black men and boys and 39 white men and boys per 100,000 are killed by police, respectively).

[51] Frank Edwards et al., *Risk of Being Killed by Police Use of Force in the United States by Age, Race—Ethnicity, and Sex*, 116 PNAS 16793, 16793 (2019), https://www.pnas.org/content/pnas/116/34/16793.full.pdf.

[52] *Id.*

[53] *See generally* Dr. Jennifer L. Eberhardt et al., *Seeing Black: Race, Crime, and Visual Processing*, 87 J. OF PERSONALITY & SOC. PSYCH. 876 (2004), https://web.stanford.edu/~eberhard/downloads/2004-SeeingBlackRaceCrimeandVisualProcessing.pdf [hereinafter Seeing Black]; Brian Keith Payne, *Prejudice and Perception: The Role of Automatic and Controlled Processes in Misperceiving a Weapon*, 81 J. OF PERSONALITY & SOC. PSYCH. 181 (2001) (finding that exposure to Black faces facilitated the categorization of crime-relevant objects), http://web.missouri.edu/~segerti/capstone/PayneBias.pdf.

[54] Natsu T. Saito, *Tales of Color and Colonialism: Racial Realism and Settler Colonial Theory*, 10 FLA. A&M U. L. REV. 1, 56 (2014) (explaining that white American political leaders advanced the criminalization of Black people to maintain social control and "undermine the impact of the abolition of slavery"); Cheryl Nelson Butler, *Blackness as Delinquency*, 90 WASH. U.L. REV. 1335, 1364 (noting that the eugenics movement promoted the idea that black people were more prone to delinquency and criminal activity).

[55] Summary of *The Condemnation of Blackness: Race, Crime, and the Making of Modern Urban America, With a New Preface* by Khalil Gibran Muhammad (2019), HARV. UNIV. PRESS, https://www.hup.harvard.edu/catalog.php?isbn=9780674238145 ("Chronicling the emergence of deeply embedded notions of black people as a dangerous race of criminals by explicit contrast to working-class whites and European immigrants, Khalil Gibran Muhammad reveals the influence such ideas have had on urban development and social policies.").

[56] L. Song Richardson & Phillip Atiba Goff, *Interrogating Racial Violence*, 12 OHIO ST. J. CRIM. L. 115, 121 (2014), https://kb.osu.edu/bitstream/handle/1811/73475/OSJCL_V12N1_115.pdf.

[57] For more on the effects of implicit bias on policing, *see generally id.*; *see also* L. Song Richardson, *Police Racial Violence: Lessons from Social Psychology*, 83 FORDHAM L. REV. 2961 (2015).

[58] Amanda Geller et al., *Aggressive Policing and the Mental Health of Young Urban Men*, 104 AM. J. OF PUB. HEALTH 2321, 2321 (2014), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4232139/pdf/AJPH.2014.302046.pdf (finding that individuals who reported more police contact also reported more symptoms of trauma and anxiety, exacerbated by the number of stops they encountered and the intrusiveness of the encounters).

[59] Abigail A. Sewell, Kevin A. Jefferson, & Hedwig Lee, *Living under Surveillance: Gender, Psychological Distress, and Stop-Question-and-Frisk Policing in New York City*, 151 SOC. SCI. & MED. 1, 1 (2016).

[60] Ana Sandoiu, *Police Violence: Physical and Mental Health Impacts on Black Americans*, MED. NEWS TODAY (June 22, 2020), https://www.medicalnewstoday.com/articles/police-violence-physical-and-mental-health-impacts-on-black-americans.
[61] Geller et al., *supra* note 58.
[62] Jeffrey Fagan, *No Runs, Few Hits, and Many Errors: Street Stops, Bias, and Proactive Policing*, 68 UCLA L. REV. 1584, 1632 (2022), https://scholarship.law.columbia.edu/cgi/viewcontent.cgi?article=4295&context=faculty_scholarship ("As concentrations of Black residents increase, officer allocations also increase.").
[63] *Id.* at 1664 (finding that the higher allocation of police in Black neighborhoods indicates an overexposure risk for Black residents).
[64] *Id.* at 1636, 1666.
[65] Juan Del Toro et al., *The Criminogenic and Psychological Effects of Police Stops on Adolescent Black and Latino Boys*, 116 PNAS 8261, 8266 (2019), https://www.pnas.org/doi/epdf/10.1073/pnas.1808976116 (citing qualitative research).
[66] *Id.*; Brenden Beck, *We Analyzed 29 Years of Police Spending in Hundreds of Cities: Here's what we learned*, SLATE (Apr. 14, 2022, 4:42 PM), https://slate.com/news-and-politics/2022/04/increased-police-spending-leads-to-more-misdemeanor-arrests.html (citing study of hundreds of U.S. cities and towns over 29 years, finding that "[w]hen cities decreased the size of their police departments, they saw fewer misdemeanor arrests and when they increased them, they saw more.").
[67] Michael S. Rogers, MD et al., *Effectiveness of Police Crisis Intervention Training Programs*, 47 J. AM. ACAD. PSYCHIATRY L. 414, 414 (2019), http://jaapl.org/content/jaapl/47/4/414.full.pdf (noting that between 2015-2018, approximately 25 percent of the roughly 1,000 people killed during a law enforcement encounter involved a person with mental illness).
[68] *See* KEVIN MARTONE ET AL., TECH. ASSISTANCE COLLABORATIVE, *OLMSTEAD* AT 20: USING THE VISION OF *OLMSTEAD* TO DECRIMINALIZE MENTAL ILLNESS 3 (Sept. 2019), https://www.tacinc.org/wp-content/uploads/2020/02/olmstead-at-twenty_09-04-2018.pdf ("[There is a] vastly disproportionate number of people with mental illness in the U.S. criminal justice system.").
[69] *Mental Illness*, NAT'L INST. OF MENTAL HEALTH (last updated Jan. 2022), https://www.nimh.nih.gov/health/statistics/mental-illness. "Serious mental illness" is a term of art that refers to individuals who have particular diagnoses and whose functioning is significantly impaired due to their illness. *See Living Well with Serious Mental Illness*, SUBSTANCE ABUSE AND MENTAL HEALTH SERVS. ADMIN., https://www.samhsa.gov/serious-mental-illness (last updated Mar. 31, 2022).
[70] JENNIFER BRONSON, PHD. & MARCUS BERZOFSKY, BUREAU OF JUST. STAT., INDICATORS OF MENTAL HEALTH PROBLEMS REPORTED BY PRISONERS AND JAIL INMATES, 2011-2012, (June 2017), https://bjs.ojp.gov/content/pub/pdf/imhprpji1112.pdf; TREATMENT ADVOC. CTR., HOW MANY INDIVIDUALS WITH SERIOUS MENTAL ILLNESS ARE IN JAILS AND PRISONS? (last updated Nov. 2014), https://www.treatmentadvocacycenter.org/storage/documents/backgrounders/how%20many%20individuals%20with%20serious%20mental%20illness%20are%20in%20jails%20and%20prisons%20final.pdf.
[71] *See* Heather Stuart, *Violence and Mental Illness: An Overview*, 2 WORLD PSYCHIATRY 121, 123 (2003) ("[M]embers of the public undoubtedly exaggerate both the strength of the relationship between major mental disorders and violence, as well as their own personal risk ... It is far more likely that people with a serious mental illness will be the victim of violence"); *Mental Health Myths and Facts*, MENTALHEALTH.GOV (last visited July 1, 2022), https://www.mentalhealth.gov/basics/mental-health-myths-facts ("The vast majority of people with mental health problems are no more likely to be violent than anyone else. Most people with mental illness are not violent and only 3%-5% of violent acts can be attributed to individuals living with a serious mental illness. In fact, people with severe mental illnesses are ... more likely to be victims of violent crime than the general population").
[72] MARTONE ET AL., *supra* note 68, at 3-4 ("Mental illness itself is not predictive of criminal behavior, and research suggests that crime rates for people with mental illness are similar to those of the general population.... As with the general population, there are people with mental illness who might commit criminal acts irrespective of their mental illness.... The risk factors that predict crime among people with serious mental illness are the same risk factors that predict crime among people without serious mental illness.").
[73] Mary Giliberti, *It's Outrageous: Jails and Prisons Are No Place to Treat Mental Illness; Just Ask Paton Blough*, HUFF. POST BLOG (May 21, 2016) https://www.huffpost.com/entry/its-outrageous-jails-and-prisons-are-no-place-to-treat-mental-illness_b_7334026. The people with mental illness who are being arrested and jailed are also cycling in and out of emergency rooms and psychiatric hospital units. In many communities, there is a discrete and identifiable group of poor and poorly served people with mental illness, often homeless, who cycle in and out of jail, emergency

rooms, and hospital beds, at great cost to the taxpayers. Studies show that for less than what is now being spent on these individuals, they could be provided housing and effective community-based mental health services. *See* Alexi Jones & Wendy Sawyer, *Arrest, Release, and Repeat: How Police and Jails are Misused to Respond to Social Problems*, PRISON POL'Y INITIATIVE (Aug. 2019), https://www.prisonpolicy.org/reports/repeatarrests.html (finding that investment in community-based mental health and substance use treatment "is estimated to yield a $12 return for every $1 spent, as it reduces future crime, costly incarceration, and lowers health care expenses"). *See also* CORP. FOR SUPPORTIVE HOUS., FREQUENT USERS OF PUBLIC SERVICES: ENDING THE INSTITUTIONAL CIRCUIT 6 (2009), https://www.csh.org/wp-content/uploads/2011/12/Report_FUFBooklet.pdf (calculating that investment in supportive housing saves between $2,953 and $7,231 in incarceration costs per person placed in that housing).

[74] *Black and African American Communities and Mental Health*, MENTAL HEALTH AM. (last visited July 1, 2022) [hereinafter *Black Communities*], https://www.mhanational.org/issues/black-and-african-american-communities-and-mental-health.

[75] William B. Hawthorne et al., *Incarceration Among Adults Who Are in the Public Mental Health System: Rates, Risk Factors, and Short-Term Outcomes*, 63 PSYCHIATRIC SERVS. 26, 29 (2012).

[76] *See The Washington Post Police Shootings Database*, WASH. POST [hereinafter DATABASE], https://www.washingtonpost.com/graphics/investigations/police-shootings-database/ (last visited June 27, 2022). *See also* Wesley Lowery et al., *Distraught People, Deadly Results*, WASH. POST (June 30, 2015), https://www.washingtonpost.com/sf/investigative/2015/06/30/distraught-people-deadly-results/ (finding that 27% of people killed by police in the first half of 2015 were in crisis); Amam Z. Saleh et al., *Deaths of People with Mental Illness During Interactions with Law Enforcement*, 58 INT'L J. OF L. AND PSYCHIATRY 110, 112-14 (2018) (estimating that 23% of people killed by police have a psychiatric disability); DORIS A. FULLER ET AL., TREATMENT ADVOC. CTR., OVERLOOKED IN THE UNDERCOUNTED: THE ROLE OF MENTAL ILLNESS IN FATAL LAW ENFORCEMENT ENCOUNTERS (Dec. 2015), https://www.treatmentadvocacycenter.org/storage/documents/overlooked-in-the-undercounted.pdf (estimating the risk of death as sixteen times greater than for people without mental illness); Shaun King, *If You Are Black and in a Mental Health Crisis, 911 Can Be a Death Sentence*, INTERCEPT (Sept. 29, 2019, 7:00 AM), https://theintercept.com/2019/09/29/police-shootings-mental-health/ ("Studies show that as many as 50 percent of people killed by American police had registered disabilities and that a huge percentage of those were people with mental illnesses"); Robert Salonga, *Report: Mentally ill are in nearly 40 percent of South Bay police shootings*, MERCURY NEWS (May 14, 2018, 9:03 AM), https://www.mercurynews.com/2018/05/11/report-mentally-ill-are-in-nearly-40-percent-of-south-bay-police-shootings/ ("[A] new civil grand jury report reveals that nearly 40 percent of officer shootings in Santa Clara County involve someone who is mentally ill.").

[77] Two circumstances contribute to this result. First, the disproportionate policing of Black people and communities, and second, the high percentage of people killed by police shootings who have a mental illness. *See* Camille A. Nelson, *Frontlines: Policing at the Nexus of Race and Mental Health*, 43 FORDHAM URBAN L. REV. 615, 621 (2016) (finding that Black people report higher rates of serious psychological stress than White people, and "people who exhibit mental health challenges are more likely to attract heightened police scrutiny and reasonable suspicion; they are less likely to respond to police in ways that comport with police behavioral expectations and may, thereby, prompt unfortunate police escalation."); King, *supra* note 76 ("[Y]oung black men with mental illnesses are in the single most at-risk category in the nation for fatal police violence").

[78] *See* DATABASE, *supra* note 76.

[79] M.D. Thomas, N.P. Jewell, & A.M. Allen, *Black and Unarmed: Statistical Interaction between Age, Perceived Mental Illness, and Geographic Region among Males Fatally Shot by Police Using Case-Only Design*, 53 ANNALS OF EPIDEMIOLOGY 42, 42 (2021).

[80] Rogers et al., *supra* note 67.

[81] *See* Martha Williams Deane et al., *Emerging Partnerships Between Mental Health and Law Enforcement*, 50 PSYCHIATRIC SERVS. 99, 100 (1999) (estimating that 7% of all police contacts involve someone with a psychiatric disability); LODESTAR, L.A. POLICE DEP'T CONSENT DECREE MENTAL ILLNESS PROJECT, FINAL REPORT 24 (May 28, 2002), https://www.prisonlegalnews.org/media/publications/lapd_executive_summary_consent_decree_mental_illness_project_2002.pdf (estimating that 2-3% of calls to the Los Angeles Police Department involve mental health); Jennifer L.S. Teller et al., *Crisis Intervention Team Training for Police Officers Responding to Mental Disturbance Calls*, 57 PSYCHIATRIC SERVS. 232, 234 (2006) (finding that 6.55% of calls to the Akron, Ohio Police Department involve mental health). *But see* Alexander Black et al., *The Treatment of People with Mental Illness in the Criminal Justice System: The Example of Oneida County, New York*, LEVITT CTR. FOR PUB. AFFS. AT HAMILTON COLL. 9 (June 2019), https://digitalcommons.hamilton.edu/cgi/viewcontent.cgi?article=1005&context=student_scholarship

(estimating that ten percent of police calls involve mental health). These encounters can be especially time-consuming. *See* LAURA DRAPER, MELISSA REULAND, & MATTHEW SCHWARZFELD, COUNCIL OF STATE GOV'TS JUST. CTR., LAW ENFORCEMENT RESPONSES TO PEOPLE WITH MENTAL ILLNESSES: A GUIDE TO RESEARCH-INFORMED POLICY AND PRACTICE 7 (2009), https://csgjusticecenter.org/wp-content/uploads/2020/02/le-research.pdf (finding that the Los Angeles Police Department spends 28,000 hours each month on calls that involve someone in psychiatric distress).

[82] *See* Brett Sholtis, *During a Mental Health Crisis, A Family's Call to 911 Turns Tragic*, NPR (Oct. 29, 2020, 5:00 AM ET), https://www.npr.org/sections/health-shots/2020/10/29/928239761/during-a-mental-health-crisis-a-familys-call-to-911-turns-tragic (discussing the fatal shooting of Ricardo Muñoz, where his mother called emergency services for assistance with Ricardo's mental health episode, but maintained that "Ricardo was never a threat to them"); *see also supra* Part I (discussing the fatal shooting of Daniel Prude, where his brother called for emergency assistance although Daniel was wandering an empty street); *see also infra* note 124 and accompanying text (stating that Walter Wallace Jr. did not show active signs of threat during his mental health crisis, even in the presence of the officers who responded to the scene).

[83] *See* Bellafante, *supra* note 17 and accompanying text.

[84] *Position Statement 59: Responding To Behavioral Health Crises*, MENTAL HEALTH AM., https://www.mhanational.org/issues/position-statement-59-responding-behavioral-health-crises#_ednref2.

[85] Taleed El-Sabawi & Jennifer J. Carroll, *A Model for Defunding: An Evidence-Based Statute for Behavioral Health Crisis Response*, 94 TEMPLE L. REV. 1, 13 (2021).

[86] Lauren Young, *Decriminalizing Disability*, 52 MD. B.J. 62, 62 (2019).

[87] El-Sabawi & Carroll, *supra* note 85, at 17.

[88] Sema A. Taheri, *Do Crisis Intervention Teams Reduce Arrests and Improve Officer Safety? A Systematic Review and Meta-Analysis*, 27 CRIM. JUSTICE POL'Y REV. 76, 90 (2016).

[89] El-Sabawi & Carroll, *supra* note 85, at 16.

[90] *Id.*

[91] *Id*. at 17.

[92] Margarita Alegría, PhD. et al., *A New Agenda for Optimizing Investments in Community Mental Health and Reducing Disparities*, 179 AM. J. PSYCHIATRY 6, 402 (2022) (citing inadequate funding as one of the underlying reasons of the racial disparity in effective and accessible public mental health care).

[93] *See* MARTONE ET AL., *supra* note 68, at 5 ("Throughout the country, communities lack the capacity to provide intensive community-based mental health services, including Assertive Community Treatment, mobile crisis services, intensive case management, peer outreach and support, and supported housing, all of which have been proven successful in reducing arrest and incarceration as well as other forms of institutionalization. For people with mental illness and co-occurring substance use disorders, there is not enough medication-assisted treatment, detoxification services, or peer outreach and support, among other treatment options."); *id.* ("Consequently, too many people with mental illness end up in crisis, landing them in … emergency rooms, hospitals, and jails."); *id.* at 3 ("a disproportionate number of people with mental illness are incarcerated in jails and prisons, segregated from society for offenses that could well have been prevented had they had access to appropriate community-based services and supports."); *id.* at 5 ("Psychiatric crisis services are often nonexistent or insufficient to respond to, divert, or refer individuals back into the mental health system, leaving law enforcement professionals with the dilemma of having to arrest a person because no treatment diversion option exists."); ROBERT BERNSTEIN, IRA BURNIM, & MARK J. MURPHY, JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH L., DIVERSION, NOT DISCRIMINATION: HOW IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT CAN HELP REDUCE THE NUMBER OF PEOPLE WITH MENTAL ILLNESS IN JAILS 24 (July 2017), http://www.bazelon.org/wp-content/uploads/2018/07/MacArthur-White-Paper-re-Diversion-and-ADA.pdf ("Public mental health systems are underfunded. While most overwhelmingly embrace the core principles of deinstitutionalization and community mental health … services such as Assertive Community Treatment and supported housing are in short supply and are reserved for frequent users of psychiatric hospitals…. Often, this tendency results in mental health systems placing too little priority on people with mental illness who are–or who are at high risk of becoming–justice-involved"); JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH L., DIVERSION TO WHAT? EVIDENCE-BASED MENTAL HEALTH SERVICES THAT PREVENT NEEDLESS INCARCERATION 2 (Sept. 2019) [hereinafter DIVERSION TO WHAT], http://www.bazelon.org/wp-content/uploads/2019/09/Bazelon-Diversion-to-What-Essential-Services-Publication_September-2019.pdf ("Investing in community-based mental health services. provides numerous benefits, including a reduction in law enforcement intervention and incarceration.").

[94] Among others, the Community Mental Health Services Act of 1963, Pub. L. 88-164, intended to provide federal support for community-based services that would help people with mental illness avoid the "cold mercy of custodial

isolation" in institutions. President John F. Kennedy, Remarks on Proposed Measures to Combat Mental Illness and Mental Retardation (Feb. 5, 1963), https://www.jfklibrary.org/asset-viewer/archives/JFKWHA/1963/JFKWHA-161-007/JFKWHA-161-007. However, because of construction and funding barriers, states only built half of the community service centers envisioned in the Act. *See* Blake Erickson, M.D., M.A., *Deinstitutionalization Through Optimism: The Community Mental Health Act of 1963*, 16 AM. J. OF PSYCH. RESIDENTS' J. 6, 6 (June 2021), https://psychiatryonline.org/doi/epdf/10.1176/appi.ajp-rj.2021.160404 (citing GERALD N. GROB, FROM ASYLUM TO COMMUNITY: MENTAL HEALTH POLICY IN MODERN AMERICA (1991)). "Those without homes often ended up on the streets, with many entering an institutional circuit of acute care hospitals, jails, prisons, and forensic facilities." *Id. See also Reflecting on JFK's Legacy of Community-Based Care*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. (Mar. 18, 2021), https://www.samhsa.gov/homelessness-programs-resources/hpr-resources/jfks-legacy-community-based-care ("[W]e have to acknowledge that the execution of the vision was flawed, that fragmented implementation of the promise it held out allowed too many people to fall through the cracks. Too many people failed to receive the help they needed. Too many became homeless or were bypassed by our society.") (quoting Rep. Patrick Kennedy). Similar state initiatives have faced similar challenges. *See*, *e.g.*, Sigrid Bathen, *Real Change Proves Elusive In Mental Health System*, CAPITOL WEEKLY (Nov. 10, 2021), https://capitolweekly.net/real-change-proves-elusive-in-mental-health-care-legislation/ ("[California's 2004 Mental Health Services Act] has provided billions in funding for mental-health programs, but has also been criticized for its complex regulatory structure and lack of state oversight. Counties have also been accused of 'hoarding' MHSA funds that should be going to mental-health programs, or using it for other purposes.").

[95] Olmstead v. L.C., 527 U.S. 581 (1999) (holding that unnecessary segregation is discrimination actionable under Americans with Disabilities Act). In *Olmstead*, the Supreme Court noted Congress's finding that "society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." *Id.* at 588. The Court also noted Congress's intent that the ADA "provide a clear and national mandate for the elimination of discrimination against individuals with disabilities. *Id.* at 589.

[96] Kristen M. Folkerts, Isra Merchant, & Chenxi Yang, *A Tri-Country Analysis of the Effects of White Supremacy in Mental Health Practice and Proposed Policy Alternatives*, 19 COLUM. SOCIAL WORK REV. 86, 97 (2022) (citing a study revealing that 25-40% of Americans with mental health illnesses face incarceration in their lifetimes).

[97] *See* Abigail Adams, *Black, Disabled and at Risk: The Overlooked Problem of Police Violence Against Americans with Disabilities*, TIME (June 25, 2020, 8:56 AM), https://time.com/5857438/police-violence-black-disabled/ ("The combination of disability and skin color amounts to a double bind"); Jeffrey Swanson et al., *Racial Disparities in Involuntary Outpatient Commitment: Are They Real?*, 28 HEALTH AFFS. 816, 821 (2009) ("Rates of outpatient commitment per 10,000 were higher for blacks than for whites at every level"); *supra* text accompanying note 75.

[98] *See generally* Elizabeth N. Chapman, MD et al., *Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities*, 28 J. GEN. INTERN. MED. 1504 (2013), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3797360/pdf/11606_2013_Article_2441.pdf (discussing research suggesting that implicit biases may shape physician behavior and result in discriminatory treatment); *see also* Alan Nelson, M.D., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, 94 J. NAT'L MED. ASS'N 666, 667 (2002), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594273/pdf/jnma00325-0024.pdf ("Bias, stereotyping, prejudice, and clinical uncertainty on the part of health care providers may contribute to racial and ethnic disparities in health care. . . . indirect evidence from several lines of research support this statement"); *see generally* Ana I. Balsa & Thomas G. McGuire, *Prejudice, Clinical Uncertainty and Stereotyping As Sources of Health Disparities*, 22 J. HEALTH ECON. 89 (2003), https://www.sciencedirect.com/science/article/abs/pii/S016762960200098X?via%3Dihub; Ana I. Balsa et al., *Testing for Statistical Discrimination in Health Care*, 40 HEALTH SERVS. RSCH. 227, 227 (2005), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1361135/pdf/hesr_00351.pdf ("In the case of depression, we find evidence that race affects decisions through differences in communication patters between doctors and minority patients.").

[99] Matthew C. Fadus et al., *Unconscious Bias and the Diagnosis of Disruptive Behavior Disorders and ADHD in African American and Hispanic Youth*, 44 ACAD. PSYCHIATRY 95, 98-99 (2019), https://link.springer.com/content/pdf/10.1007/s40596-019-01127-6.pdf.

[100] *Id.*

[101] *Id.*

[102] *See* Jude Mary Cénat, *How to provide anti-racist mental health care*, 7 LANCET PSYCHIATRY 929, 929 (2020), https://www.thelancet.com/action/showPdf?pii=S2215-0366%2820%2930309-6 ("[R]acial discrimination, racial

profiling, microaggressions, and racism exist within physical and mental health-care institutions and services in western countries. These widespread and chronic factors are associated with lack of training of mental health professionals on racial issues and disparities."); Vickie Mays et al., *Perceived Discrimination in Health Care and Mental Health/Substance Abuse Treatment Among Blacks, Latinos, and Whites*, 55 MED. CARE 173, 180 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5233585/pdf/nihms807350.pdf (finding that experiences of discrimination in mental health or substance abuse visits contributes to early treatment discontinuation for Black people, which could be a factor in poorer mental health outcomes).

[103] *See* MARTIN SUMMERS, MADNESS IN THE CITY OF MAGNIFICENT INTENTIONS: A HISTORY OF RACE AND MENTAL ILLNESS IN THE NATION'S CAPITAL (2019) (tracing our country's history of institutionalization in Black communities and explaining how Black communities and patients approached institutions with caution, fearing unequal treatment and care and the possibility of violence, abuse, and long-term confinement).

[104] Rachel L. Johnson, MD, PhD et al., *Patient Race/Ethnicity and Quality of Patient-Physician Communication During Medical Visits*, 94 AM. J. OF PUB. HEALTH 2084, 2087 (2004), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1448596/pdf/0942084.pdf.

[105] Chapman et al., *supra* note 98.

[106] *Demographics of U.S. Psychology Workforce [interactive data tool]*, AM. PSYCH. ASS'N (2020), https://www.apa.org/workforce/data-tools/demographics.

[107] *Black Communities*, *supra* note 74.

[108] Mays et al., *supra* note 102.

[109] *See generally* Mary S. Garner & Dorcas E. Kunkel, *Quality Improvement of Pastoral Care For Major Depression in the Community of an African American Religious Organization*, 41 ISSUES MENTAL HEALTH NURSING 568 (2020) (explaining that, because Black Americans are less likely to receive appropriate diagnosis and culturally competent care for depression, their depression tends to become chronic and more severe).

[110] *See, e.g.*, First Amended Complaint at ¶ 2, Disability Rights California v. County of Alameda, 2021 WL 212900 (N.D. Cal. Feb. 22, 2021) (No. 5:20-cv-05256-CRB) ("During a recent two-year period, over 2,300 people were detained at the County's psychiatric facilities more than three times, the majority of whom were Black."); Press Release, Dep't of Justice, Justice Department Finds that Alameda County, California, Violates the Americans with Disabilities Act and the U.S. Constitution (Apr. 22, 2021), https://www.justice.gov/opa/pr/justice-department-finds-alameda-county-california-violates-americans-disabilities-act-and-us (finding that Alameda County failed to provide services to its constituents with mental health disabilities and unnecessarily institutionalized them at various psychiatric facilities instead of providing appropriate community-based services).

[111] First Amended Complaint, *supra* note 110, at ¶ 57.

[112] *Id.* at ¶ 2.

[113] *Id*. at ¶ 74.

[114] *Id*. at ¶ 84.

[115] AM. PSYCHIATRIC ASS'N, MENTAL HEALTH DISPARITIES: AFRICAN AMERICANS (2019), https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Mental-Health-Disparities/Mental-Health-Facts-for-African-Americans.pdf; Tahmi Perzichilli, *The Historical Roots of Racial Disparities in the Mental Health System*, COUNSELING TODAY (May 7, 2020), https://ct.counseling.org/2020/05/the-historical-roots-of-racial-disparities-in-the-mental-health-system/ (listing barriers for BIPOC individuals seeking mental health care, including racism and discrimination, greater vulnerability to being uninsured, access and communication barriers, and fear and mistrust of treatment); *see also* Sirry M. Alang, *Mental health care among blacks in America: Confronting racism and constructing solutions*, 54 HEALTH SERVS. RSCH. 346, 352 (2019), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6407345/pdf/HESR-54-346.pdf (finding that racism causes mistrust in mental health service systems and that Black people usually receive lower quality mental health care than white people).

[116] Richardson & Goff, *supra* note 56, at 121.

[117] Richardson, *supra* note 57.

[118] *Id.*

[119] Richardson & Goff, *supra* note 56.

[120] Robert E. Worden et al., *On the Meaning and Measurement of Suspects' Demeanor Toward the Police: A Comment on "Demeanor and Arrest,"* 33 J. RSCH. CRIME & DELINQ. 324, 325 (1996) (noting that the proposition that police officers respond punitively to those they believe are not according them deference "emerged from some of the earliest systematic inquiry into police behavior"). Research also shows significantly high levels of stigma against mental illness among law enforcement officers. *See* El-Sabawi & Carroll, *supra* note 85, at 11. One study reported that a majority of surveyed police officers viewed being treated for a mental illness as a "sign of personal

failure." Heather Stuart, *Mental Illness Stigma Expressed by Police to Police*, 54 ISR. J. PSYCHIATRY RELATED SCI. 18, 20 (2017).
[121] Richardson & Goff, *supra* note 56, at 137.
[122] Inappropriate and unnecessary contact between Black people with mental illness and law enforcement officers also violates our nation's Constitution and its civil rights laws. *See*, *e.g.*, C.R. DIV., U.S. DEP'T OF JUST., INVESTIGATION OF THE BALTIMORE CITY POLICE DEPARTMENT 3, 8 (Aug. 10. 2016), https://www.justice.gov/crt/file/883296/download. Following the killing of Freddie Gray in 2014, the Department of Justice conducted a comprehensive investigation of the Baltimore Police Department's (BPD's) policies and practices. *Id*. at 10. Among other things, the Department found that the BPD engaged in a pattern or practice of use of excessive force against Baltimore's residents, including Black residents with mental health disabilities. *Id.* at 74-85. The BPD also failed to make reasonable modifications to its policies for interactions for people with mental health disabilities, in violation of the Americans with Disabilities Act (ADA). *Id.* at 80-85. At the same time, the BPD also engaged in racially discriminatory stops, searches, arrests, and use of force, in violation of the Constitution and Title VI of the Civil Rights Act. *Id.* at 47-72. The Department, the BPD, and the City of Baltimore resolved the Department's findings through a Consent Decree, which is still being implemented by the parties under court supervision. Consent Decree, United States v. Police Dep't of Baltimore City, 282 F. Supp. 3d 897 (2017) (No. 17-cv-00099-JKB), 2017 WL 4481156, https://www.justice.gov/opa/file/925056/download; CONSENT DECREE MONITORING TEAM, SEVENTH SEMIANNUAL REPORT (Feb. 15, 2022), https://static1.squarespace.com/static/59db8644e45a7c08738ca2f1/t/620c205fdfa1535274047ae2/1644961899345/7th+Semiannual+Report.pdf. The Department continues to investigate police departments across the country for potential violations of the Constitution, Title VI, and the ADA. *See*, *e.g.*, *Attorney General Merrick B. Garland Delivers Remarks Announcing a Pattern or Practice Investigation into the City of Phoenix and the Phoenix Police Department*, U.S. DEP'T OF JUST., (Aug. 5, 2021), https://www.justice.gov/opa/speech/attorney-general-merrick-b-garland-delivers-remarks-announcing-pattern-or-practice (announcing the Justice Department's investigation into whether the Phoenix Police Department uses unconstitutional excessive force, engages in discriminatory policing practices, and "respond[s] to people with disabilities in a manner that violates the Americans with Disabilities Act").
[123] Mallika Kallingal & Brynn Gingras, *The Family of a Philadelphia man is suing two police officers who fatally shot him last year*, CNN (Apr. 2, 2021, 5:11 AM ET), https://www.cnn.com/2021/04/02/us/walter-wallace-jr-lawsuit-vs-police/index.html.
[124] *Id*.
[125] NBC10 Philadelphia, *VIDEO: Body-Worn Camera Footage From Walter Wallace Jr. Shooting*, YOUTUBE (Nov. 4, 2020) [hereinafter NBC Video], https://www.youtube.com/watch?v=USiOvzp-PP4.
[126] Scott Calvert, *Philadelphia Police Shooting: Who Was Walter Wallace Jr., and What Happened?*, WALL ST. J. (Oct. 28, 2020, 6:33 PM ET), https://www.wsj.com/articles/philadelphia-police-shooting-who-is-walter-wallace-jr-and-what-happened-11603906148.
[127] Doha Madani, *Philadelphia police release 911 calls, body camera video in fatal shooting of Walter Wallace*, NBC NEWS (Nov. 4, 2020, 10:18 PM EST), https://www.nbcnews.com/news/nbcblk/philadelphia-police-release-911-calls-body-camera-video-fatal-shooting-n1246461.
[128] NBC Video, *supra* note 125.
[129] Vanessa Romo, *Philadelphia Police Release 'Traumatic' Bodycam Video of Walter Wallace Jr. Shooting*, NPR (Nov. 4, 2020, 11:28 PM ET), https://www.npr.org/2020/11/04/931598467/philadelphia-police-release-traumatic-bodycam-video-of-walter-wallace-jr-shooting.
[130] Claudia Lauer, *Philadelphia victim's family sought ambulance, not police*, AP NEWS (Oct. 27, 2020), https://apnews.com/article/us-news-arrests-shootings-philadelphia-racial-injustice-f1d460e37c7d407f52743f06cbfe8e23.
[131] Madani, *supra* note 127.
[132] *Id.*
[133] *Id.*
[134] Calvert, *supra* note 126.
[135] *Id.*
[136] *Id.*
[137] *See supra* note 122.
[138] The community mental health services in which substantial investment is needed is described in DIVERSION TO WHAT, *supra* note 93, at 2. *See also* MARTONE ET AL., *supra* note 68, at 3 (noting that "many states have implemented policies, programs, and new housing options" that effectively serve people with mental illness in the community and "[w]hile progress has been slow, …many more people with mental illness [are] living in integrated,

community-based settings"). Among these, Assertive Community Treatment (ACT) is "an individualized package of services and supports effective in meeting the needs of people with serious mental illness living in the community," delivered by a multi-disciplinary team that provides case management, assessments, psychiatric services, substance use disorder services, housing assistance, and supported employment. DIVERSION TO WHAT, *supra* note 93, at 3. "The team is on call 24 hours a day to address the individual's needs and any crises that may occur." *Id.*

[139] *See, e.g.*, JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH L., REPLACING SCHOOL POLICE WITH SERVICES THAT WORK (Aug. 2021), https://secureservercdn.net/198.71.233.111/d25.2ac.myftpupload.com/wp-content/uploads/2021/08/Replacing-Police-in-Schools-1.pdf.

[140] *Peer Support: Research and Reports*, MENTAL HEALTH AM. (last visited July 1, 2022), https://www.mhanational.org/peer-support-research-and-reports; NAT'L LEAGUE OF CITIES, CITY & COUNTY LEADERSHIP TO REDUCE THE USE OF JAILS: ENGAGING PEERS IN JAIL USE REDUCTION STRATEGIES, https://www.nlc.org/wp-content/uploads/2020/10/Peers_Support_Brief_v3.pdf (last visited July 1, 2022).

[141] CAHOOTS stands for Crisis Assistance Helping Out On The Streets. *What is CAHOOTS?*, WHITE BIRD CLINIC (Oct. 29, 2020) [hereinafter WHITE BIRD CLINIC], https://whitebirdclinic.org/what-is-cahoots/.

[142] '*CAHOOTS': How Social Workers and Police Share Responsibilities in Eugene, Oregon*, NPR (June 10, 2020), https://www.npr.org/2020/06/10/874339977/cahoots-how-social-workers-and-police-share-responsibilities-in-eugene-oregon. A joint response by both CAHOOTS staff and police happens infrequently. Anna V. Smith, *There's Already an Alternative to Calling the Police*, MOTHER JONES (June 13, 2020), https://www.motherjones.com/environment/2020/06/theres-already-an-alternative-to-calling-the-police/.

[143] Scottie Andrew, *This Town of 170,000 Replaced Some Cops with Medics and Mental Health Workers. It's Worked for Over 30 Years*, CNN (July 5, 2020, 10:10 PM), https://www.cnn.com/2020/07/05/us/cahoots-replace-police-mental-health-trnd/index.html.

[144] *See, e.g., Support Team Assisted Response (STAR) Program*, CITY OF DENVER [hereinafter STAR PROGRAM], https://www.denvergov.org/Government/Agencies-Departments-Offices/Agencies-Departments-Offices-Directory/Public-Health-Environment/Community-Behavioral-Health/Behavioral-Health-Strategies/Support-Team-Assisted-Response-STAR-Program (last visited July 1, 2022); Tess Riski, *Portland Street Response Expands City-Wide, With 24/7 Service Still On Hold*, WILLAMETTE WEEK (Mar. 28, 2022, 5:28 PM PDT), https://www.wweek.com/news/city/2022/03/28/portland-street-response-expands-citywide-with-247-service-still-on-hold/.

[145] *See What is the Street Crisis Response Team?*, CITY & CNTY. S.F, https://sf.gov/street-crisis-response-team (last visited July 1, 2022). "San Francisco's new, unarmed, non-police teams are scheduled, at first, to take over the police calls for code 800 – a broad, catch-all category the police describe as a 'report of a mentally disturbed person.' The police here got nearly 17,000 of those code 800s last year, according to SFPD data, and nearly 22,000 overall from persons in mental or behavioral crisis. The vast majority of them were non-violent. Of those code 800 calls, the police data show, only 132 of them reported 'a potential for violence or a weapon.'" S.F. DEP'T PUB. HEALTH, STREET CRISIS RESPONSE TEAM ISSUE BRIEF (Feb. 2021), https://www.sfdph.org/dph/files/IWG/SCRT_IWG_Issue_Brief_FINAL.pdf. There are several different mental health crisis response models with varying degrees of law enforcement involvement, including none at all. A few community-based mental health programs in California importantly conduct all of their services without any law enforcement involvement. For a more in-depth description of the various mental health crisis response teams, see MIMI E. KIM ET AL., INTERRUPTING CRIMINALIZATION, DEFUND THE POLICE - INVEST IN COMMUNITY CARE: A GUIDE TO ALTERNATIVE MENTAL HEALTH RESPONSES (May 2021), https://static1.squarespace.com/static/5ee39ec764dbd7179cf1243c/t/60ca7e7399f1b5306c8226c3/1623883385572/Crisis+Response+Guide.pdf.

[146] *See GBRICS Partnership (Greater Baltimore Regional Integrated Crisis System): Transforming Behavioral Health Crisis Services*, BEHAV. HEALTH SYS. BALT. [hereinafter *GBRICS Partnership*], https://www.bhsbaltimore.org/learn/gbrics-partnership/ (last visited July 1, 2022) (describing Baltimore region's plans to "[e]xpand capacity of mobile crisis teams (non-law enforcement) so that they are available 24/7 across the region," with the goal of "[r]educ[ing] unnecessary emergency department use and police interaction for people in behavioral health crisis").

[147] *See* Letter from Daniel Tsai, Deputy Admin. & Director, Ctrs. for Medicare & Medicaid Servs., to U.S. Dep't of Health & Human Servs. (Dec. 28, 2021) [hereinafter CMS Letter], https://www.medicaid.gov/federal-policy-guidance/downloads/sho21008.pdf.

[148] DIVERSION TO WHAT, *supra* note 93, at 7-8. The federal government has endorsed the clinician-peer worker model as a "best practice." *See* SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., NAT'L GUIDELINES FOR

BEHAV. HEALTH CRISIS CARE: BEST PRACTICE TOOLKIT 18 (2020) [hereinafter TOOLKIT], https://www.samhsa.gov/sites/default/files/national-guidelines-for-behavioral-health-crisis-care-02242020.pdf.

[149] *See, e.g.* Eric Westervelt, *Removing Cops From Behavioral Health Crisis Calls: "We Need To Change the Model,"* NPR (Oct. 19, 2020), https://www.npr.org/2020/10/19/924146486/removing-cops-from-behavioral-crisis-calls-we-need-to-change-the-model (stating that the goal of San Francisco's Street Crisis Response Team program is to "better guide people to long-term supportive services, and to end the in-and-out emergency rooms and homeless shelter cycle").

[150] *See* NAT'L ALL. ON MENTAL ILLNESS, CRISIS SERVICES FACT SHEET 2 (Mar. 2015), https://www.nami.org/NAMI/media/NAMI-Media/Images/FactSheets/Crisis-Service-FS.pdf ("Crisis respite centers and apartments provide 24-hour observation and support by crisis workers or trained volunteers until a person is stabilized and connected with other supports"); DIVERSION TO WHAT, *supra* note 93, at 7-8 (describing "community crisis apartments where individuals can stay for a short period as an alternative to hospitalization, incarceration, or stays in costly and hospital-like crisis facilities" that provide support from clinicians and peers); DANIEL FISHER ET AL., SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., PEER-RUN RESPITES: AN EFFECTIVE CRISIS ALTERNATIVE, https://www.nasmhpd.org/sites/default/files/Peer%20Run%20Respite%20slides.revised.pdf (last visited July 1, 2022).

[151] "Crisis drop-off centers that are open 24 hours a day and have a 'no refusal' policy enable law enforcement to divert persons with mental illness away from the criminal justice system." MARTONE ET AL., *supra* note 68, at 10-11.

[152] Most psychiatric crises can be addressed without resort to hospitalization, however. *See, e.g.*, TREATMENT ADVOC. CTR., PSYCHIATRIC BED SUPPLY NEED PER CAPITA 1 (Sep. 2016), https://www.treatmentadvocacycenter.org/storage/documents/backgrounders/bed-supply-need-per-capita.pdf ("[M]ost people with a diagnosed mental illness never require hospitalization, and many with the most serious conditions can be successfully treated in the community . . . ."); Margie Balfour, M.D., Ph.D., Chief of Quality & Clinical Innovation, Connections Health Sols., Presentation to the Ohio Mental Health Admin.: The Ideal Crisis System: Strategies for Mental Health and Law Enforcement Collaboration to Prevent Justice Involvement 21 (Nov. 18, 2019), https://mha.ohio.gov/static/Portals/0/assets/SchoolsAndCommunities/CommunityAndHousing/Community-Planning/Crisis%20Services/Ideal-Crisis-System.pdf?ver=2019-11-18-104750-667 (noting that in southern Arizona's behavioral health crisis system, 80% of crisis calls were resolved by phone; of the rest, 71% were resolved in the field by mobile crisis teams, and 68% of the remaining individuals were stabilized in care centers and returned to their communities without hospitalization).

[153] A widely respected example of such a center is the Houston Recovery Center. *Harris County Confidential Jail Diversion Programs*, HOUS. RECOVERY CTR., https://houstonrecoverycenter.org/harris-county-confidential-jail-diversion-programs/ (last visited July 1, 2022).

[154] Exec. Order No. 14,074, 87 Fed. Reg. 32945 (May 25, 2022), https://www.whitehouse.gov/briefing-room/presidential-actions/2022/05/25/executive-order-on-advancing-effective-accountable-policing-and-criminal-justice-practices-to-enhance-public-trust-and-public-safety/. The Executive Order requires the Attorney General and the Secretary of Health and Human Services to lead a study of co-responder and alternative responder models and issue guidance on best practices for responding to calls for and from people experiencing mental health crises. *Id* at § 14(a)-(b). Studies show, however, that co-responder models are ineffective. *See generally* Taheri, *supra* note 88. While it is important to consider alternatives, focusing on the co-responder model will continue to result in criminalization and physical violence against people with mental illness, especially those who are Black. Alternative responder models like the community response program piloted in Denver, CO, on the other hand, are proven to reduce the criminalization of people experiencing mental health crises and reduce the actual level of crime in the community altogether. *See* Thomas S. Dee & Jaymes Pyne, *A community response approach to mental health and substance abuse crises reduced crime*, 8 SCI. ADV. 1, 6 (2022), https://www.science.org/doi/pdf/10.1126/sciadv.abm2106.

[155] *See generally* Taheri, *supra* note 88; El-Sabawi & Carroll, *supra* note 85.

[156] In addition, the training models that exist have produced mixed results. For example, some studies of Crisis Intervention Training (CIT) for police, a popular approach, have indicated that it does not change the outcomes from police interventions. El-Sabawi & Carroll, *supra* note 85, at 13 ("Despite the enormous number of programs in operation in the thirty years following CIT's conception, little evidence exists to show that the CIT approach is effective at reducing incidents of police use of force (or even simply reducing incidents of *excessive* police use of force) during behavioral-health-related calls.").

[157] *See supra* notes 81-83 and accompanying text.

[158] Taheri, *supra* note 88, at 90.
[159] There are different ways to implement a joint response. A pre-existing team of police and mental health personnel can be dispatched, or the police and mental health system can separately deploy personnel who coordinate and converge on the scene. Communities have implemented a variety of co-responder models. ASHLEY KRIDER ET AL., POL'Y RSCH. , INC. & NAT'L LEAGUE OF CITIES, RESPONDING TO INDIVIDUALS IN BEHAVIORAL HEALTH CRISIS VIA CO-RESPONDER MODELS: THE ROLES OF CITIES, COUNTIES, LAW ENFORCEMENT, PROVIDERS (Jan. 2020), https://www.theiacp.org/sites/default/files/SJCResponding%20to%20Individuals.pdf.
[160] *See, e.g.*, S. Rebecca Neusteter, Ph.D., Exec. Dir., Univ. Chi. Health Lab, Presentation to the National Association of Counties: Understanding Law Enforcement Response 5-19, (Jan. 27, 2021) [hereinafter Neusteter Presentation], https://www.naco.org/sites/default/files/event_attachments/Coordinating%20a%20System%20Response%20to%20911%20Dispatch.pdf.
[161] DIVERSION TO WHAT, *supra* note 93, at 7-8.
[162] *See* CMS Letter, *supra* note 147 (discussing enhanced federal Medicaid financing for qualifying mobile crisis services); Richard G. Frank & Vikki Wachino, *Building A Sustainable Behavioral Health Crisis Continuum*, BROOKINGS (Jan. 6, 2022), https://www.brookings.edu/blog/usc-brookings-schaeffer-on-health-policy/2022/01/06/building-a-sustainable-behavioral-health-crisis-continuum/ ("The new Medicaid mobile crisis incentive is modeled on the CAHOOTS (Crisis Assistance Helping Out on the Streets) mobile crisis intervention program in Eugene Oregon.").
[163] *See* MARTONE ET AL., *supra* note 68, at 5 (noting these services "have been proven successful in reducing arrest and incarceration as well as other forms of institutionalization"); Bernstein, Burnim, & Murphy, *supra* note 93, at 18 (noting these services' success in preventing needless institutionalization and pointing out that their availability increases jurisdictions' compliance with the Americans with Disabilities Act); DIVERSION TO WHAT, *supra* note 93, at 7-8 (describing these services and the evidence of their success in preventing incarceration).
[164] In November 2021, the House of Representatives passed the Build Back Better Act, which included $150 billion in federal financial resources for Medicaid reimbursement for services like ACT, crisis services, supported employment, and peer support services. Emily Cochrane & Jonathan Weisman, *House Narrowly Passes Biden's Social Safety Net and Climate Bill*, N.Y. TIMES (Nov. 21, 2021), https://www.nytimes.com/2021/11/19/us/politics/house-passes-reconciliation-bill.html; Elise Aguilar, *The Build Back Better Act: $150 Billion for Medicaid HCBS Funding and Other Important Programs*, AM. NETWORK CMTY. OPTIONS & RES. (Nov. 2, 2021), https://www.ancor.org/newsroom/news/build-back-better-act-150-billion-medicaid-hcbs-funding-and-other-important-programs. The Build Back Better Act also allocated another $150 billion in federal housing resources, including Department of Housing and Urban Development (HUD) housing vouchers that can be used by people with mental illness so that they can afford safe and stable housing. Will Fischer, *Housing Investments in Build Back Better Would Address Pressing Unmet Needs*, CTR. BUDGET & POL'Y PRIORITIES (Feb. 10, 2022), https://www.cbpp.org/research/housing/housing-investments-in-build-back-better-would-address-pressing-unmet-needs#:~:text=The%20House%2Dpassed%20Build%20Back%20Better%20bill%20would%20provide%20more,expansion%20is%20fully%20phased%20in.
[165] CTR. CONNECTED HEALTH POL'Y, COVID-19 TELEHEALTH COVERAGE POLICIES (Mar. 2021), https://www.cchpca.org/2021/11/Spring2021_COVIDPolicies-1.pdf. This recommendation also applies to state lawmakers, as well as to private insurance regulators.
[166] This recommendation also applies to state lawmakers, as well as to private insurance regulators.
[167] This summer will see the roll-out of 988, the new three-digit number for calls to the national network of call centers affiliated with the National Suicide Prevention Lifeline. Designating 988 for the National Suicide Prevention Lifeline, 47 CFR § 52.200 (2020). 988 is intended to be a new "mental health 911" for calls involving mental health crises including but not limited to threats of self-harm. National Suicide Hotline Designation Act of 2020, Pub. L. 116-172 (2020). As currently constituted, the 988 network is inadequate to meet the needs of all those who are expected to call 988, or to serve as an effective resource to the 911 system. JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH L., A NEW DAY OR MORE OF THE SAME? OUR HOPES AND FEARS FOR 988 (AND 911) (June 2022) [hereinafter HOPES AND FEARS FOR 988], https://secureservercdn.net/198.71.233.111/d25.2ac.myftpupload.com/wp-content/uploads/2022/06/A-New-Day-or-More-of-the-Same-Our-Hopes-Fears-for-988-and-911.pdf. Congress has enacted legislation permitting states to place fees on mobile phone networks to pay for staffing and training for 988, *see id.*, but more federal support has been proposed and is needed.
[168] For example, under the Mental Health Justice and Parity Act of 2022, introduced in the House of Representatives by Congresswoman Katie Porter, the Department of Health and Human Services (HHS) would provide grants to

communities for programs in which clinicians and/or peers respond to service calls instead of the police. Mental Health Justice and Parity Act of 2022, H.R. 7254, 117th Cong. (introduced Mar. 28, 2022). These alternative responders would be trained in the principles of de-escalation and antiracism, and grantees could receive additional funds if they demonstrate a notable reduction in incarceration or death of people with mental illness, or a notable increase in referrals of people with mental illness to voluntary community-based services. *Id.* Federal funding for other initiatives, such as the 988 network, *see* HOPES AND FEARS FOR 988, *supra* note 167, was included in the Bipartisan Safer Communities Act of 2022, enacted by Congress and signed by President Biden in June 2022. *See* President Joseph R. Biden, Remarks at the Signing of S.2938, the Bipartisan Safer Communities Act (June 25, 2022), https://www.whitehouse.gov/briefing-room/speeches-remarks/2022/06/25/remarks-by-president-biden-at-signing-of-s-2938-the-bipartisan-safer-communities-act/.

[169] *See, e.g.*, *Fact Sheet: President Biden to Announce Strategy to Address Our National Mental Health Crisis, As Part of Unity Agenda in his First State of the Union*, WHITE HOUSE (Mar. 1, 2022) (announcing President's FY2023 budget request for mental health workforce capacity-building programs), https://www.whitehouse.gov/briefing-room/statements-releases/2022/03/01/fact-sheet-president-biden-to-announce-strategy-to-address-our-national-mental-health-crisis-as-part-of-unity-agenda-in-his-first-state-of-the-union/. Existing programs such as the National Health Service Corps, Nurse Corps, Behavioral Health Workforce Education and Training Program, Substance Use Disorder Treatment and Recovery Loan Repayment Program, and the Minority Fellowship Program, provide training, access to scholarships and loan repayment to mental health clinicians committed to practicing in underserved communities.

[170] *Assertive Community Treatment Grants*, SUBSTANCE ABUSE & MENTAL HEALTH SERV. ADMIN. (Mar. 2021), https://www.samhsa.gov/grants/grant-announcements/sm-18-013.

[171] *See, e.g.*, DIVERSION TO WHAT, *supra* note 93 (calling on communities to implement supported housing and supported employment programs).

[172] *See About*, NAT'L NETWORK TO ELIMINATE DISPARITIES IN BEHAV. HEALTH (NNED), https://nned.net/about/ (last visited July 1, 2022) (stating that NNED supports community-based organizations in learning about and implementing training and other efforts to increase behavioral health equity).

[173] *See, e.g.*, Lucy Tompkins, *If Housing Is a Health Care Issue, Should Medicaid Pay the Rent?*, N.Y. Times (June 14, 2022), https://www.nytimes.com/2022/06/14/headway/medicaid-housing-rent-health.html; Jennifer Mathis, *Housing is Mental Health Care: A Call for Medicaid Demonstration Waivers Covering Housing*, PSYCHIATRY ONLINE (Dec. 18, 2020), https://ps.psychiatryonline.org/doi/10.1176/appi.ps.202000252 (stating that Medicaid should "approve demonstrations covering housing for people with serious mental illnesses. If these demonstrations show that providing Medicaid financing for housing improves mental health outcomes and reduces use of more costly services, those results should spur a conversation about modifying Medicaid to allow reimbursement for housing in appropriate circumstances"). Studies show that providing permanent, scattered-site supported housing to people with mental illness fosters better outcomes, in terms of reduced emergency room and hospital utilization, reduced engagement with law enforcement, and increased measures of social interaction and community engagement. *See, e.g.*, JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH L., SUPPORTIVE HOUSING: THE MOST EFFECTIVE AND INTEGRATED HOUSING FOR PEOPLE WITH MENTAL DISABILITIES (Apr. 2017), http://www.advancingstates.org/sites/nasuad/files/hcbs/files/155/7711/Supportive_Housing.pdf; *Position Statement 38: Supportive Housing and Housing First*, MENTAL HEALTH AM. (Sep. 18, 2018), https://www.mhanational.org/issues/position-statement-38-supportive-housing-and-housing-first#_ednref13; Tim Aubry et al., *A randomized controlled trial of the effectiveness of Housing First in a small Canadian City*, 19 BMC PUB. HEALTH 1154 (2019), https://bmcpublichealth.biomedcentral.com/track/pdf/10.1186/s12889-019-7492-8.pdf. Providers of mental health services report that it is easier to engage people with mental illness in considering other services, and in active participation in service planning and recovery. *See, e.g.*, *What We Do: Housing First Teams*, PATHWAYS TO HOUSING DC [hereinafter PATHWAYS], https://pathwaystohousingdc.org/what-we-do/housing-first/ ("After receiving housing first, every client is matched with a support team[,] . . . which works together to provide a client-centered, comprehensive community-based treatment and support services around the clock. . . . Using this model, we have been able to maintain a housing retention rate of at least 91% with clients who have traditionally been viewed as 'treatment resistant,' and 'not ready for housing") (last visited July 1, 2022).

[174] *See* Letter from Dennis G. Smith, Dir., Ctrs. for Medicare & Medicaid Servs., to U.S. Dep't of Health & Hum. Servs. (Aug. 15, 2007), https://downloads.cms.gov/cmsgov/archived-downloads/smdl/downloads/smd081507a.pdf (stating that supervision of peer support workers is a "core component" of peer services, and must be provided by a "competent mental health professional"). Although consulting with clinicians such as psychologists or social workers may be beneficial to people working as peers, it should not be a requirement for reimbursement of all peer support services. The lived experience of peers, and their ability to share these experiences with other people with

mental illness, are intrinsically valuable, and there are other approaches to ensuring that peer services are effective, including those in which networks of peers share their experiences among themselves, that should be considered. *See, e.g., People USA's Rose Houses*, PEOPLE USA, https://people-usa.org/program/rose-houses/ (last visited July 1, 2022) ("Rose Houses are short-term crisis respites that are home-like alternatives to hospital psychiatric ERs and inpatient units. They are 100% operated by peers who have their own lived experiences with behavioral health challenges, crisis, and moving toward wellness."); *Online and Phone Supports*, WILDFLOWER ALL. [hereinafter Wildflower Phone Supports], https://wildfloweralliance.org/online-support-groups/ (last visited July 1, 2022) (hosting peer-led suicide-related support groups both online and by phone); *The Living Room: Forever Hope*, THRESHOLDS, https://www.thresholds.org/programs-services/peer-services/the-living-room (last visited July 1, 2022) ("The Living Room . . . is an entirely peer-led crisis respite center, an alternative to psychiatric hospitalization. . . . [The] Living Room is a calm, peaceful, and inviting space with plenty of natural light. … Staff at The Living Room help guests through a screening and assessment process in a natural, comfortable setting."); *What is the Evidence for Peer Recovery Support Services?*, RECOVERY RSCH. INST., https://www.recoveryanswers.org/research-post/what-is-the-evidence-for-peer-recovery-support-services/ (last visited July 1, 2022) (citing Reif et al., *Peer recovery support for individuals with substance use disorders: assessing the evidence*, 65 PSYCHIATRIC SERV. 853 (2014)); DIVERSION TO WHAT, *supra* note 93, at 11.

[175] *See, e.g.*, Phyllis Jordan, Anne Dwyer, Bella DiMarco & Margaux Johnson-Green, *How Medicaid Can Help Schools Sustain Support for Students' Mental Health*, GEO. UNIV. HEALTH POLY INST. CTR. FOR CHILDREN & FAMILIES (May 2022), https://ccf.georgetown.edu/2022/05/17/how-medicaid-can-help-schools-sustain-support-for-students-mental-health/.

[176] DIVERSION TO WHAT, *supra* note 93, *passim*. These services include intensive case management, peer support services, Assertive Community Treatment (ACT, which should serve as a crisis response resource for its clients), supported employment, and supported housing. *Id.* For children and youth, available services should be wrapped around the child and family, through a plan developed by a multi-disciplinary team partnering with the child and family. *See, e.g.*, Letter from Vanita Gupta, Principal Deputy Assistant Att'y Gen., C.R. Div., U.S. Dep't of Just., to Honorable Earl Ray Tomblin, Governor, W. Va. 9 (June 1, 2015), https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf.; CINDY MANN & PAMELA S. HYDE, CTR. FOR MEDICAID & CHIP SERVS. & SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., JOINT CMCS & SAMHSA INFORMATIONAL BULLETIN: COVERAGE OF BEHAVIORAL HEALTH SERVICES FOR CHILDREN, YOUTH, AND YOUNG ADULTS WITH SIGNIFICANT MENTAL HEALTH CONDITIONS 3-6 (2013), https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf. Services should be adapted to make them effective for all communities, including Black communities. RAHN K. BAILEY, M.D., AM. PSYCHIATRIC ASS'N, BEST PRACTICE HIGHLIGHTS: AFRICAN AMERICANS/BLACKS, https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Treating-Diverse-Populations/Best-Practices-AfricanAmerican-Patients.pdf (last visited June 14, 2022).

[177] *See, e.g.*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., TREATMENT IMPROVEMENT PROTOCOL 57, TRAUMA-INFORMED CARE IN BEHAVIORAL HEALTH SERVICES (2014). So delivered, participation in these services can help people with mental illness avoid crises which may prompt involvement with law enforcement. *See, e.g.*, *Addressing Law Enforcement Violence as a Public Health Issue*, AM. PUB. HEALTH ASS'N (Nov. 13, 2018), https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2019/01/29/law-enforcement-violence.

[178] *See, e.g.*, HOPES AND FEARS FOR 988, *supra* note 167, at 10-11. Effective call centers resolve requests for help by providing advice, making referrals, and/or providing transportation to a community-based service provider. *Id.*

[179] DIVERSION TO WHAT, *supra* note 93, at 7.

[180] HOPES AND FEARS FOR 988, *supra* note 167, at 11. These include respite apartments or "living room" model care centers. *Id.* All of the components of the behavioral health crisis response system should be coordinated so that provider capacity and an individual's progress through the system are tracked and outcomes monitored. *See, e.g.*, TOOLKIT, *supra* note 148.

[181] *See, e.g.*, PATHWAYS, *supra* note 173.

[182] *See, e.g.*, WHITE BIRD CLINIC, *supra* note 141 (describing implementation of the CAHOOTS program in the Eugene-Springfield metro area of Oregon); STAR PROGRAM, *supra* note 144.

[183] *See, e.g.*, Natasha Hinds Fitzsimmins, Lenore Bromley, & Liben Gebremikael, *City of Toronto Launches Black Mental Health Campaign Ahead of Black History Month*, CITY OF TORONTO (Jan. 30, 2020), https://www.toronto.ca/news/city-of-toronto-launches-black-mental-health-campaign-ahead-of-black-history-month/; *see generally Identity and Cultural Dimensions: Black/African American*, NAT'L ALL. ON MENTAL ILLNESS,

https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/Black-African-American (last visited July 1, 2022).

[184] *See, e.g.*, HOPES AND FEARS FOR 988, *supra* note 167, at 12; NAT'L SUICIDE PREVENTION LIFELINE, POLICY FOR HELPING CALLERS AT IMMINENT RISK OF SUICIDE 1 (Dec. 2010), https://www.madinamerica.com/wp-content/uploads/2020/11/SAMHSA-Lifeline-Policy-for-Helping-Callers-at-Imminent-Risk-of-Suicide.pdf (finding that in a 2007 study of four Lifeline centers, deployment of emergency rescue services varied from 0.5% of calls at one center to 8.5% of calls at another center). 988 and 911 service providers, and law enforcement agencies, should audit those instances when police are dispatched to better understand whether involving the police was appropriate. *See, e.g.*, Neusteter Presentation, *supra* note 160.

[185] *See Delivering Behavioral Health: Police-Mental Health Collaboration (PMHC) Toolkit*, U.S. DEP'T OF JUST., BUREAU OF JUST. ASSISTANCE, https://bja.ojp.gov/program/pmhc/behavioral-health#:~:text=Non%2DCrisis%20Diversion%20%E2%80%93%20In%20non,support%20and%20services%20as%20appropriate (last visited Jun. 14, 2022).

[186] *See, e.g.*, *GBRICS Partnership*, *supra* note 146 (describing 21-member stakeholder group providing guidance to behavioral health crisis reform effort; members are required to participate in committees including to promote community engagement). This may mean providing stipends or childcare to community members so that they can participate in meetings.

[187] *See, e.g.*, *Community Mental Health Services Block Grant*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. (Apr. 2020), https://www.samhsa.gov/grants/block-grants/mhbg; *Substance Abuse Prevention and Treatment Block Grant*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. (Apr. 2022), https://www.samhsa.gov/grants/block-grants/sabg; *What is a CCBHC?*, NAT'L COUNCIL FOR MENTAL WELLBEING, https://www.thenationalcouncil.org/program/ccbhc-success-center/ccbhc-overview/ (last visited June 30, 2022).

[188] *See, e.g.*, *Peers*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. (Apr. 2022), https://www.samhsa.gov/brss-tacs/recovery-support-tools/peers.

[189] *See, e.g.*, PEER RESPITES: ACTION & EVALUATION, https://www.peerrespite.com/ (last visited June 14, 2022).

[190] *See, e.g.*, *Expanding the Peer Bridger Program*, WASH. MENTAL HEALTH SUMMIT, https://www.wamhsummit.org/peer-bridger-program (last visited July 1, 2022).

[191] *See, e.g.*, Wildflower Phone Supports, *supra* note 174; NAT'L ALL. ON MENTAL ILLNESS, NAMI NATIONAL WARMLINE DIRECTORY (Apr. 2021), https://www.nami.org/NAMI/media/NAMI-Media/BlogImageArchive/2020/NAMI-National-HelpLine-WarmLine-Directory-3-11-20.pdf; WARMLINES, https://warmline.org/ (last visited May 31, 2022).

[192] *See, e.g.*, *Individualized Placement and Support (IPS) Supported Employment for People Experiencing Homelessness*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. (June 2022), https://soarworks.samhsa.gov/article/individual-placement-and-support-ips-supported-employment-for-people-experiencing.

[193] *See, e.g.*, SUPPORT, TECH. ASSISTANCE & RES. CTR., CULTURAL COMPETENCY IN MENTAL HEALTH PEER-RUN PROGRAMS AND SELF-HELP GROUPS: A TOOL TO ASSESS AND ENHANCE YOUR SERVICES 8 (2010), https://power2u.org/wp-content/uploads/2017/09/CulturalCompetencyInMentalHealthPeer-runProgramsSelf-helpGroups.pdf (advising providers of peer support services to look at "cultural composition of your peer staff, volunteers or leadership").

[194] *See, e.g.*, DIVERSION TO WHAT, *supra* note 93; LAUREN WOOD & LAUREN BLOCK, NAT'L GOVERNORS ASS'N SUPPORTING STATE BEHAVIORAL HEALTH SYSTEMS DURING COVID-19 RECOVERY AND RESPONSE (Nov. 2020), https://www.nga.org/wp-content/uploads/2020/11/Supporting-State-Behavioral-Health-Systems-During-COVID-19-Response-and-Recovery.pdf.

[195] *See, e.g.*, JESSICA ALLEN ET AL., WORLD HEALTH ORG., SOCIAL DETERMINANTS OF MENTAL HEALTH (2014), https://apps.who.int/iris/bitstream/handle/10665/112828/9789241506809_eng.pdf.

[196] The American Rescue Plan Act (ARPA) allocated $122 billion to support school districts through the Elementary and Secondary School Emergency Relief (ESSER) program. *See, e.g.*, U.S. DEP'T OF EDUC., FACT SHEET: AMERICAN RESCUE PLAN ACT OF 2021 ELEMENTARY AND SECONDARY SCHOOL EMERGENCY RELIEF FUND (Mar. 2021), https://oese.ed.gov/files/2021/03/FINAL_ARP-ESSER-FACT-SHEET.pdf. Schools who obtain ESSER funds from their states must commit them to specific projects on designated deadlines through September 2024, but then have another 18 months from their "obligation" deadline to spend the funds. Letter from Roberto J. Rodríguez, Assistant Sec'y, Off. of Planning, Evaluation & Pol'y Dep't, U.S. Dep't of Educ., to Daniel Domenech, Exec. Dir., School Superintendents Ass'n (May 13, 2022), https://aasa.org/uploadedFiles/AASA_Blog_The_Total_Child(1)/AASA%20Response%20Letter%205_13_22.pdf.

[197] U.S. DEP'T OF EDUC., FREQUENTLY ASKED QUESTIONS: ELEMENTARY AND SECONDARY SCHOOL EMERGENCY RELIEF PROGRAMS & GOVERNOR'S EMERGENCY EDUCATION RELIEF PROGRAMS 29-30 (May 2021), https://oese.ed.gov/files/2021/05/ESSER.GEER_.FAQs_5.26.21_745AM_FINALb0cd6833f6f46e03ba2d97d30aff953260028045f9ef3b18ea602db4b32b1d99.pdf.

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Memorandum in Support

March 16, 2023

S. 4007-B, Part DD
A. 3007-B, Part DD

By: BUDGET
By: BUDGET
Senate Committee: Finance
Assembly Committee: Ways and Means
Effective Date: 90th day after it shall have become law

THE TASK FORCE ON MENTAL HEALTH AND TRAUMA INFORMED REPRESENTATION SUPPORTS THIS LEGISLATION

New York State Bar Association's Task Force on Mental Health and Trauma Informed Representation supports an 8.5% Cost of Living Increases for Human Service Programs.

The New York State Bar Association's Task Force on Mental Health and Trauma Informed Representation ("Task Force") is tasked with evaluating all areas of the law where clients living with mental illness and trauma need representation, and what lawyers need to provide the best possible representation. As part of this evaluation, the Task Force has reviewed the underlying funding for staffing provided annually for those who serve in housing, clinical and treatment roles in community-based services and finds significant additional funding is needed.

Part CC of the Executive's Mental Health and Hygiene Budget Bill (S.4007-A/A.3007-A) establishes a "2.5% COLA" (Cost of Living Adjustment) for designated Human Service Programs. This COLA increase would be added to the state funding in support of the services of numerous community-based health care provider organizations. Among those providers are the hundreds of nonprofits providers of "behavioral health services": those which help to meet the needs of individuals living with mental health, addiction, and developmental/intellectual disabilities, as well as co-occurring disorders.

New York, like most of the states, is facing a healthcare worker shortage. Following COVID-19, when combined with the already challenging work and often irregular hours, low wages become one of the core contributors to this staffing shortage. "*COVID-19 certainly played a major role, said Bryan O'Malley, CDPAANYS executive director, with people quitting because they didn't want to take the risk, or because they needed to care for their own children or a sick person in their household. Despite that, almost 50 percent of the clients responding to the association's survey said a home health aide had quit because of low pay or having found a better job. "COVID definitely made the situation worse, but it was already a crisis," O'Malley said.*[i]

In 2006, the State Legislature enacted a COLA for the benefit of mental hygiene and human services providers. The statutory COLA authority has been extended every year since then, however the language included "notwithstanding" language, which has allowed the COLA to be ignored in subsequent years. A COLA was provided in 2006 but was "notwithstood" in all except three years since then creating a lack of necessary funding to provide proper services to those in need.

In those three years in which a COLA was provided, there was a 0.2%, 1.0% and a 5.4% COLA totaling 6.6%, while the consumer price index increased during that period a total of 35.31%. (In two other years, there were modest salary increases for mental hygiene programs but no across-the-board increases.) The cumulative, compounded impact of deferred COLA increases is approximately a 30% loss in reimbursement, which directly translates to wage increases for front-line and support workers, when compared to the increase in inflation, over those 16 years.

As a result, most mental health, addiction and ID/DD community-based have seen little increase in wages, resulting in extreme difficulty hiring and retaining staff positions. Thus, many currently have double digit vacancy rates.

NYSBA applauds Governor's Hochul's historic proposed expansion of mental health services in her 2023-24 Executive Budget, however, it is clear that it will have limited impact without increasing funding to existing providers to pay competitive salaries to recruit and retain competent staff. The Assembly and Senate proposed budgets include the 8.5% COLA that is necessary for these services to expand.

As Task Force Co-Chair Joseph A. Glazer, who serves as Deputy Commissioner of the Department of Community Mental Health in Westchester County wrote in his budget testimony to the Joint Hearing on the Health and Mental Hygiene Article VII budget proposal, "*Our service providers are in a staffing crisis… Should these … crises be left unaddressed, the Governor's proposed budget will effectively bring little change in our system. We will have a huge, robust system on paper, and the static inability to fill new apartments and hire employees, unless the legislature addresses the on-going woeful inadequacy of funding for our workforce…"*[ii]

Based on the foregoing, the Task Force **supports** efforts proposed by the Assembly and Senate budgets increasing the **8.5% COLA for Human Services Programs**.

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[i] https://citylimits.org/2021/12/27/whats-driving-the-shortage-of-home-healthcare-workers-in-ny-low-wages-advocates-say/

[ii] https://www.nysenate.gov/sites/default/files/westchester_dept._of_community_mental_health.pdf

Interim Report: Respite Care Services Workgroup

Submitted April 2011

Introduction, Background and Charge

In February, 2010, The Commissioners' Committee on Cross-Systems Youth asked its Senior Staff and Family & Youth Partners to form a study and work group to identify issues related to Respite Care with a cross-system focus. Through multiple vehicles and venues, including personally attended regional hearings across the state, the cross-systems Commissioners heard about a range of issues associated with the supply, demand, access to, understanding, availability, accessibility, affordability, and effectiveness of local respite care services. Respite care issues to be studied included access, planned and emergency respite services. The group was also asked to recommend remedial strategies and outline a plan moving forward. By way of this interim report, the Respite Care Services Workgroup conveys its findings to date and suggests strategic directions for the Senior Staff and Family & Youth Partners and Commissioners' Committee's consideration.

Group Membership Representatives of the Following State Agencies, Organizations and Systems

- Council on Children and Families (CCF)
- Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC)
- Families Together in NYS (FTNYS)
- Office of Children and Family Services (OCFS)
- Department of Health (DOH)
- Office of Mental Health (OMH)
- Office for People With Developmental Disabilities (OPWDD)

Findings

- Planned respite care is lacking in NYS, especially for cross-systems youth.
- No cross-systems serving programs that came to our attention have adequate emergency and crisis respite capabilities.
- There is no consistent definition of respite care, policy, procedure, or practices across state agencies. While common themes for defining and providing respite care services exist, there are some regulatory differences among the state agencies.
- Regulations do not adequately differentiate between types of respite services, (i.e. planned, emergency, crisis, etc.) across the child serving systems.
- Cross-system coordination is inconsistent on the county level; each child-serving system has its own referral pathways, triage efforts, and contracting patterns.

- For youth enrolled in NYS sponsored programs (OMH, OPWDD, OCFS), planned respite frequently takes several months to establish as part of a treatment plan and is barely adequate.
- Emergency respite availability is virtually non-existent for youth not currently enrolled in OMH, OPWDD, OCFS, or DOH programs, in some cases; eligibility is limited to waiver-enrollment.
- Local respite planning and response varies widely for cross-system youth. These variances have had none to relatively little state inquiry or intervention and are driven by local conditions including but not limited to geography, the political and economic landscape, creativity of key community staff, issues of supply and demand, cultural traditions, etc.
- The lack of crisis respite results in children being picked up by law enforcement or presenting in emergency rooms. Reliable data is not available to measure the impact on our Juvenile Justice, Child Welfare, and Mental Health service systems.
- Local service systems need to maximize available funding streams through more creative approaches. This currently results in children being inappropriately placed in higher levels of care. (I.e. psychiatric care, PINS petitions, diagnostic units, detention).
- There is insufficient data and even less cross-system data available to track the number of units of service being provided, the number of children being served, or the number of homes and slots available at any point in time. With the expansion of community prevention programs such as the OMH waiver and B2H Waiver, the demand for planned and emergency respite will likely increase in the coming years. Some residential care agencies, TBH's, have apparent capacity to serve, but regulatory, supervision strategies and financing model(s) do not exist for cross-systems populations.

Research Activities

- Review of available literature (limited availability).
- Review of applicable laws and regulations of involved state agencies (OMH, OPWDD, DOH, OCFS, DPCA).
- Review of respite care services under HCBS Waivers in OPWDD, OMH, OCFS (B2H).
- Review of available hard data and information including sampling of local service delivery Plans across systems, select County social services information, indications of local utilization of respite services delivered in accordance with B2H service menus.
- Interviews from a sample of county and regional parent partners, Department of Social Services (DSS) officials, mental health (MH) officials, Youth Advocates, Single Point of Access (SPOA) coordinators, OPWDD officials and Developmental Disabilities Services Office (DDSO) representatives, Regional Technical Assistance Team (RTAT) leaders and members, OCFS youth, Coordinated Children's Services Initiative (CCSI) coordinators, planners, voluntary child welfare services providers, and others.
- Interviews with National Technical Assistance Center for Children's Mental Health at Georgetown University Center for Child and Human Development.
- Identification of local, state and national best practices.

- Presentation by Parsons Child and Adolescent Crisis Mobile Team.
- Interview with Ellis Hospital Emergency Room Administrator.
- Review of a sample of approximately 15 Local Service Plans across systems.
- Review of sample contacts with planned and emergency respite services providers.
- Participation in national webinar on respite care.

Systemic Recommendations and Strategic Directions (in Priority Order)

- If tasks related to strengthening respite care services are to remain a cross-systems priority, a clear and stronger commitment by the involved agencies will need to be made to develop consistent definitions, practice and financing models. As one example, each agency should be asked to conduct a thorough review of its respite services with a goal of identifying areas for shared training, collaboration, and resource utilization. Efforts to identify policy and practice differences among the state agencies must be rectified if a common respite practice is to emerge across children serving agencies.
- In the same vein, agencies will need to provide their expertise to develop the practice, business, and fiscal models for each of the respite services. Key program and fiscal staff will need to lend their expertise in this effort across systems to develop viable respite care alternatives.
- Ideally, respite care is one preventive strategy within a system of care that employs multiple prevention strategies to meet the needs of high-risk youth. CCF, through the implementation of the Children's Plan and long-term commitment to cross-systems leadership efforts, is available to assist localities in developing local and regional systems of care and respite care services programs. Consultation with RTAT's and appropriate state agencies will enhance efforts to improve local systems of care and building respite care capacity.
- As a component of model building, more accurate data is needed to identify the need for emergency and planned respite. This data needs to be broken down by county and by system. RTAT's are an implementation partner resource. The Council on Children and Families is a resource identified in the Children's Plan.

Short-Term Actions

- Respite Care is one strategic intervention in a cross-agency child serving system that requires increased coordination, collaboration, and access**.** The Council of Children and Families in implementing the Children's Plan and building local systems of care can provide technical assistance in this effort with the assistance of state agencies.
- Treatment plans need to anticipate crisis situations and team members need to be well versed in addressing these needs. As a quality assurance measure, state agencies should review whether/how prevention and waiver programs are developing appropriate crisis diversion responses.
- Programs need to ensure the availability of culturally and linguistically competent respite programs that encourage familial informal and natural support networks to be available after services end.

- The original request to state agency and family representatives on the Workgroup for feedback on barriers in their respective agencies/systems by June 30, 2011 has been deferred until further notice.

- The provision of respite services must include children with a wide range of supervision needs. A demonstration allowing a downsizing of RTC's may provide valuable data on the cost effectiveness of respite, and assist in longer term financing preparation.

- A range of respite options from familial to group care options should be part of a flexible continuum of services. Some localities have paid an "on-call" per diem for approved Therapeutic Foster Care families that have provided some relief for emergency respite situations. This is the most cost-effective option next to a robust emergency response to crisis situations.

- Revisit and prepare regulatory amendment recommendations in order to better serve children with cross-system needs. (i.e., by enabling more flexibility with respect to mixing of ages and populations in planned and crisis respite programs and multiple state agency approval processes). As one example, if a respite provider is approved by one state system, that approval process should suffice for other state systems wishing to approve the same provider. Communities should develop protocols to anticipate the needs of children with complex needs (OPWDD & OMH eligible) and make a rapid response to these youth. (Ex. Oneida County agencies cooperatively planned for cross-system children's respite needs.)

- Adjoining counties need to work together to identify and respond to respite needs. The Workgroup recommends the continued strengthening of RTAT's, agency regional offices, and other regional groups be trained to help organize these responses.

Long-Term Actions

- Agencies should continue to conduct comprehensive, intra-agency reviews of their working definitions and implementation of respite care services with a report back to the Workgroup on efforts to standardize working definitions where feasible by June 30, 2011.

- The state's regulatory framework is not conducive to build a true cross-systems respite care services system without regulatory, financing, and practice models that are cross-systems orientated.

- Cross-systems crisis management training and mentoring opportunities must be developed, implemented, and administered for each child and family entering each agency's service system**.** The lack of agreed upon and consistent practice, business, and fiscal models is prohibitive in advancing respite care services conversations. Planned respite care and emergency/crisis respite care would each benefit from this tripartite paradigm.

- As a long-range strategy, a children's cross-systems reinvestment plan should be considered as one cornerstone for identified financial models. The possibility of a cross-systems sourced, dedicated funding stream for respite services and related supports has been discussed. In the immediate term, gathering useful data and information on ways select counties are ensuring that funding is flexible enough to follow the youth who needs temporary emergency respite placements.

- Additionally, another financial and funding cornerstone relates to ensuring the availability of and payment for respite care services through the present waiver services menus and derivatives as well as in any future waiver services enhancements, developments, and allowances by the Federal government.
- Any proposed financial-funding models should be tied to outcome metrics which in turn should be linked to performance outcome measures to promote a *pay for performance* financing framework based on quality.
- Explore and be prepared to address the development/replication of service-effective and cost-conscious mobile crisis teams for children and youth (e.g. Parsons Team) as an innovative service delivery direction and remain aware of the need for both urban/suburban and rural crisis team service approaches. Demonstration of the cost-benefit and value of such a proposition should be identified as a discrete task. An assessment/evaluation through the University at Albany, for example, may be proposed to further develop and advance this concept.

Interim Report: Submitted April, 2011

NEW YORK STATE BAR ASSOCIATION
One Elk Street, Albany, New York 12207 • PH 518.463.3200 • www.nysba.org

Memorandum in Support

May 13, 2022

S. 2881-B
A. 8524-A

By: Senator Ramos
By: M. of A. Forrest
Senate Committee: Alcoholism and Substance Abuse
Assembly Committee: Codes
Effective Date: 180 days after it shall have become a law

AN ACT An act to amend the criminal procedure law and the judiciary law, in relation to judicial diversion programs; and to repeal certain provisions of the criminal procedure law relating thereto.

THE NEW YORK STATE BAR ASSOCIATION SUPPORTS THIS LEGISLATION

The New York State Bar Association (NYSBA) strongly supports the Treatment Not Jails (TNJ) legislation (S.2881B & A.8524A). This proposed legislation amends Judicial Diversion as codified in Criminal Procedure Law Article 216, to go beyond the eligible substance use disorders and limited specified crimes. If the TNJ amendment is passed, CPL 216 would also be available to people accused of *any* charge under the penal law and to those who have mental health diagnoses or other "functional impairments."[1] The TNJ bill would also expand judicial powers to grant diversion, offer pre-plea participation in treatment, ensure clinical and scientific individual-oriented and harm-reduction based models of treatment rather than punitive ones, embrace "procedural justice," and create diversion parts in every county in New York State.

Poverty frequently exacerbates mental health and developmental problems which in turn prevent individuals and families from leaving poverty, creating an intergenerational cycle of poverty and poor health.[2] Poverty in childhood is associated with lower school achievement; worse cognitive, behavioral, and attention-related outcomes; higher rates of depressive and anxiety disorders; and higher rates of almost every psychiatric disorder in adulthood. Poverty in adulthood is linked to depressive disorders, anxiety disorders, psychological distress, and suicide.[3] Approximately 1 in 4 individuals with serious mental illness also have a substance use disorder.[4]

People living in poverty with mental illness and substance use challenges are less likely to be able to access therapeutic services.[5] The criminalization of mental illness and substance use is evidenced by the fact that jails and prisons have become larger mental health providers than psychiatric hospitals.[6] Notably, more than half (52%) of the people in NYC DOC custody have received mental health services, up from 44% in 2016.

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[1] Functional impairments include mental health, intellectual, neurocognitive and physical disabilities as defined by the DSM-5.
[2] McLoyd VC. Socioeconomic disadvantage and child development. Am Psychol. 1998; 53:185-204.
[3] https://www.psychiatrictimes.com/view/addressing-poverty-and-mental-illness
[4] https://www.drugabuse.gov/publications/research-reports/common-comorbidities-substance-use-disorders/part-1- connection-between-substance-use-disorders-mental-illness
[5] For example, among children experiencing poverty who need mental health care, less than 15% receive services, and even fewer complete treatment.
[6] https://www.treatmentadvocacycenter.org/key-issues/criminalization-of-mental-illness

In 2020, an average of 17% were diagnosed with a "serious mental illness," up from 10% four years earlier.[7] Statistics for counties outside of New York City reveal similar patterns. "Nearly 1 in 5 women and 1 in 10 men entering New York jails has a serious mental illness. The Cost of Incarceration in New York State shows that 1 in 9 women and 1 in 10 men entering New York jails has a serious mental illness."[8]

Per a January 2021 report by the Vera Institute:[9]

"Much of the problem lies at the feet of State government. Although most spending on social services, mental health, and public health flows through - and is reflected in - county budgets, the bulk of the money in those categories comes from state aid, not money the county itself raises or controls. From 2011 to 2019, New York State**:** cut aid to counties for behavioral health and social services by 8 percent — from $12.3 billion to $11.3 billion; and reduced state spending (that does not flow through county budgets) on human services by 21 percent from 2011 to 2017 and by 26 percent from 2017 to 2018."

Vera's report states further: **"**These deep cuts in funding for social services, mental health, and public health have left counties without sufficient resources to provide treatment, care, and supports that help people get and stay healthy. Even before the coronavirus hit**…**75 percent of counties reported that they needed more heroin- and opioid-related programs and services; 68 percent of counties said they did not have enough drug crisis services; 74 percent of counties —particularly those in rural areas where there is little to no public transportation — reported that they needed more resources to help people travel to drug treatment; and 84 percent of counties reported that they did not have enough housing for people with behavioral health issues, leaving many to live on the street or in substandard rentals, including places without heat or utilities. TheState requires counties to fund public health, mental health, and emergency assistance for families in addition to county jails. But last year, counties collectively spent approximately 11 times as much on jails as they spent on community mental health."

There is no statute affording Judicial Diversion in New York State for persons with mental health disorders or cognitive or intellectual disabilities charged with crimes despite the fact that public safety is notably increased by expanded opportunities as reflected by lower rates of recidivism for graduates.

Criminal Procedure Law 216 was enacted in 2009.This statute allows Judicial Diversion for persons with alcohol or substance use disorders who are charged with a select number of drug and property-related non-violent class B, C, D or E felonies and who have no violent felony convictions within the last ten years.[10]

Even when they otherwise meet the criteria for admission under Criminal Law Procedure 216, people with psychiatric disorders are generally excluded from such treatment courts, based on the recommended practices of the Office of Court Drug Treatment Programs.[11] Even with the recommended addition of new "mental health tracks" in Manhattan Drug Court, as an example, this does not change the fact that a limited number of charges are eligible for statutory judicial diversion. All other applicants for court mandated mental health treatment must rely on the complete discretion of prosecutors.

However, there is presently no statute delineating Judicial Diversion for persons with mental health disorders or cognitive or intellectual disabilities. As such, mental health treatment courts are not available in every county in New York: only 26 criminal courts statewide have ad hoc mental health treatment courts which

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[7] New York City Comptroller. (March 2021). FY 2022 Agency Watch List: Department of Correction.
[8] New York State Office of Mental Health, "Mental Health Resource Handbook Chapter 2: Providing Mental HealthServices in Local Detention/Correctional Facilities"
[9] The Cost of Incarceration in New York State(vera.org)
[10] Criminal Procedure Law 216, Judicial Diversion Program for Certain Felony Offenders.
[11] https://rockinst.org/wp-content/uploads/2018/05/5-23-18-Drug-Court-Report.pdf

solely rely on prosecutorial gatekeeping.[12]

Yet in New York State, one in 5 people have a mental health diagnosis.[13] Moreover, more than 50% of individuals experiencing mental health challenges will also experience a substance use disorder, and vice versa.[14]

New York State's jails and prisons have replaced hospitals and community treatment providers as the primary facility for people with mental illness. New York State incarcerates more people with serious mental illnesses in its jails and prisons than it treats in hospitals[15], and there are more people with serious mental illness living in Rikers Island than in any psychiatric hospital in the United States.[16]

Additionally, the rate in jails and prison of people with mental health or other disabilities is higher than that in communities.[17] For example, the number of people incarcerated in NYC jails receiving ongoing mental health care in jail (designated "Brad H" because of the court settlementof the same name) outnumber incarcerated people without mental health issues. At the end of July 2021, 49.6% of incarcerated people were designated with Brad H status by the City Department of Correction.[18] Barry Virts, Wayne County sheriff and president of the New York State Sheriffs' Association has reported that "Sheriffs have increasingly found that individuals are coming to their jail facilities with serious medical, mental health, and substance use issues."[19]

The numbers of people with mental health challenges and other disabilities are expected to rise as we see the impact of the collective trauma of the COVID-19 pandemic. This has exacerbated existing mental health challenges as well as created its own challenges via post-pandemic-stress-syndrome and cognitive issues related to long-haul- COVID.[20]

Additionally, many jails are at an extraordinary level of chaos and disorder – for example the situation at Riker's Island has been aptly described as a humanitarian crisis. In addition to the high rates of force and violence, there is an alarming level of staff absenteeism that is causing demonstrably dangerous disruptions to both security and basic services to people in custody fromthe moment they arrive at a reception facility. [21]

Critics of treatment courts may claim that they do not protect public safety or reduce crime. However, mental health courts throughout New York have reportedly been proven successful inlowering recidivism for its graduates.[22]

As the trends of the past three decades also indicate, more jail does not equal more safety. To thecontrary, an emerging body of research indicates that the overuse of jail, while temporarily incapacitating people, can actually lead to more criminal activity and risks undermining the health of individuals, families, and entire neighborhoods. Those who go into jail or prison with challenges— substance use, mental health concerns, joblessness, unstable housing, etc.—tend tocome out with those challenges worsened. Jail also comes at

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[12] New York State Mental Health Courts, A Policy Study. Center for Court Innovation, 2015.

[13] https://www.health.ny.gov/prevention/prevention_agenda/mental_health_and_substance_abuse/mental_health.htm

[14] NIH National Institute on Drug Abuse, Common Comorbidities with Substance Use Disorders Research Report.

[15] Treatment Advocacy Center, "New York".

[16] Serious Mental Illness Prevalence in Jails and Prisons - Treatment Advocacy Center

[17] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5008459

[18] Source: Vera Institute of Justice.

[19] ID. (*The Cost of Incarceration)*

[20] https://www.psychiatrictimes.com/view/post-covid-stress-disorder-emerging-consequence-global-pandemic

[21] On August 24, 2021, the court-appointed federal Monitor in *Nuñez* filed a special report advising the court of "grave concerns about the conditions and pervasive high level of disorder and chaos in the New York City jails." Available here.

[22] https://ps.psychiatryonline.org/doi/10.1176/appi.ps.201700107

tremendous financial cost: incarcerating one person on Rikers for a year costs a staggering $556,000.[23] In June 2020 there were more than 10,000 fewer people in jail in counties outside New York City than on any givenday in 2012. If counties build on their commitment to decrease jail populations and take steps to turn those transformations into savings, New York State could free up valuable dollars during this fiscal crisis - dollars that could be key to addressing behavioral health crises, mitigating the surge in unemployment and housing instability that is already underway, and investing in building healthy, safe communities.[24]

Thus, TNJ promotes public safety, relying on a robust body of research that consistently shows that jailing those entangled in the criminal legal system leads to *more* - not less - criminal involvement. As the research and our collective experience demonstrates, incarceration is a profoundly destabilizing and traumatizing experience. That is especially true for those with mental health and substance use challenges, who are often brought into the criminal legal systemprecisely because of a fundamental lack of basic services, like stable housing, treatment and community supports. In our current carceral system, these individuals lose whatever semblance of stability they previously possessed when they become confined, and emerge from jail even more unmoored and unsupported, and by extension, more likely to be rearrested."

Mental illness, substance use disorders and other disabilities have disparate impacts along race, income, gender/gender identity, geographic and ethnic lines including disproportionate involvement by these groups in the criminal legal system; this can be addressed by expanding the reach and revising the structure of problem-solving courts.

While codification of Judicial Diversion under CPL 216 in 2009 was intended to address systemic inequities, over a full decade later, it is apparent it did not go far enough. The 2021 TNJ bill aims to make those corrections to protect and improve the lives of vulnerable people who intersect with the criminal legal system in NYS often a result of their behavioral health challenges.

This legislation would amend the current codification of judicial diversion to include individuals who have mental health diagnoses or other disabilities regardless of criminal history or offense charged.

Much of the prevailing "wisdom" driving treatment court exclusion of people with mental illness or people previously convicted of or charged with violent crimes has been proven false. People with mental health challenges are no more violent than the general population and in fact more likely to be the victims of violent crime rather than the perpetrators.[25]Studies show that people accused of violent charges are as likely to succeed in community-based treatment as those charged with non-violent charges.[26]

TNJ would also expand the authority of judges to accept people into Judicial Diversion when there are clinical and scientific bases for doing so, and implement due process safeguards against arbitrary rejection, punishment and expulsion. This would help ensure that people who are most in need receive treatment, streamlining the process. CPL 216 currently permits eligibility when there is a showing that "the defendant has a history of substance abuse or dependence," "such alcohol or substance abuse or dependence is a contributing factor to the defendant's criminal behavior," "the defendant's participation in judicial diversion could effectively address such abuse or dependence" and "institutional confinement of the defendant may or may not be necessary for the protection of the public." TNJ would effectively replace this outdated and exclusive language by requiring a showing that "the defendant's functional impairment (e.g., mental illness, disability and/or substance use disorder) is likely a contributing factor to their current or future involvement in the criminal legal system"; "the defendant's participation in judicial diversion could effectively address such functional impairment; and, "the defendant's access to treatment through this

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[23] https://comptroller.nyc.gov/newsroom/comptroller-stringer-cost-of-incarceration-per-person-in-new-york-city- skyrockets-to-all-time-high-2/

[24] The Hidden Cost of Incarceration | The Marshall Project. See also Prison AndJail Reentry And Health | Health Affairs

[25] https://www.mentalhealth.gov/basics/mental-health-myths-facts

[26] Can Persons with Co-occurring Disorders and Violent Charges Be Successfully Diverted? (researchgate.net)

article would benefit the public and the defendant."

The bill allows for participation in treatment without requiring a guilty plea to avoid dire collateral consequences of a such a conviction. Criminal convictions may compromise a person's lawful immigration status and otherwise prevent educational, housing and employment opportunities. People who sustain criminal convictions can lose access to public benefits, parenting rights, licensure, freedom of movement, and suffer financial instability. These consequences affect a person's family relationships, self-worth, stability, motivation to succeed and can have the adverse effect of bringing about more criminal legal involvement, and by extension, jeopardize public safety.[27]

The impact of collateral consequences to communities of color was also previously noted by this committee when debating automatic sealing and expungement of criminal convictions. Pre- and post-plea outcomes also disproportionately fail to protect majority BIPOC communities. For example**,** Syracuse County Treatment Court, a court that serves a majority white population, allows some individuals to participate pre-plea. Since participants must live in Onondaga County, the population of which is 80% white (as compared to the population of NYC, which is 42.7% white) we see a more open and accepting model benefitting the majority white residents in Onondaga County, whereas a similar model has been rejected in other courts serving Black and Brown populations.[28]

A pre-plea model also reduces the coercive aspects of our legal system and addresses the reality that poor people, particularly those who are Black and Brown, too often plead guilty to crimes they did not commit every single day in order to get out of jail, access treatment, protect their jobs, keep their housing, maintain their schooling, return to their loved ones, and avoid the hassle of having to return to court over and over again. A pre-plea resolution acknowledges criminal legal involvement as a public health issue, making inroads towards viewing behavioral health as a health and not criminal issue. The majority of people who enter into the criminal legal system struggle with a diagnosable condition under the DSM-5: a mental health condition, a substance use disorder, a neurocognitive disability, or other disorders and disabilities. If a person's mental illness or addiction played a role in their criminal legal system involvement, the resulting legal experience and treatment must also be treated as a matter of public health equity. The TNJ amendment to CPL 216 would also presume treatment rather than incarceration, which would in effect mitigate racial and gendered disparities in carceral policies' impact.[29] It would also ensure that mental health and substance use practitioners collaborate with participants in treatment based on scientific and clinical models of treatment rather than outdated punitive models which are proven to have disparate impacts on[30] and exacerbate harm to people with mental health and substance use issues.
Treatment courts have an ethical obligation - and a practical imperative - to evolve their practices in the face of a changing public health and legal landscape.[31] To that end, the bill would base treatment on evidence-based practices, including "harm reduction," which is now recognized around the world as a safe, smart, effective and humane to way to view "treatment," deferring to the expertise and clinical opinions of

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[27] See National Inventory of Collateral Consequences; for example, a conviction can affect employment requiring licensurein New York. As outlined here, the Department of State reviews criminal convictions and open cases when an individual applies for licensure.

[28] Syracuse Community Treatment Court Policy; Census Facts Onondaga County ; Census Facts New York City

[29] Prison Policy Review, New York State. In New York, per 100,000 people incarcerated:1,655 are Black,709 are American Indian/Alaska Native, 607 are Hispanic, 219 are white. Prison Policy Review, LGBTQ. In both prisons and jails, lesbian or bisexual women are sentenced to longer periods of incarceration than straight women. Gay and bisexual men are more likely than straight men to have sentences longer than 10 years in prison.

[30] Once incarcerated, people with mental illness often spend longer in prison than their counterparts without mental illness. Paula M. Ditton, *Special Report: Mental Health and Treatment of Inmates and Probationers*, Bureau of Justice Statistics 8 (1999),(people with mental illness are incarcerated on average 15 months longer than those without disabilities with similar convictions);*Prevalence And Severity Of Mental Illness Among California Prisoners On The Rise*, Stanford Justice Advocacy Project 1, 2 (2017), (on average, California incarcerated people with mental illness receive sentences 12% longer than those without diagnosis for same crimes).

[31] Alezandra Garcia and David Lucas, Bridging the Gap A Practitioner's Guide to Harm Reduction in Drug Courts (2021).

mental health and substance use practitioners and ensuring the focus remains on the individual's success in treatment.[32] The bill thus encourages judges to use incarceration as a last option for positive drug screenings and mental health crises. TNJ will, further, reduce dangerous overdose and death related to substance use, adopting a much needed and widely recommended "harm reduction" model which recognizes that "cold turkey" approaches to treating substance use is dangerous and counterproductive to meaningful, autonomous, and safe recovery.

Over the last decade, there has been even greater acknowledgement of the harm inflicted upon BIPOC[33] communities marginalized by barriers to accessing wealth and services.[34] TNJ Bill, which will ensure that problem-solving court models reduce rather than reproduce disparities along race, income, gender/gender identity and ethnic lines in the health and criminal legal systems. TNJ will effectively "legislate" mental health courts in recognition of the nexus between a person's mental health condition or other disability with criminal legal involvement and the shared goal of protecting public safety and reducing recidivism.

Based on the foregoing, the State Bar Association **SUPPORTS** the enactment of this legislation.

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[32] Bourgon G., Guiterrez L. (2013) The Importance of Building Good Relationships in Community Corrections: Evidence, Theory and Practice of the Therapeutic Alliance. In: Ugwudike P., Raynor P. (eds) What Works in Offender Compliance. Palgrave Macmillan, London.; Horvath, A. (2015). Therapeutic/Working Alliance,Blasko, B, Serran, G., Abracen, J. (2018), The Role of the Therapeutic Alliance in Offender Therapy: The Translation of Evidence-Based Practices to Correctional Settings. In New Frontiers in Offender Treatment.; Cournoyer, L., Brochu, S.,Bergeron, J. (2007). Therapeutic alliance, patient behaviour and dropout in a drug rehabilitation program: the moderating effect of clinical subpopulations.

[33] "BIPOC" stands for Black, Indigenous, and People of Color.

[34] *See, e.g.,* the resources cited under "Racism and Health (Physical & Mental)" at https://www.nysda.org/page/RacialJusticeandEquity

Report of the Disability Rights Committee -New York State Bar Association[1]

Guardianship for People with Developmental Disabilities: *Examination and Reform of Surrogate's Court Procedure Act Article 17-A is a Constitutional Imperative.*

Preamble : The Free Britney controversy has illuminated the dangers of the guardianship process, and its potential for abuse. A person's right to determine the course of his or her life is a fundamental value in American law and firmly embodied in New York State jurisprudence. Guardianship is the legal means by which a court appoints a third party, either an individual, a not-for-profit corporation or government official, to make some or all decisions on behalf of a person determined unable to manage his or her own affairs. The civil liberties of the person subjected to guardianship yield to that decision. Because the decision exacts such a pervasive personal cost, procedural and substantive due process requirements must be observed by the court. A failure to afford due process to a respondent in a guardianship proceeding imposes burdens on the individual, but also upon societal values. This report examines article 17-A of the Surrogate's Court Procedure Act (SCPA), a discrete guardianship statute for people with developmental disabilities. In the opinion of the Committee, article 17-A requires immediate reform by the Legislature because the statute violates procedural and substantive due process, the Americans With Disabilities Act, and other well established principles addressing the rights of people with developmental disabilities and their need for empowerment, advocacy and quality decision-making. Reform of article 17-A must also recognize various forms of decision-making alternatives to guardianship for people with disabilities that are described within this report. [2]

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[1] This report places reliance on earlier published articles written by Disability Rights Committee Members Rose Mary Bailly, Lawrence Faulkner, Lisa Klee Friedman, Kristin Booth Glen, Jennifer Monthie, Beth Haroules and Sheila Shea (*see* Rose Mary Bailly, *Article 81 of the Mental Hygiene Law-Appointment of a Guardian for Personal Needs and/or Property Management*, Disability Law and Practice, Book Two [New York State Bar Association 2015]; Lawrence Faulkner, Lisa Klee Friedman, Genoveffa Flagello, *Guardianship Article 17-A Proceedings Under Surrogate's Court Procedure Act,* Disability Law and Practice, Book Two [New York State Bar Association 2015]; Rose Mary Bailly, Charis B. Nick-Tovok, *Should We Be Talking?--Beginning a Dialogue on Guardianship in New York*, 75 Alb. L. Rev. 807 (2011-2012); Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 Colum. Hum. Rts. L. Rev 93, 116 [2012]; Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine I. Hermann, Maria Kuns, Aditi Shah, Naomi Weinstein, *A Report Of The Mental Health Law Committee And The Disability Law Committee Of The New York City Bar Association, Revisiting S.C.P.A. 17-A: Guardianship for People with Developmental Disabilities,* 18 CUNY L. Rev. 287 [2015]; Jennifer Monthie, *The Myth of Liberty and Justice for All: Guardianship in New York State*, 80 Alb. L. Rev. 947 (2016-2017); Sheila Shea and Carol Pressman, *Guardianship: A Civil Rights Perspective*, 90 N. Y. St. B. J. 19 [2018]).

[2] This report does not address reform of SCPA 1750-b, the health care decision making statute for people with developmental disabilities. The Legislature tapped the New York State Task Force on Life and the Law with the responsibility to reconcile the Family Health Care Decisions Act (FHCDA), SCPA 1750-b and other statutes and regulations governing surrogate health care decision making for people with mental disabilities (*see* L. 2010, c 8, section 28 – "[T]he task force shall consider whether the FHCDA should be amended to incorporate procedures, standards and practices for decisions about the withdrawal or withholding of life-sustaining treatment from patients with mental illness or mental retardation or developmental disabilities, and from patients residing in mental health facilities…"). The Task Force issued its report entitled *Recommendations for Amending the Family Health Care Decisions Act for Persons with Developmental Disabilities and Patients In or*

I. Guardianship and Civil Rights - Historical Perspectives and Modern Context

Guardianship has been employed since Ancient Rome to protect people who are unable to manage their personal and financial affairs because of incapacity[3] by removing their right to make decisions and transferring legal power to another person, the guardian. Guardianship is a matter of state law. Before a guardian may be appointed, an individual must be determined to be an incapacitated person, defined in various ways, but codified in uniform acts as:

> an individual who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance.[4]

In most states, a single guardianship statute applies to all populations, regardless of the alleged cause of the person's incapacity- New York is one of six states, the others being California, Connecticut, Idaho, Kentucky and Michigan, that have a separate statute that may be invoked for people with developmental disabilities.[5] Guardianships may be plenary in nature, divesting all autonomy from the person subject to the regimen, or tailored to the individual needs of the person found to lack capacity.

Given its ancient origins, guardianship laws predate not only modern civil rights laws, such as the Americans with Disabilities Act, but also precede the United States Constitution and the Magna Carta. Although often examined through the lens of benevolence, the appointment of a guardian divests autonomy from another person and has severe civil rights implications. As stated in 1987 by the House of Representatives Special Committee on Aging:

Transferred from Mental Health Facilities in 2016 (*see* https://www.health.ny.gov/regulations/task_force/). Legislation has not yet been introduced to implement the Task Force's recommendations.

[3] The term "incapacity" is not a term of art as used in this section of the report. As described later in this report, "incapacity" is a defined at Mental Hygiene Law § 81.02 (b). Article 17-A does not employ the term "incapacity," but by its own definitional terms allows for plenary adjudications upon a finding that the respondent in the proceeding is *incapable* of managing his/her affairs. SCPA 1750 provides: "For the purposes of this article, a person who is intellectually disabled is a person who has been certified by one licensed physician and one licensed psychologist, or by two licensed physicians …. as being incapable to manage him or herself and/or his affairs by reason of intellectual disability and that such condition is permanent in nature and likely to continue indefinitely" (*see also*, SCPA 1750-a for the definition of "developmental disability").

[4] *See* Shea and Pressman, *Guardianship a Civil Rights Perspective*, 1-2 and authorities cited therein; Uniform Guardianship and Protective Proceedings Act, Art, 1, Definitions 102 (11)(1997)

[5] Cal. Prob. Code § 1801(d); Conn. Gen. Stat. Ann. § 45a-669 *et. seq.*; Idaho Code Ann. § 15-5-301 *et. seq.*, Mich. Comp. Laws Ann. Ch. 330 (Mental Health Code) § 330.1600 *et. seq.*; Ky. Rev. Stat. Ann. § 387.500-.800; N.Y. Sur. Ct. Proc. Act (SCPA) 1750-1761. Other states afford more due process protections to respondents with developmental disabilities in guardianship proceedings. For example, the Connecticut statute provides for the appointment of counsel: "Unless the respondent is represented by counsel, the court shall immediately appoint counsel for the respondent" (Ct. St. 45a-673). If the respondent is indigent, counsel is provided at public expense.

> By appointing a guardian, the court entrusts to someone else the power to choose where [he/she] will live, what medical treatment [he/she] will get and, in rare cases, when [he/she] will die. It is in one short sentence, the most punitive civil penalty that can be levied against an American citizen ... [6]

The "civil death" characterization of guardianship arises because a person subjected to it loses autonomy over matters related to his or her person and property. Indeed, in many jurisdictions a person with a legal guardian will be deprived of fundamental rights, such as the right to vote, marry and freely associate with others.[7]

Since the enactment of article 17-A in 1969, there have been several national and international calls for the fundamental guardianship reform, but not of them have touched article 17-A. It should not be lost on our society that over two generations have passed following the 1975 passage of the Developmentally Disabled Assistance and Bill of Rights Act[8] when the American Bar Association ("ABA") undertook a broad study of major areas of law affecting developmentally disabled children and adults. This study, known as the Developmental Disabilities State Legislative Project, included guardianship. The goal was to encourage "well-conceived" legislation that drew on "the best thinking, most advanced concepts, and outstanding work products from other states."[9] After a review of state guardianship statutes, the Project concluded that the standards for appointing guardians for individuals with disabilities were frequently "broad and vague" and, most importantly, "failed to recognize that individuals with disabilities are often capable of doing many things for themselves." [10] The Project proposed a Model Guardianship and Conservatorship Act, the purpose of which was to establish:

> a system which permits partially disabled and disabled persons and minors to participate as fully as possible in all decisions which affect them, which assists such persons in meeting the essential requirements for their physical health and safety, protecting their rights, managing their financial resources, and developing or regaining their abilities to the maximum extent possible, and which accomplishes these objectives through the use of the least restrictive alternatives. [11]

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6 H.R. Doc. No. 100-641, at 4 (1987). Subcomm. on Health and Longterm Care of the House Select Comm. on Aging 100th Cong. *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace*. Prepared Statement of Chairman Claude Pepper.

7 *See* Michael Perlin, *"Striking for Guardians and Protectors of the Mind:" The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 Penn. St. L. Rev. 1159 (2013)

8 Developmentally Disabled Assistance and Bill of Rights Act of 1975, Pub. L. No. 94-103, 89 Stat. 486 (1975). Over the years, the Act has been reorganized and amended extensively (*see* Rose Mary Bailly, Charis B. Nick-Tovok, *Should We Be Talking?--Beginning a Dialogue on Guardianship in New York*, 75 Alb. L. Rev. 807, 813, n. 36).

9 *See* Bailly & Nick-Tovok, *supra* note 6, *Should We Be Talking,* pp. 813-14 and the authorities cited therein.

10 *Id*.

11 *Id*. at 814, citing, ABA Commission on the Mentally Disabled, Guardianship & Conservatorship 1-2 (1979); Model Guardianship and Conservatorship Act.

Furthermore, a powerful counter voice to guardianship as civil death is the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol. [12] Adopted in 2006, the CRPD is the first international human rights treaty drafted specifically to protect the rights of people with disabilities. [13]Even though the United States Senate has not ratified the treaty, legal scholars argue that the CRPD will provide the impetus for reshaping guardianship laws in the United States as "CRPD dictates supported--as opposed to substituted - decision making."[14]

Despite all of these efforts at reform and the passage of time, article 17-A remains stuck in time and a counterweight to progressive principles that typically emerge in New York State. The NYSBA Disability Rights Committee argues that there is an urgent need to reform article 17-A, particularly as the Office for People with Developmental Disabilities (OPWDD) is advancing a program bill codifying supported decision making in New York State. As a Committee, we set forth the following general principles which a guardianship statute for adults with intellectual and developmental disabilities should contain and explain in this report the underpinnings of the principles we articulate.

Principles of Guardianship

1. Neither the alleged developmental disability nor the age of the individual alleged to have a developmental disability should be the sole basis for the appointment of a guardian. Rather, the individual's ability to function in society with available supports should be the focus of the Court's inquiry into the need for a guardian.

2. The appointment of a guardian must be designed to encourage the development of maximum self-reliance and independence in the individual. The standard for appointment should be that the person is unable to provide for personal needs and/or property management with available supports; and the person cannot adequately understand and appreciate the nature and consequences of such inability.

3. The appointment of a guardian must be necessary and the least restrictive form of intervention available to meet the personal and/or property needs of the individual as determined by a court.

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12 *See* http://www.un.org/disabilities/documents/convention/convopt-prot-e.pdf.

13 Arlene S. Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights*, Routledge (2015).

14 Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157, 161 (2010); Nina Kohn, Jeremy Blumenthal, Amy Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 Penn. St. L. Rev. 1111 (2013).

4. A guardianship petition must allege the other available resources for decision-making, if any, that have been considered by the petitioner and the petitioner's opinion as to their sufficiency and appropriateness, or lack thereof. Other resources include, but are not limited to, powers of attorney, health care proxies, trusts, representative and protective payees, and supported decision making.

5. All persons alleged to be in need of the appointment of a guardian are entitled to due process protections including, but not limited to, notice of the proceeding in plain language and right to counsel of their own choosing or the appointment of counsel guaranteed at public expense.

6. A guardian should not be appointed absent a hearing where the person alleged to be in need of a guardian is present. The person's appearance at the hearing may be dispensed with in exceptional circumstances at the court's discretion and in accordance with statutory standards. The person has the right to a jury trial.

7. The need for the guardianship must be established by clear and convincing evidence of the person's functional limitations which impair the person's ability to provide for personal needs, the person's lack of understanding and appreciation of the nature and consequences of his or her functional limitations; the likelihood that the person will suffer harm because of the person's functional limitations and inability to adequately understand and appreciate the nature and consequences of such functional limitations; and necessity of the appointment of a guardian to prevent such harm.

8. The powers of the guardian should be identified in the order/decree issued by the court and tailored to meet the needs of the individual in the least restrictive manner possible. The person subject to guardianship retains any powers not expressly conveyed to the guardian.

9. The individual must be included in all decisions to the maximum extent possible and practicable, in order to encourage autonomy. The Guardian should be encouraging the development of maximum self-reliance and independence in the individual.

10. The duties of the guardian should be specified in the order/decree.[15] Among other things, the guardian's duty is to make decisions that give maximum consideration to the individual's preferences, wishes, desires, and functioning level. A guardian

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[15] *See* MHL § 81.20. Among the duties of an article 81 guardian are that the guardian shall exercise only those powers that the guardian is authorized to exercise by court order, the guardian shall exercise the utmost care and diligence when acting on behalf of the incapacitated person, and that the guardian shall exhibit the utmost degree of trust, loyalty and fidelity in relation to the incapacitated person (MHL § 81.20 [a][1-3]). A guardian of personal needs should also promote the individual's independence and self-determination (*see* MHL § 81.20 [7]) and comment annually on whether facts indicate the need to terminate the guardianship or alter the powers of the guardian (*see* MHL §81.31 [b][10]).

should protect the individual from unreasonable risks of harm, while supporting and encouraging the individual to achieve maximum autonomy.

11. The duration of a guardianship should be determined by the court and conform to the proof adduced at the hearing. For instance, time limited guardianships may be appropriate including where a guardianship is sought for a young adult between the ages of 18-25. Where a guardianship of limited duration has been ordered by the court, any application to extend the guardianship should require proof by clear and convincing evidence by the petitioner that it is necessary to continue the guardianship.

12. A person under guardianship has a right to seek review of the guardianship and restoration of rights. There must be a clear process to initiate restoration that permits the person under guardianship to initiate and obtain access to counsel at public expense.

13. The court should retain jurisdiction over the guardianship and entertain modification and termination proceedings where the burden of proof shall be on the person objecting to discharge or seeking increased powers for the guardian rather than on the respondent.

14. The person or entity appointed guardian must be subject to monitoring and oversight by the court. For instance, Guardians should periodically file reports as to their activities.

II. Guardianship in New York

The general adult guardianship statute in New York is codified at article 81 of the Mental Hygiene Law (MHL). The purpose of article 81 is to: satisfy either personal or property management needs of an incapacitated person in a manner tailored to the individual needs of that person, which takes in account the personal wishes, preferences and desires of the person, and which affords the person the greatest amount of independence and self-determination and participation in all the decisions affecting such person's life.[16] A discrete statute exists, however, that may be invoked for people alleged to be in need of a guardian by reason of an intellectual or other developmental disability.[17] In contrast, that statute, codified at article 17-A of the SCPA is a plenary statute the purpose of which at its inception in 1969 was largely to permit parents to exercise continued control over the affairs of their adult children with disabilities. In essence, the statute rested upon a widely

[16] MHL § 81.01.

[17] SCPA 1750, 1750-a. An Article 17-A proceeding may also be commenced for a person alleged to have a traumatic brain injury (*see* SCPA 1750-a [l]).

embraced assumption that "mentally retarded" people were perpetual children.[18] Under New York law, a person with developmental disabilities can be subject to either guardianship statute, despite the considerable substantive and procedural variations between article 81 and article 17-A. An injustice arises, as a result, because a petitioner for guardianship can choose between two statutes and petitioner's choice will determine the due process protections to be afforded to a respondent with developmental disabilities.[19]

Article 81 of the Mental Hygiene Law [20]

Article 81 of the MHL, proceedings for appointment of a guardian for personal needs or property management, became effective on April 1, 1993.[21] Article 81 replaced the former dual structure conservatorship and committee statutes that operated in New York.[22] By way of history, the appointment of a committee, pursuant to former Article 78 of the MHL, was the only available legal remedy to address the affairs of a person alleged to be incompetent.[23] However, the committee statute required a plenary adjudication of incompetence. Because of the stigma and loss of civil rights accompanying such a finding, the judiciary became reluctant to adjudicate a person in need of a committee.[24] In 1972, the conservatorship statute (former article 77 of the MHL) was enacted into law as a less restrictive alternative to the committee procedure.[25] Unlike the committee statute, the appointment of a conservator did not require a finding of incompetence. Rather, the former law authorized the appointment of a conservator of the property for a person who had not been:

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18 To elaborate, there is an undue emphasis under article 17-A that people with developmental disabilities are children forever. First, is the ambiguous nature of article 17A. It appears to apply to adults, yet its main provisions mirror those applicable to minors in article 17. Article 17-A also incorporates article 17 by reference (*see* SCPA 1761 - "To the extent that the context thereof shall admit, the provisions of article seventeen of this act shall apply to all proceedings under this article with the same force and effect"). In addition, while article 17-A does not specifically state that the statute is applicable to minors as well as adults, the statute appears to contemplate such. For example, a guardian appointed pursuant to article 17-A does not terminate "at the age of majority" (*see* SCPA 1759). Further, article 17-A, provides that the standard for appointment of a guardian is "best interests," the same standard applicable to minors in article 17 (s*ee* SCPA 1701 - "the court may appoint a permanent guardian of a child if the court finds that such appointment is in *the best interests* of the child." (emphasis added); SCPA 1707 -"If the court be satisfied that *the interests of the infant* will be promoted by the appointment of a guardian or by the issuance of temporary letters of guardianship of his or her person or of his or her property, or of both, it must make a decree accordingly. If the court determines that appointment of a permanent guardian is in the *best interests of the infant* or child, the court shall issue a decree appointing such guardian.") (emphasis added). Finally, there is no required hearing under article 17 or 17-A of the SCPA (*see* SCPA 1706, 1754).

19 *See* Shea and Pressman, *supra* note 2, *Guardianship a Civil Rights Perspective*, at 21.

20 The following discussion of article 81 of the Mental Hygiene Law and article 17-A of the SCPA is largely borrowed from Shea and Pressman, *supra* note 2, *Guardianship a Civil Rights Perspective*, pp 21-23.

21 1992 N.Y. Laws c. 698.

22 *Id*.

23 *Id*.

24 *In re Fisher*, 147 Misc. 2d 329, 332 (Sup. Ct. N.Y. County 1989).

25 1972 N.Y. Laws, c. 251

> [J]udicially declared incompetent and who by reason of advanced age, illness, infirmity, mental weakness, alcohol abuse, addiction to drugs or other cause suffered substantial impairment of his ability to care for his property or has become unable to provide for himself or others dependent upon him for support.[26]

However, by design, the statute limited the power of the conservator to property and financial matters.[27] Chapter amendments to the MHL were enacted in 1974 attempting to expand the role of conservators. The first established a statutory preference for the appointment of a conservator.[28] A second chapter amendment authorized conservators to assume a limited role over the personal needs of the person who was the subject of the proceeding.[29] Cast as reform measures, the amendments actually contributed to the "legal blurring" between articles 77 and 78.[30] In 1991, the Court of Appeals was confronted with a case requiring a construction of the statutory framework to determine the parameters of the authority of a conservator. The question presented to the tribunal was whether a conservator could authorize the placement of his ward in a nursing home. In the case of *In re Grinker*,[31] the Court of Appeals determined that such power could be granted only pursuant to the committee statute. The *Grinker* decision "settled the debate" surrounding the authority of a conservator to make personal needs decisions.[32] However, the *Grinker* holding also "dramatized the very difficulty the courts were trying to resolve, namely, choosing between a remedy which governs property and finances or a remedy which judges a person completely incompetent."[33]

To resolve the difficulties inherent in the conservator-committee dichotomy, the New York State Law Revision Commission proposed the enactment of Article 81 as a single remedial statute with a standard for appointment dependent upon necessity and the identification of functional limitations.[34] The new statute rejected plenary adjudications of incompetence in favor of a procedure for the appointment of a guardian whose powers are specifically tailored to the needs of the individual. Going forward, the right to counsel would be guaranteed and monitoring of guardianships would be required. The objective of the proceeding as declared by the legislature was to arrive at the "least restrictive form of intervention" to meet the needs of the person while, at the same time, permitting the person to exercise the independence and self-determination of which he or she is capable.[35]

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[26] MHL § 77.01 (repealed 1992 N. Y. Laws c. 698).

[27] *Id*.

[28] MHL 77.04 & 70.02 (repeated 1992 N. Y. Laws c. 698).

[29] 1974 N. Y. Laws c. 623 § 3.

[30] *See* Julie M. Solinski, *Guardianship Proceedings in New York: Proposals for Article 81 to Address Both Lack of Funding and Resource Problems,* 17 Pace L. Rev. 445 *(1977), citing,* G. Oliver Kopell & Kenneth J. Munnelly, *The New Guardian Statute: Article 81 of the Mental Hygiene Law*, N. Y. St. B. J., Feb. 1993, at 16.

[31] 77 N.Y.2d 703 (1991).

[32] Solinski, *supra* note 27 at 450.

[33] *Id*.

[34] Memorandum of the Law Revision Commission Relating to Article 81 of the Mental Hygiene Law Appointment of a guardian for Personal Needs and/or Property Management, Senate No. 4498, Assembly No. 7343, Leg. Doc. No. 65 [C] (1992).

[35] MHL § 81.01.

Article 17-A of the SCPA

Under article 17-A, the basis for appointing a guardian is whether the person has a qualifying diagnosis of an intellectual or other developmental disability. Current law permits the appointment of a guardian upon proof establishing to the "satisfaction of the court" that a person is intellectually or developmentally disabled and that his or her best interests would be promoted by the appointment.[36] As a jurisdictional prerequisite, a 17-A petition must be accompanied by certifications of two physicians or a physician or a psychologist that the respondent meets the diagnostic criteria of an intellectual or other developmental disability. [37] On its face, article 17-A provides only for the appointment of a plenary guardian and does not expressly authorize or require the surrogate to dispose of the proceeding in a manner that is least restrictive of the individual's rights. Indeed, article 17-A does not even require the court to find that the appointment of a guardian is necessary, does not guarantee the right to counsel and permits the proceeding to be disposed without a hearing at the discretion of the court.[38] That said, article 17-A has been revered by families because of its relative ease in commencing the proceeding, often without the assistance of counsel.[39] In contrast, article 81 proceedings can be very complex and expensive to prosecute.[40] The convenience of article 17-A proceedings as compared to article 81 proceedings causes tension in New York. As aptly stated by one commentator:

> If guardianship is made too expensive, incapacitated people who need the protection and assistance of a guardianship may not have those needs met. However, if guardianship fails to protect the rights of respondents, then respondents can be unjustly deprived of their right to autonomy.[41]

Given the many substantive and procedural variations between article 17-A and article 81, the Governor's *Olmstead* Cabinet[42] and commentators have called for reform or

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[36] *See* SCPA 1750, 1750-a. An article 17 proceeding may also be commenced for a person alleged to have a traumatic brain injury (SCPA 1750-a[1]).

[37] *Id.*

[38] *See* Bailly & Nick-Tovok, *supra* note 6, *Should We Be Talking,* 821-825.

[39] *See* Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine I. Hermann, Maria Kuns, Aditi Shah, Naomi Weinstein, *A Report Of The Mental Health Law Committee And The Disability Law Committee Of The New York City Bar Association, Revisiting S.C.P.A. 17-A: Guardianship for People with Developmental Disabilities,* 18 CUNY L. Rev. 287, n. 23 at 300, where the authors not that 17-A procedure is relatively simply and can be typically managed by *pro se* petitioners.

[40] The cost of an article 81 proceeding will often encompass the fees of petitioner's counsel, counsel for respondent and the Court Evaluator. The person alleged to be incapacitated is generally liable for fees when a petition is granted (see MHL§§ 81.09 [f], 81/10[f], 81/16[f]). Efforts have been made to reduce the expenses associated with article 81 proceedings. For example, article 81 forms are now uploaded to the New York State Office of Court Administration website for the 6th Judicial District: http://ww2.nycourts.gov/article-81-forms-31251

[41] *See* Jennifer Wright, *Protecting Who from What and Why and How: A Proposal for an Integrative Approach to Adult Proceedings,* 12 Elder L. J. 53 (2004).

[42] The Olmstead Cabinet derives its name from the United States Supreme Court decision in *Olmstead v. L.C.,* 527 U.S. 581 (1999). The Cabinet's mandate is to recommend law and policy changes to ensure that people with disabilities receive services and supports in settings that do not segregate them from the community. https://www.ny/gov/programs/olmstead-communityintegration-every-new-yorker-1ast.

"modernization" of article 17-A.[43] In some cases, Surrogates are bringing enhanced scrutiny to article 17-A adjudications and dismissing petitions where guardianship is not the least restrictive form of intervention.[44] Further, a lawsuit was commenced on September 26, 2016 in the U.S. District Court for the Southern District of New York by Disability Rights New York seeking to enjoin the appointment of guardians pursuant to article 17-A. While the lawsuit was subsequently dismissed on *Younger* abstention grounds,[45] the complaint alleged that Article 17-A violates the due process and equal protection clauses of the Fifth and Fourteenth Amendments to the U.S. Constitution, the ADA and § 504 of the Rehabilitation Act.[46] The federal court's decision to abstain does not prejudice the right of the plaintiffs to challenge the statute in state court.[47]

III. Article 17-A is indefensible under the lens of constitutional analysis

The Fifth Amendment to the United States Constitution provides that the federal government shall not deprive any person "of life, liberty, or property, without due process of law."[48] The Fourteenth Amendment makes this requirement applicable to the states, and together, the Fifth and Fourteenth Amendments forbid the government from infringing on a fundamental liberty interest where the matter is not narrowly tailored to serve a compelling governmental interest.[49] Guardianship impacts both the fundamental liberties and property interests of individuals. An individual may be subject to guardianship indefinitely, interfering with the individual's ability to maintain personal relationships, seek and obtain employment, marry, or vote. While the Supreme Court has not specifically defined "liberty," the term is broadly interpreted and "extends to the full range of conduct which the individual is free to pursue," and must not be restricted without proper governmental objective.[50]

These fundamental liberty and property rights are at stake in a guardianship proceeding. Guardianship can infringe on a person's fundamental right to privacy to engage in personal conduct; fundamental right to refuse unwanted medical treatment; a fundamental right to make personal decisions regarding marriage, procreation, contraception, family relationships, child rearing, and education; and a fundamental right to vote.[51] New York

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43 *See* Bailly & Nick-Tovok, *supra* note 6; Andreasian *et al.*, *supra* note 36.

44 *See In re D.D.,* 50 Misc. 3d 666 (Sur Ct., Kings Co. 2015).

45 *Disability Rights New York v. New York*, 916 F. 3d 129 (2d Cir. 2019).

46 *See* Jennifer Monthie, *The Myth of Liberty and Justice for All: Guardianship in New York State*, 80 Alb. L. Rev. 947 (2016-2017).

47 916 F. 3d at 137. Our Committee also notes that an action in state court may implicate New York State constitutional guarantees. New York courts "have not hesitated [,] when [they] concluded that the Federal Constitution as interpreted by the Supreme Court fell short of adequate protection for our citizens [,] to rely upon the principle that that document defines the minimum level of individual rights and leaves the States free to provide greater rights for its citizens through its Constitution, statutes or rule-making authority (*Cooper v. Morin,* 49 N.Y.2d 69, 79 [1979]).

48 U.S. Const. amend V.

49 *See* U. S. Const. amend. XIV § 1; *Reno v. Flores*, 507 U.S. 292, 301-02 (1993).

50 *See* Monthie, *supra* note 42 at 961 and the authorities cited therein.

51 *Id*., at 961-962 and the authorities cited therein. The right to vote in New York State should not be impacted by the appointment of a guardian under either article 17-A or article 81 due to administrative pronouncement that the exclusions found in the New York State Election Law are obsolete and unenforceable

courts have described guardianship as "calculated to deprive a citizen not only of the possession of his property, but also of his personal liberty."[52] Two New York Surrogate's Courts (New York County and Kings County) have consistently invoked the liberty and property interests of individuals subjected to Article 17-A guardianship. The New York County Surrogate's Court found:

> The appointment of a plenary guardian of the person under article 17-A gives that guardian virtually total power over her ward's life ... including virtually all medical decisions, where the ward shall live, with whom she may associate, when and if she may travel, whether she may work or be enrolled in habilitation programs, etc. This imposition of virtually complete power over the ward clearly and dramatically infringes on a ward's liberty interests.[53]

Procedural Due Process

There are three factors to determine whether a taking of liberty or property violates a person's rights to procedural due process. First, the private interest that will be affected by the official action; second, the risk of an erroneous deprivation of such interest through the procedures used, and the probable value, if any, of additional or substitute procedural safeguards; and finally, the Government's interest, including the function involved and the fiscal and administrative burdens that the additional or substitute procedural requirement would entail.[54] A brief review of pleading requirements of article 17-A and the procedures employed to dispose of guardianship applications reveals their patent insufficiency given the liberty interests at stake in the proceeding.

- The statute is entirely diagnosis driven and will turn upon certificates filed in conjunction with the petition alleging that the respondent has an intellectual disability or other developmental disability; [55]

(*see* Sadie Ishee and Sheila Shea, *Make Every Vote Count: Reform of New York's Election Law to Protect the Franchise for People with Disabilitie*s, 14 Alb. Gov't. Law Review, 1, 15-16, 17-18 [2021]). Nonetheless, persistent ambiguity about the reach of New York's Election Law § 5-106(6) and its exclusion from voter rolls for people "adjudged incompetent" call for its repeal.

[52] *Id.*, *citing*, *In re Burke*, 125 A.D. 889, 891 (N.Y. App. Div. 1908); *In re Ginnel*, 44 N. Y. S. 2d 232, 235 (N.Y. Sup. Ct. 1943).

[53] *In re Mark C.H.*, 28 Misc. 3d 765, 776 (Sur. Ct. New York Co., Glen, J.).

[54] *See Matthews v. Eldridge*, 424 U.S. 319, 335 (1976); In a guardianship proceeding, the State is exercising its parens patriae power (*see Rivers v. Katz*, 67 N.Y.2d 485 [1986] - "the *sine qua non* for the state's use of its *parens patriae* power as justification for the forceful administration of mind-affecting drugs is a determination that the individual to whom the drugs are to be administered lacks the capacity to decide for himself whether he should take the drugs … We hold, therefore, that in situations where the State's police power is not implicated, and the patient refuses to consent to the administration of antipsychotic drugs, there must be a judicial determination of whether the patient has the capacity to make a reasoned decision . . ."

[55] The certifications are often entirely conclusory, hearsay and/or are not subject to cross-examination.

- There is no requirement that the 17-A petitioner even allege that the appointment of a guardian is necessary or that there are less restrictive alternatives to guardianship;

- There is no right to counsel for the respondent in the proceeding;

- In most cases there is no hearing and the determination of what is in the respondent's best interests is left to the discretion of the court.

- The guardianship is plenary; that is, the person under guardianship loses to right to make any and all decisions;

- The appointment of a guardian has no time limit and continues indefinitely; indeed, guardianship does not terminate at the age of majority of upon the marriage of the person who is developmentally disabled, but shall continue during the life of such person, or until terminated by the court.

- There is no requirement that a guardian of the person ever report on the respondent's personal circumstances and there is no review of the necessity for continuation of guardianship by the court; and

- In a guardianship modification or termination proceeding, the statute does not identify the party with the burden of proof and case law leans toward requiring the respondent to demonstrate a change in circumstances before a guardianship decree may be modified or terminated.

As this brief description of the statute demonstrates, it is entirely out of date with regard to procedural protections that are now both statutorily and constitutionally required when compared with article 81 of the MHL.[56]

Substantive Due Process

Under the Fourteenth Amendment to the United States Constitution, a state government may not deprive an individual "of life, liberty, or property, without due process of law."[57] The Supreme Court has interpreted the guarantee of "due process of law" in the Fifth and Fourteenth Amendments to include "a substantive component that bars certain

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[56] In 2010, then Judge Glen wrote that "in 1990 the legislature mandated review of SCPA Article 17-A, first enacted in 1969, in light of both the changing views of, and more sophisticated knowledge about, the populations covered by the statute, and changes in law and constitutional requirements over the intervening 20 year period. Although the Law Revision Commission was then in the midst of proposing massive changes to the state's conservator and committee laws for adult guardianship, resulting in Mental Hygiene Law Article 81, there was no report, no proposal, and no change to 17-A. Twenty years later there still has been no action, but the need for reconsideration of our scheme for guardianship of persons with mental retardation and developmental disabilities is greater than ever" (*In re Mark C. H.*, 28 Misc. 3d at 769-771) (internal citations omitted).

[57] *See* U. S. Const. amend. XIV.

arbitrary, wrongful government actions regardless of the fairness of the procedures used to implement them." [58] As discussed above, article 17-A has numerous procedural flaws that may lead to erroneous determinations. In addition, the statute also violates the substantive due process rights of respondents for lack of any clear criteria for the court to adjudicate when presented with a guardianship application and by not requiring that there be any inquiry into whether guardianship is the least restrictive alternative.[59]

For example, article 81 requires clear and convincing evidence of the necessity of guardianship before a guardian will be appointed and functional limitations must be proven before a guardianship is imposed.[60] By contrast, the decision to appoint a guardian of the person or property, or both, under article 17-A is based upon the less-stringent best interest standard.[61] The best interest standard has been described as "amorphous"[62] and the "criteria necessary to support a finding that appointment of a guardian is appropriate in a particular case are rarely articulated but frequently assumed."[63] Given the gravity of the liberty and property interests at stake in an article 17-A guardianship proceeding, the best interest standard must be substituted with a functional test requiring the court to scrutinize a respondent's abilities, rather than permitting the court to rest on a diagnosis when disposing of the application. Indeed, the subjective best interest standard, makes a guardianship order difficult to appeal and poses obstacles to restoration of the respondent's rights in the future.

Equal Protection of the Law

Under the Fourteenth Amendment of the U.S. Constitution, individuals subjected to Article 17-A guardianship proceedings are also denied the equal protection of the laws. "While the end to be achieved by article 17-A and article 81 is the same, the means is not, and the inequality of treatment is not justifiable." [64]

The Fourteenth Amendment requires that where a person's fundamental rights and liberties are implicated, "classifications which might invade or restrain them must be closely

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58 *Zinermon v. Burch*, 494 U.S. 113 (1990).

59 In the case of *In re Guardianship of Dameris* L., Surrogate's Court New York County (Glen, J.) wrote that "in order to withstand constitutional challenge, including, particularly, challenge under our own state Constitution's due process guarantees, SCPA article 17-A must be read to include the requirement that guardianship is the least restrictive alternative to achieve the state's goal of protecting a person with intellectual disabilities from harm connected to those disabilities. Further, the court must consider the availability of "other resources," like those in Mental Hygiene Law § 81.03(e), including the support network of family, friends and professionals before the drastic judicial intervention of guardianship can be imposed (38 Misc. 3d 570, 578-579 [2012]).

60 *See Addington v. Texas*, 441 U.S. 418 (1979) -- , adopting a "standard of proof is more than an empty semantic exercise." In cases involving individual rights, whether criminal or civil, "[t]he standard of proof [at a minimum] reflects the value society places on individual liberty."

61 SCPA 1754

62 *Koppenhoefer v. Koppenhoefer*, 159 A.D.2d 113 (2d Dept. 1990).

63 *See*, *Matter of Joshua J.K.*, 71 Misc. 3d 843, 847 (Sur. Ct. Westchester County 2021), *citing*, *Matter of Chiam A.K.,* 26 Misc. 3d 837,844, *Matter of Hytham M.G.*, 52 Misc. 3d 1211 (A), 2016 N.Y.Slip. Op 51113 (U).

64 *See*, Monthie, *supra* note 42 at 988.

scrutinized and carefully confined."[65] The U.S. Supreme Court requires a strict scrutiny test for state laws affecting fundamental rights, even when the class affected is not a suspect class, stating:

> The guaranty of "equal protection of the laws is a pledge of the protection of equal laws." When the law lays an unequal hand on those who have committed intrinsically the same quality of offense and sterilizes one and not the other, it has made as invidious a discrimination as if it had selected a particular race or nationality for oppressive treatment.[66]

As demonstrated above, the due process protections afforded to individuals subjected to these guardianship proceedings depends on whether guardianship is being considered pursuant to article 17-A or article 81. Specifically, article 81 directs the court to limit the appointment of a guardianship even if the person is found to be incapacitated, while an article 17-A proceeding relies exclusively on the best interest standard for appointment of guardianship. There are also stark differences with the level of notice that each of the statutes requires: article 81 directs that the notice inform the alleged incapacitated person of the nature and potential consequences of the proceeding and the right to a hearing and counsel, whereas article 17-A is silent as to notice beyond providing a copy of the petition to the individual with a disability. Once the petition proceeds to a hearing, the right to counsel, the right to a mandatory evidentiary hearing, and the standard of proof applied at the hearing all differ dramatically. [67]

Also, when the court appoints a guardian, the article 81 process directs that the guardianship be tailored and that the person's right to participate in decision-making not be encumbered to the greatest extent possible. Article 81 specifically directs that guardianship must be administered in the least restrictive manner after consideration of all other alternatives. Article 17-A directs the appointment of only a plenary guardianship. Furthermore, article 17-A uses a lower standard of proof as compared to article 81. Article 81 expressly requires courts to apply a clear and convincing evidence standard of proof, whereas article 17-A uses a best interest standard.[68]

Restoration of Rights

A person subjected to an article 17-A guardianship faces greater difficulty when attempting to terminate or modify the guardianship. Article 17-A is silent on the burden of proof in a termination proceeding, but the majority of written decisions place the burden on the person seeking to terminate the guardianship--the person with a disability. [69] On the

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65 *Harper v. Va. State Bd. Of Elections,* 383 U.S. 663, 670 (1966).
66 *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).
67 *See* Monthie, *supra* note 42, 968-970.
68 *See* Monthie, *supra* note 42, 980-983.
69 *See Matter of Joshua J.K.*, 71 Misc. 3d 843 (Sur. Ct., Westchester Co. 2021).

other hand, article 81 specifically prescribes a mechanism for termination of the guardianship and places the burden on the party seeking to continue the guardianship.[70]

Closing Thoughts on Constitutional Analysis

"The line drawn between individuals subjected to article 17-A and article 81 is an artificial one, and one that should be (and is) prohibited by the due process clause."[71] In fact, the New York judges have struggled with these divergent processes and have recognized that people with developmental disabilities can be subject to either article 17-A or article 81 guardianships and should treated equally.[72] In *Matter of Derek*,[73] Judge Eugene Peckham, then the Broome County Surrogate's Court held: "There [was] no rational reason why the respondent in a contested article 81 guardianship proceeding should be [able] to assert [a] ... privilege while the respondent in a contested article [17-A] guardianship ... cannot."[74] Judge Peckham's pronouncement captures the disparities in the statutory schemes governing guardianship in New York State.

IV. Article 17-A is indefensible under the Americans with Disabilities Act

Article 17-A provides inferior due process protections to people with developmental disabilities and traumatic brain injuries compared to all other New Yorkers who are afforded the superior protections of article 81 of the Mental Hygiene Law. This is clearly discriminatory on the basis of type of disability, and, as such, violates Title II of the Americans with Disabilities Act. Additionally, in November 2012, New York State created the Olmstead Development and Implementation Cabinet ("Olmstead Cabinet"), "charged with developing a plan consistent with New York's obligations under the ... *Olmstead v. L.C.*" decision.[75]

By way of background, on June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C*. that unjustified segregation of individuals with disabilities constituted discrimination in violation of Title II of the ADA. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity. This decision placed an affirmative duty on states to ensure that the state's services, programs, and activities for people with disabilities are administered in the most integrated setting appropriate to the person's needs.

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70 *See* Monthie, *supra* note 42, 987-988.

71 *See* Monthie, *supra* note 42, at 990.

72 *See*, *In re Guardianship of B.*, 190 Misc. 3d 581, 585 (Co. Ct. Tompkins County. Peckham, J.) - "The equal protection provisions of the federal and state Constitutions would require that mentally retarded person in a similar situation be treated the same whether they have a guardian appointed under [A]rticle 17-A or [A]rticle 81."

73 12 Misc. 3d 1132 (Sur. Ct., Broome County 2006).

74 *Id*., at 1134-1135

75 527 U.S. 581 (1999).

The Olmstead Cabinet examined New York's compliance with Olmstead, and issued a thirty-one-page report with recommendations in October 2013.[76] This report concluded that Article 17-A discriminated against people with intellectual and developmental disabilities under the ADA, because:

(i) Under Article 17-A, the basis for appointing a guardian is diagnosis driven and is not based upon the functional capacity of the person with disability. A hearing is not required, but if a hearing is held, Article 17-A does not require the presence of the person for whom the guardianship is sought.

(ii) Additionally, Article 17-A does not limit guardianship rights to the individual's specific incapacities, which is inconsistent with the least-restrictive philosophy of *Olmstead*.

(iii) Once guardianship is granted, Article 17-A instructs the guardian to make decisions based upon the "best interests" of the person with a disability and does not require the guardian to examine the choice and preference of the person with a disability.

The Olmstead Cabinet recommended that article 17-A be modernized in light of the *Olmstead* mandate to mirror the more recent article 81 with respect to appointment, hearings, functional capacity, and consideration of choice and preference in decision-making." In 2015, the Office for People With Developmental Disabilities proposed a (OPWDD) departmental bill to the legislature, which sought to redress the discrimination criticized in the Olmstead report. The bill was not enacted. In 2016, two new bills were introduced: Senate bill 5840 and Assembly bill 8171. Neither of these bills were enacted and legislative reform efforts since 2017 have remained elusive as priorities changed with the advent of the COVID public health crisis in 2019.

Reform of Article 17-A must also recognize that there are less restrictive decision-making alternatives to guardianship that are described below. These alternatives are identified as a continuum of options available to potentially meet the needs of individuals with developmental disabilities.

V. Alternatives to Plenary Guardianship

Health Care Proxies and other Health Care Advance Directives;

Article 29-C of the Public Health Law establishes a decision-making process that allows a competent adult (the principal) to appoint an agent to decide about health care in the event the principal becomes unable to decide for him or herself. The proxy law covers decisions to consent to or refuse any treatment, service or procedure to diagnose or treatment an individual's physical or mental condition. Adults are presumed competent to

[76] The Cabinet's mandate is to recommend law and policy changes to ensure that people with disabilities receive services and supports in settings that do not segregate them from the community. https://www.ny/gov/programs/olmstead-communityintegration-every-new-yorker-1ast.

designate a health care agent unless they have a guardian appointed for them. [77] OPWDD regulations encourage the execution of health care proxies for people with developmental disabilities.[78] Pursuant to OPWDD regulations, in order for a person (the "principal") to execute a health care proxy, the person must have the requisite capacity to understand that he or she is delegating to another person the authority to make medical decisions in the event of incapacity. [79]

A 2008 chapter amendment to article 33 of the MHL authorized the creation of a simplified advance directive for persons with developmental disabilities. [80] The form shall specify, at the option of the principal, what end-of-life treatment the person wishes to receive; may designate a health care agent consistent with the provisions of this article; and may, at the option of the principal, authorize the health care agent to commence making decisions immediately upon the execution of the proxy, provided that all such decisions made prior to a determination of incapacity pursuant to section twenty-nine hundred eighty-three of the public health law shall be made in direct consultation with the principal and the attending physician; and provided, further, that if, after such consultation, the principal disagrees with the agent's proposed decision, the principal's wishes shall prevail; and provided, further, that, in the case of any decision to withhold or withdraw artificial nutrition or hydration, the principal's wishes must have been recorded in the health care directive or stated in the presence of the agent and the attending physician; and further, provided, that the consultation among principal, agent and attending physician must be summarized and recorded in the principal's medical record. [81]

The feature of the law permitting the proxy to be effective immediately upon execution, have led to the phrase "Act Now" health care proxy being ascribed to this initiative. The 208 chapter amendment also requires that the form for the simplified advance health care directive be developed by the commissioner of OPWDD in consultation with the commissioner of health, providers of service authorized to provide services pursuant to article sixteen of this chapter, advocates, including self-advocates, and parents and family members of persons receiving services from such providers. A workgroup was formed to implement the chapter amendment shortly after its enactment. Regrettably, a form has yet

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[77] Public Health Law (PHL) § 2981[1][b]); *but see*, *Matter of John T. (Hanson)*, 119 A.D. 3d 948 (2d Dept. 2014) where the Court reversed the presumption of competency based upon a diagnosis of moderate to severe mental retardation.

[78] *See* 14 N.Y.C.R.R. 633.20

[79] 14 N.Y.C.R.R. 633.20 (a)(1)(iii). There are also special witnessing requirements when a health care proxy is executed by a person with developmental disabilities**.** Specifically, for persons who reside in OPWDD facilities**,** at least one witness shall be an individual who is not affiliated with the facility and at least one witness shall be a physician, nurse practitioner, physician assistant or clinical psychologist who either is employed by a developmental disabilities services office named in section 13.17 of the MHL or who has been employed for a minimum of two years to render care and service in a facility operated or licensed by the office for people with developmental disabilities, or has been approved by the commissioner of developmental disabilities in accordance with regulations approved by the commissioner. Such regulations shall require that a physician, nurse practitioner, physician assistant, or clinical psychologist possess specialized training or three years experience in treating developmental disabilities (see PHL § 2981[2][c]).

[80] L. 2008, c. 210; MHL 33.03[e]).

[81] *Id*.

to be approved by OPWDD so this statutory innovation, while potentially beneficial to people with developmental disabilities, remains dormant.

Powers of Attorney

A Power of Attorney is a legal instrument that is used to delegate legal authority to another.[82] The person who signs (executes) a Power of Attorney is called the Principal. The Power of Attorney gives legal authority to another person (called an Agent) to make property, financial and other legal decisions for the Principal. [83] There is no health care decision making authority attached to a Power of Attorney.[84]

A Principal can give an Agent broad legal authority, or very limited authority. The Power of Attorney is frequently used to help in the event of a Principal's illness or disability, or in legal transactions where the principal cannot be present to sign necessary legal documents. A person with a developmental disability who has capacity to execute a power of attorney may do subject to regulations of the department of mental hygiene that may apply if the person resides in an OPWDD operated or licensed facility.[85]

Representative payment, supplemental needs trusts, ABLE accounts

A person with a disability who is receiving public benefits but who may be unable to manage his or her funds, may have a representative payee appointed which can negate the need for a property guardian. For example, the Social Security Administration (SSA) has a regulatory scheme implementing representative payment.[86] As a matter of policy, SSA states that every beneficiary has the right to manage his or her own benefits. However, some beneficiaries due to a mental or physical condition or due to their youth may be unable to do so. Under these circumstances, SSA may determine that the interests of the beneficiary would be better served if SSA [we] certified benefit payments to another person as a representative payee. [87]

A Supplemental Needs Trust (also called a Special Needs Trust) is a trust which, under federal and State law, allows a trustee (either a corporation authorized by law or an individual) to manage funds for the benefit of a person with a disability (the "beneficiary"), while preserving that person's eligibility for government benefits such as Supplemental Security Income or Medicaid. [88] Such means-tested public benefits can make a significant

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82 The New York State Power of Attorney statute was recently amended, effective June 13, 2021. *See,* L. 2020, c. 323.

83 *See,* definitions at General Obligations Law (GOL) § 5-1501.

84 However, an agent may make financial decisions relative to health care (see GOL§ 5-1502k).

85 14 N.Y.C.R.R. 22.3 - when a patient may sign a legal instrument.

86 20 C.F.R. Part 404, subpart U; Part 416 (Supplemental Security Income). SSA's policy is that every beneficiary has the right to manage his or her benefits. However, some beneficiaries due to a mental or physical condition or due to their youth may be unable to do so (*see* 20 C.F.R. 416.601).

87 20 C.F.R. 2010; to the extent the SSA regulations afford due process rights to beneficiaries alleged to need a representative payee those remedies are found cross-referenced to sub-part J of the regulations (20 C.F.R. 2030[b]).

88 *See Cricchio v. Pennisi*, 90 N.Y.2d 296 (1997); *In re Abraham XX.*, 11 N.Y. 3d 429 (2008).

positive impact on the quality of life available to the person with disabilities, permitting them to live successfully in their home communities, while the trust funds can pay for supplemental needs and wants of the beneficiary which the public funds do not provide.[89]

In contrast, an ABLE account (Achieving a Better Life Experience [ABLE] Act)[90] is a tax-advantaged savings program for individuals with disabilities enabled by federal law and modeled after the federal college savings plans. ABLE accounts enjoy tax free growth on the income within the account. Future distributions are allowed on a tax-free basis so long as they are for "qualified expenses." In addition, these distributions generally will not count as income to the beneficiary for the purposes of means tested government programs such as SSI and Medicaid. States implement the federal law and in New York, the ABLE program administered by the New York State Comptroller under authority granted in the State Finance Law and MHL. [91]

Single Transaction Orders

An underutilized provision of New York's adult guardianship law, MHL § 81.16(b), permits a judge to "authorize a [necessary] transaction or transactions" that can solve a single problem or a series of interrelated problems that stem from a health concern. Informally known as a "*one-shot*" provision, section 81.16(b) can meet a health care provider's need for informed consent to a medical procedure, or for authorization for a hospital discharge without the requirement of first establishing guardianship. Using section 81.16(b) thus avoids the imposition of guardianship, permits a person to retain all their rights, personhood, and dignity, while offering a solution to the vulnerable person's immediate health concerns and, importantly, takes into consideration that individual's specific, related challenges. In addition to decisions that are directly related to a person's health and medical treatment, a "one-shot" solution can also encompass related issues that impact on a person's health, such as preserving that person's home from foreclosure, securing an inheritance that makes it possible to pay for necessities. For clients served in the OPWDD system, single transaction guardianships have been used very effectively to establish SNTs in those instances where the person may have received an inheritance of a retroactive SSA benefit.

Supported Decision Making

Whereas guardianships involve a third party making decisions for the individual subject to the regimen, supported decision-making focuses on supporting the individuals' own decisions. As stated by the American Bar Association:

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89 *See generally*, Joseph A. Rosenberg, *Supplemental Needs Trust for People with Disabilities. The Development of a Private Trust in the Public Good,* 10 B. U. Pub. Int. L. J. 91 (2010).

90 26 U.S.C. 529A

91 *See* MHL art. 84; State Finance Law 99-x.

> Supported decision-making constitutes an important new resource or tool to promote and ensure the constitutional requirement of the least restrictive alternative. As a practical matter, supported decision-making builds on the understanding that no one, however abled, makes decisions in a vacuum or without the input of other persons whether the issue is what kind of car to buy, which medical treatment to select, or who to marry, a person inevitably consults friends, family, coworkers, experts, or others before making a decision. Supported decision making recognizes that older persons, persons with cognitive limitations and persons with intellectual disability will also make decisions with the assistance of others although the kinds of assistance necessary may vary or be greater than those used by persons without disabilities. [92]

Supported Decision-Making New York (SDMNY) is a consortium of Hunter/CUNY, The New York Alliance for Innovation and Inclusion, and Arc of Westchester with Disability Rights New York (DRNY) as its legal partner which recently concluded a five year pilot funded by the Developmental Disabilities Planning Council.[93] Drawing on the expertise of its members, and on the work of advocates and pilots in other countries, SDMNY has developed a three-phase model, utilizing trained facilitators who, in turn, are supported by experienced mentors. The facilitators work with people with intellectual and developmental disabilities (who are referred to as "Decision Makers," to emphasize their centrality to the process) and the trusted persons in their lives who they have chosen as their supporters. They assist the Decision Makers in identifying the areas in which they want support, the kinds of support they want, and the ways in which that support should be given. The "product" of the facilitation, which typically involves monthly meetings over a period of nine to twelve months, is a contract negotiated by the Decision Maker and her/his supporters, the Supported Decision-Making Agreement (the SDMA) that reflects their agreement. The SDMA is not just a piece of paper, but describes and memorializes a flexible *process*, which the Decision Maker can use for the rest of her/his life to make her/his own decisions, with the support s/he needs and desires.[94]

Presently in New York, the SDMA has no binding legal effect, and third parties--health care professionals, financial institutions, landlords, for example-- are under no legal obligation to honor it. An SDM program bill was introduced during the 2020 session, however, and if enacted, the bill would, as other states have done, require acceptance by third parties of SDMA agreements and relieve those third parties from liability for good faith reliance. [95]

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92 *See* Proposed Resolution and Report, American Bar Association, Commission on Disability Rights, Section of Civil Rights and Social Justice, Section of Real Property, Trust and Estate Law, Commission on Law and Aging, Report to the House of Delegates (2017).

93 https://sdmny.hunter.cuny.edu/

94 *See* Kristin Booth Glen, *Supported-Decision Making From Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 Alb. Gov't L. Rev. 94 (2019-2020).

95 S. 7107 (2020). If enacted, OPWDD will be charged with developing regulations to implement the statute. The regulations, among other things, will further define the rights of decision makers and the training required for supporters to ensure the law meets its intended objectives.

VI. Recommendations and Conclusions

The NYSBA Disability Rights Committee urges the reform of Article 17-A of the SCPA and recognition that people with developmental disabilities should not be deprived of their agency, autonomy, and civil rights based upon misassumptions about their abilities or the quality of their lives. The Committee offers an Appendix with legislative proposals that can be advanced and supported in the upcoming 2022 legislative session.

VII. Proposed Statutory Reform - APPENDIX

a. Law Revision Commission - proposal to reform article 17-A
b. Office of Court Administration - program bill #30
c. Document comparing the two legislative proposals
d. Supported Decision Making- 2020 OPWDD program bill (S. 7107)
e. Stakeholder Comments on OPWDD program bill

Dated: November 15, 2021

Joseph Ranni
Alison Morris
Co-Chairs
New York State Bar Association Committee on Disability Rights

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January 4, 2022

Re: January 2022 Report and Recommendations of Disability Rights Reform Article 17-A

Dear President Brown and Delegates:

On behalf of the committee members of the NYSBA's Committee on Civil Rights ("CCR"), we strongly support the Report and Recommendations from the Disability Rights Committee reforming Article 17-A of the Surrogates Court Procedure Act.

Respectfully submitted,

Co-Chairpersons: Hanna F. Madbak & Matthew W. Alpern

From: Anoush Koroghlian-Scott <akoroghlianscott@lippes.com>
Sent: Wednesday, December 15, 2021 11:07 AM
To: Sheila E. Shea <sshea@nycourts.gov>
Subject: Report of the Committee on Disability Rights
Importance: High

Hi Sheila,
As promised, we surveyed the Executive Committee of the Health Law Section and met this morning. The Health Law Section supports the DRC Report and agrees that Article 17-A does not sufficiently protect the rights of persons with intellectual disabilities and that Article 81 of the Mental Hygiene Law offers a preferable and constitutionally defensible model. We would further suggest that for the same or similar reasons, consideration should be given to eliminating SCPA 1750-b and applying the Family Health Care Decisions Act in its place as the guiding statute for purposes of making end of life decisions for persons with intellectual disabilities.
Thank you for your continuing work in this space. Please let me know if you have questions or wish to discuss.
Kind regards,
Anoush

Anoush Koroghlian-Scott
Partner

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Legislative Bill Drafting Commission
10073-01-9

S. --------
Senate

IN SENATE--Introduced by Sen

--read twice and ordered printed, and when printed to be committed to the Committee on

-------- A.
Assembly

IN ASSEMBLY--Introduced by M. of A.

with M. of A. as co-sponsors

--read once and referred to the Committee on

SURCPRAC *Office of Court Administration 30*
(Relates to guardians of persons who are intellectually and developmentally disabled; and repeals certain provisions of the surrogate's court procedure act relating thereto)

SCPA. guardianship, disability

AN ACT

to amend the surrogate's court procedure act, in relation to guardians of persons who are intellectually and developmentally disabled; and to repeal certain provisions of such law relating thereto

IN SENATE

Senate introducer's signature

The senators whose names are circled below wish to join me in the sponsorship of this proposal

s15 Addabbo	s02 Flanagan	s09 Kaminsky	s25 Montgomery	s23 Savino
s52 Akshar	s55 Funke	s07 Kaplan	s20 Myrie	s32 Sepulveda
s46 Amedore	s59 Gallivan	s26 Kavanagh	s58 O'Mara	s41 Serino
s50 Antonacci	s05 Gaughran	s63 Kennedy	s62 Ortt	s29 Serrano
s36 Bailey	s12 Gianaris	s28 Krueger	s21 Parker	s51 Seward
s30 Benjamin	s22 Gounardes	s24 Lanza	s19 Persaud	s39 Skoufis
s34 Biaggi	s47 Griffo	s01 LaValle	s13 Ramos	s16 Stavisky
s04 Boyle	s40 Harckham	s45 Little	s61 Ranzenhofer	s35 Stewart-Cousins
s44 Braslin	s54 Helming	s11 Liu	s48 Ritchie	
s08 Brooks	s27 Hoylman	s03 Martinez	s33 Rivera	s49 Tedisco
s38 Carlucci	s31 Jackson	s53 May	s56 Rolach	s06 Thomas
s14 Comrie	s60 Jacobs	s37 Mayer	s18 Salazar	s57 Young
s17 Felder	s43 Jordan	s42 Metzger	s10 Sanders	

IN ASSEMBLY

Assembly introducer's signature

The Members of the Assembly whose names are circled below wish to join me in the multi-sponsorship of this proposal:

a049 Abbate	a072 De La Rosa	a029 Hyndman	a144 Morris	a090 Seyegh
a092 Abinanti	a034 DenDekker	a104 Jacobson	a069 O'Donnell	a140 Schimminger
a084 Arroyo	a003 DeStefano	a097 Jaffee	a051 Ortiz	a099 Schmitt
a107 Ashby	a070 Dickens	a011 Jean-Pierre	a091 Otis	a076 Seawright
a035 Aubry	a054 Dilan	a135 Johns	a132 Palmesano	a052 Simon
a120 Barclay	a081 Dinowitz	a115 Jones	a002 Palumbo	a036 Simotas
a030 Barnwell	a147 DiPietro	a077 Joyner	a088 Paulin	a005 Smith
a106 Barrett	a016 D'Urso	a040 Kim	a141 Peoples-Stokes	a118 Smullen
a060 Barron	a048 Richenstein	a131 Kolb		a022 Solages
a082 Benedetto	a004 Englebright	a105 Lalor	a058 Perry	a114 Stec
a042 Bichotte	a074 Epstein	a013 Lavine	a023 Pheffer Amato	a110 Steck
a079 Blake	a109 Faby	a134 Lawrence		a010 Stern
a117 Blankenbush	a061 Fall	a050 Lentol	a086 Pichardo	a127 Stirpe
a098 Brabenec	a090 Fernandez	a125 Lifton	a089 Pretlow	a102 Tague
a026 Braunstein	a126 Finch	a009 LiPetri	a073 Quart	a071 Taylor
a138 Bronson	a008 Fitzpatrick	a123 Lupardo	a019 Ra	a001 Thiele
a093 Buchwald	a124 Friend	a129 Magnarelli	a012 Raia	a031 Titus
a142 Burke	a046 Frontus	a064 Mallistakis	a006 Ramos	a033 Vanel
a119 Buttenschon	a095 Galef	a130 Manktelow	a018 Reynor	a116 Walczyk
a094 Byrne	a137 Gantt	a108 McDonald	a062 Reilly	a055 Walker
a133 Byrnes	a007 Garbarino	a014 McDonough	a087 Reyes	a143 Wallace
a103 Cahill	a148 Giglio	a146 McMahon	a043 Richardson	a112 Walsh
a044 Carroll	a066 Glick	a017 Mikulin	a078 Rivera	a041 Weinstein
a047 Colton	a150 Goodell	a101 Miller, B.	a068 Rodriguez	a024 Wegrin
a032 Cook	a075 Gottfried	a038 Miller, M.G.	a136 Romeo	a059 Williams
a085 Crespo	a021 Griffin	a020 Miller, M.L.	a027 Rosenthal, D.	a113 Woerner
a122 Crouch	a100 Gunther	a015 Montesano	a067 Rosenthal, L.	a056 Wright
a039 Cruz	a139 Hawley	a145 Morinello	a025 Rozic	a096 Zebrowski
a063 Cusick	a083 Heastie	a057 Mosley	a149 Ryan	
a045 Cymbrowitz	a028 Hevesi	a065 Niou	a121 Salka	
a053 Davila	a128 Hunter	a037 Nolan	a111 Santabarbara	

1) Single House Bill (introduced and printed separately in either or both houses). Uni-Bill (introduced simultaneously in both houses and printed as one bill. Senate and Assembly introducer sign the same copy of the bill).

2) Circle names of co-sponsors and return to introduction clerk with 2 signed copies of bill and 4 copies of memorandum in support (single house); or 4 signed copies of bill and 8 copies of memorandum in support (uni-bill).

LBDC 12/20/18

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Section 1750 of the surrogate's court procedure act is REPEALED and a new section 1750 is added to read as follows:

§ 1750. Definitions

When used in this article:

1. "Developmental disability" shall mean a developmental disability within the meaning of subdivision twenty-two of section 1.03 of the mental hygiene law.

2. "Traumatic brain injury" shall mean an injury, as defined in section twenty-seven hundred forty-one of the public health law, which originated before the age of twenty-two.

3. "Respondent" shall mean an individual listed in the petition as alleged to have a developmental disability or traumatic brain injury, which disability originates before such person attains age twenty-two.

§ 2. Section 1750-a of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1750-a. Guardianship of persons [who are developmentally disabled] with a developmental disability or traumatic brain injury

1. When it shall appear to the satisfaction of the court [that a person is a person who is developmentally disabled, the court is authorized to appoint a guardian of the person or of the property or of both if such appointment of a guardian or guardians is in the best interest of the person who is developmentally disabled. Such appointments shall be made pursuant to the provisions of this article, provided however that the provisions of section seventeen hundred fifty of this article shall not apply to the appointment of a guardian or guardians of a person who is developmentally disabled. For the purposes of this article, a person who is developmentally disabled is a person who has been certified by one licensed physician and one licensed psychologist, or by

two licensed physicians at least one of whom is familiar with or has professional knowledge in the care and treatment of persons with developmental disabilities, having qualifications to make such certification, as having an impaired ability to understand and appreciate the nature and consequences of decisions which result in such person being incapable of managing himself or herself and/or his or her affairs by reason of developmental disability and that such condition is permanent in nature or likely to continue indefinitely, and whose disability:

(a) is attributable to cerebral palsy, epilepsy, neurological impairment, autism or traumatic head injury;

(b) is attributable to any other condition of a person found to be closely related to intellectual disability because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of persons with intellectual disabilities; or

(c) is attributable to dyslexia resulting from a disability described in subdivision one or two of this section or from intellectual disability; and

(d) originates before such person attains age twenty-two, provided, however, that no such age of origination shall apply for the purposes of this article to a person with traumatic head injury.

2. Notwithstanding any provision of law to the contrary, for the purposes of subdivision two of section seventeen hundred fifty and section seventeen hundred fifty-b of this article, "a person who is intellectually disabled and his or her guardian" shall also mean a person and his or her guardian appointed pursuant to this section; provided that such person has been certified by the physicians and/or psychologists, specified in subdivision one of this section, as (i) having an intellectual disability, or (ii) having a developmental disa-

bility, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability] based on clear and convincing evidence that the respondent is a person with a developmental disability or traumatic brain injury, the court may appoint pursuant to the provisions of this article a guardian of the person or of the property or both provided that guardianship shall be imposed only if necessary and in the least restrictive manner specifically considering the respondent's functional abilities.

2. Every decree issued pursuant to this article shall include a finding as to whether the respondent has the capacity to make health care decisions, as defined by subdivision three of section twenty-nine hundred eighty of the public health law. A determination that the respondent has the capacity to make health care decisions shall not preclude the appointment of a guardian to make other decisions on behalf of the respondent.

§ 3. Section 1750-b of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1750-b. Health care decisions for persons [who are intellectually disabled] with a developmental disability or traumatic brain injury

1. Scope of authority. Unless specifically prohibited by the court after consideration of the determination, if any, regarding a person [who is intellectually disabled's capacity] with a developmental disability or traumatic brain injury to make health care decisions, which is required by section seventeen hundred fifty of this article, the guardi-

an of such person appointed pursuant to section seventeen hundred fifty of this article shall have the authority to make any and all health care decisions, as defined by subdivision six of section twenty-nine hundred eighty of the public health law, on behalf of the person [who is intellectually disabled] with a developmental disability or traumatic brain injury that such person could make if such person had capacity. Such decisions may include decisions to withhold or withdraw life-sustaining treatment. For purposes of this section, "life-sustaining treatment" means medical treatment, including cardiopulmonary resuscitation and nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period. Cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician. The provisions of this article are not intended to permit or promote suicide, assisted suicide or euthanasia; accordingly, nothing in this section shall be construed to permit a guardian to consent to any act or omission to which the person [who is intellectually disabled] with a developmental disability or traumatic brain injury could not consent if such person had capacity.

(a) For the purposes of making a decision to withhold or withdraw life-sustaining treatment pursuant to this section, in the case of a person for whom no guardian has been appointed pursuant to section [seventeen hundred fifty or] seventeen hundred fifty-a of this article, a "guardian" shall also mean a family member of a person who (i) has [intellectual disability] a traumatic brain injury, or (ii) has a developmental disability[, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a

similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability]. Qualified family members shall be included in a prioritized list of said family members pursuant to regulations established by the commissioner of the office for people with developmental disabilities. Such family members must have a significant and ongoing involvement in a person's life so as to have sufficient knowledge of their needs and, when reasonably known or ascertainable, the person's wishes, including moral and religious beliefs. In the case of a person who was a resident of the former Willowbrook state school on March seventeenth, nineteen hundred seventy-two and those individuals who were in community care status on that date and subsequently returned to Willowbrook or a related facility, who are fully represented by the consumer advisory board and who have no guardians appointed pursuant to this article or have no qualified family members to make such a decision, then a "guardian" shall also mean the Willowbrook consumer advisory board. A decision of such family member or the Willowbrook consumer advisory board to withhold or withdraw life-sustaining treatment shall be subject to all of the protections, procedures and safeguards which apply to the decision of a guardian to withhold or withdraw life-sustaining treatment pursuant to this section.

In the case of a person for whom no guardian has been appointed pursuant to this article or for whom there is no qualified family member or the Willowbrook consumer advisory board available to make such a decision, a "guardian" shall also mean, notwithstanding the definitions in section 80.03 of the mental hygiene law, a surrogate decision-making committee, as defined in article eighty of the mental hygiene law. All

declarations and procedures, including expedited procedures, to comply with this section shall be established by regulations promulgated by the commission on quality of care and advocacy for persons with disabilities.

(b) Regulations establishing the prioritized list of qualified family members required by paragraph (a) of this subdivision shall be developed by the commissioner of the office for people with developmental disabilities in conjunction with parents, advocates and family members of persons who are intellectually disabled. Regulations to implement the authority of the Willowbrook consumer advisory board pursuant to paragraph (a) of this subdivision may be promulgated by the commissioner of the office for people with developmental disabilities with advice from the Willowbrook consumer advisory board.

[(c) Notwithstanding any provision of law to the contrary, the formal determinations required pursuant to section seventeen hundred fifty of this article shall only apply to guardians appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article.]

2. Decision-making standard. (a) The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the person [who is intellectually disabled] <u>with a developmental disability or traumatic brain injury</u> and, when reasonably known or ascertainable with reasonable diligence, on [the person who is intellectually disabled's] <u>such person's</u> wishes, including moral and religious beliefs.

(b) An assessment of [the person who is intellectually disabled's] <u>such person's</u> best interests shall include consideration of:

(i) the dignity and uniqueness of every person;

(ii) the preservation, improvement or restoration of [the person who is intellectually disabled's] such person's health;

(iii) the relief of [the person who is intellectually disabled's] such person's suffering by means of palliative care and pain management;

(iv) the unique nature of artificially provided nutrition or hydration, and the effect it may have on [the] such person [who is intellectually disabled]; and

(v) the entire medical condition of the person.

(c) No health care decision shall be influenced in any way by:

(i) a presumption that persons [who are intellectually disabled] with a developmental disability or traumatic brain injury are not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to persons without [an intellectual disability or] a developmental disability or traumatic brain injury; or

(ii) financial considerations of the guardian, as such considerations affect the guardian, a health care provider or any other party.

3. Right to receive information. Subject to the provisions of sections 33.13 and 33.16 of the mental hygiene law, the guardian shall have the right to receive all medical information and medical and clinical records necessary to make informed decisions regarding the [person who is intellectually disabled's] health care of the person with a developmental disability or traumatic brain injury.

4. Life-sustaining treatment. The guardian shall have the affirmative obligation to advocate for the full and efficacious provision of health care, including life-sustaining treatment. In the event that a guardian makes a decision to withdraw or withhold life-sustaining treatment from a person [who is intellectually disabled] with a developmental disability or traumatic brain injury:

(a) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, must confirm to a reasonable degree of medical certainty that the person [who is intellectually disabled] with a developmental disability or traumatic brain injury lacks capacity to make health care decisions. The determination thereof shall be included in [the person who is intellectually disabled's] such person's medical record, and shall contain such attending physician's opinion regarding the cause and nature of [the person who is intellectually disabled's] such person's incapacity as well as its extent and probable duration. The attending physician who makes the confirmation shall consult with another physician, or a licensed psychologist, to further confirm [the person who is intellectually disabled's] such person's lack of capacity. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, must (i) be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or (ii) have been employed for a minimum of two years to render care and service in a facility or program operated, licensed or authorized by the office for people with developmental disabilities, or (iii) have been approved by the commissioner of the office for people with developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three years experience in treating intellectual disability. A record of such consultation shall be included in the [person who is intellectu-

ally disabled's] medical record of the person with a developmental disability or traumatic brain injury.

(b) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, with the concurrence of another physician with whom such attending physician shall consult, must determine to a reasonable degree of medical certainty and note on the [person who is intellectually disabled's] chart of the person with a developmental disability or traumatic brain injury that:

(i) [the] such person [who is intellectually disabled] has a medical condition as follows:

A. a terminal condition, as defined in subdivision twenty-three of section twenty-nine hundred sixty-one of the public health law; or

B. permanent unconsciousness; or

C. a medical condition other than such person's [intellectual] developmental disability or traumatic brain injury which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and

(ii) the life-sustaining treatment would impose an extraordinary burden on such person, in light of:

A. such person's medical condition, other than such person's [intellectual] developmental disability or traumatic brain injury; and

B. the expected outcome of the life-sustaining treatment, notwithstanding such person's [intellectual] developmental disability or traumatic brain injury; and

(iii) in the case of a decision to withdraw or withhold artificially provided nutrition or hydration:

A. there is no reasonable hope of maintaining life; or

B. the artificially provided nutrition or hydration poses an extraordinary burden.

(c) The guardian shall express a decision to withhold or withdraw life-sustaining treatment either:

(i) in writing, dated and signed in the presence of one witness eighteen years of age or older who shall sign the decision, and presented to the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or

(ii) orally, to two persons eighteen years of age or older, at least one of whom is the person who is [intellectually disabled's] the attending physician to the person with a developmental disability or traumatic brain injury, as defined in subdivision two of section twenty-nine hundred eighty of the public health law.

(d) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, who is provided with the decision of a guardian shall include the decision in the [person who is intellectually disabled's] medical chart of the person with a developmental disability or traumatic brain injury, and shall either:

(i) promptly issue an order to withhold or withdraw life-sustaining treatment from [the] such person [who is intellectually disabled], and inform the staff responsible for such person's care, if any, of the order; or

(ii) promptly object to such decision, in accordance with subdivision five of this section.

(e) At least forty-eight hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible

time prior to the implementation of a decision to withhold life-sustaining treatment, the attending physician shall notify:

(i) the person [who is intellectually disabled] with a developmental disability or traumatic brain injury, except if the attending physician determines, in writing and in consultation with another physician or a licensed psychologist, that, to a reasonable degree of medical certainty, the person would suffer immediate and severe injury from such notification. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, shall:

A. be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or

B. have been employed for a minimum of two years to render care and service in a facility operated, licensed or authorized by the office for people with developmental disabilities, or

C. have been approved by the commissioner of the office for people with developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three years experience in treating intellectual disability. A record of such consultation shall be included in the [person who is intellectually disabled's] medical record of the person with a developmental disability or traumatic brain injury;

(ii) if the person is in or was transferred from a residential facility operated, licensed or authorized by the office for people with developmental disabilities, the chief executive officer of the agency or

organization operating such facility and the mental hygiene legal service; and

(iii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.

5. Objection to health care decision. (a) Suspension. A health care decision made pursuant to subdivision four of this section shall be suspended, pending judicial review, except if the suspension would in reasonable medical judgment be likely to result in the death of the person [who is intellectually disabled] <u>with a developmental disability or traumatic brain injury</u>, in the event of an objection to that decision at any time by:

(i) the person [who is intellectually disabled] <u>with a developmental disability or traumatic brain injury</u> on whose behalf such decision was made; or

(ii) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the person [who is intellectually disabled] <u>with a developmental disability or traumatic brain injury</u>; or

(iii) the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or

(iv) any other health care practitioner providing services to the person [who is intellectually disabled] <u>with a developmental disability or traumatic brain injury</u>, who is licensed pursuant to article one hundred thirty-one, one hundred thirty-one-B, one hundred thirty-two, one hundred thirty-three, one hundred thirty-six, one hundred thirty-nine, one hundred forty-one, one hundred forty-three, one hundred forty-four, one hundred fifty-three, one hundred fifty-four, one hundred

fifty-six, one hundred fifty-nine or one hundred sixty-four of the education law; or

(v) the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section; or

(vi) if the person is in or was transferred from a residential facility or program operated, approved or licensed by the office for people with developmental disabilities, the mental hygiene legal service; or

(vii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.

(b) Form of objection. Such objection shall occur orally or in writing.

(c) Notification. In the event of the suspension of a health care decision pursuant to this subdivision, the objecting party shall promptly notify the guardian and the other parties identified in paragraph (a) of this subdivision, and the attending physician shall record such suspension in the [person who is intellectually disabled's] medical chart <u>of the person with a developmental disability or traumatic brain injury</u>.

(d) Dispute mediation. In the event of an objection pursuant to this subdivision, at the request of the objecting party or person or entity authorized to act as a guardian under this section, except a surrogate decision making committee established pursuant to article eighty of the mental hygiene law, such objection shall be referred to a dispute mediation system, established pursuant to section two thousand nine hundred seventy-two of the public health law or similar entity for mediating disputes in a hospice, such as a patient's advocate's office, hospital chaplain's office or ethics committee, as described in writing and

adopted by the governing authority of such hospice, for non-binding mediation. In the event that such dispute cannot be resolved within seventy-two hours or no such mediation entity exists or is reasonably available for mediation of a dispute, the objection shall proceed to judicial review pursuant to this subdivision. The party requesting mediation shall provide notification to those parties entitled to notice pursuant to paragraph (a) of this subdivision.

6. Special proceeding authorized. The guardian, the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section, the mental hygiene legal service (if the person is in or was transferred from a residential facility or program operated, approved or licensed by the office for people with developmental disabilities) or the commissioner of the office for people with developmental disabilities or his or her designee (if the person is not in and was not transferred from such a facility or program) may commence a special proceeding in a court of competent jurisdiction with respect to any dispute arising under this section, including objecting to the withdrawal or withholding of life-sustaining treatment because such withdrawal or withholding is not in accord with the criteria set forth in this section.

7. Provider's obligations. (a) A health care provider shall comply with the health care decisions made by a guardian in good faith pursuant to this section, to the same extent as if such decisions had been made by the person [who is intellectually disabled] <u>with a developmental disability or traumatic brain injury</u>, if such person had capacity.

(b) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require a private hospital to honor a guardian's health care decision that the hospital would not honor if the decision had been made by the person [who is intellectually disabled] with a developmental disability or traumatic brain injury, if such person had capacity, because the decision is contrary to a formally adopted written policy of the hospital expressly based on religious beliefs or sincerely held moral convictions central to the hospital's operating principles, and the hospital would be permitted by law to refuse to honor the decision if made by such person, provided:

(i) the hospital has informed the guardian of such policy prior to or upon admission, if reasonably possible; and

(ii) the person [who is intellectually disabled] with a developmental disability or traumatic brain injury is transferred promptly to another hospital that is reasonably accessible under the circumstances and is willing to honor the guardian's decision. If the guardian is unable or unwilling to arrange such a transfer, the hospital's refusal to honor the decision of the guardian shall constitute an objection pursuant to subdivision five of this section.

(c) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require an individual health care provider to honor a guardian's health care decision that the individual would not honor if the decision had been made by the person [who is intellectually disabled] with a developmental disability or traumatic brain injury, if such person had capacity, because the decision is contrary to the individual's religious beliefs or sincerely held moral convictions, provided the individual health care provider promptly informs the guardian and the facility, if any, of his or her refusal to honor the guardian's

decision. In such event, the facility shall promptly transfer responsibility for the person [who is intellectually disabled] with a developmental disability or traumatic brain injury to another individual health care provider willing to honor the guardian's decision. The individual health care provider shall cooperate in facilitating such transfer of the patient.

(d) Notwithstanding the provisions of any other paragraph of this subdivision, if a guardian directs the provision of life-sustaining treatment, the denial of which in reasonable medical judgment would be likely to result in the death of the person [who is intellectually disabled] with a developmental disability or traumatic brain injury, a hospital or individual health care provider that does not wish to provide such treatment shall nonetheless comply with the guardian's decision pending either transfer of the person [who is intellectually disabled] with a developmental disability or traumatic brain injury to a willing hospital or individual health care provider, or judicial review.

(e) Nothing in this section shall affect or diminish the authority of a surrogate decision-making panel to render decisions regarding major medical treatment pursuant to article eighty of the mental hygiene law.

8. Immunity. (a) Provider immunity. No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring reasonably and in good faith a health care decision by a guardian, or for other actions taken reasonably and in good faith pursuant to this section.

(b) Guardian immunity. No guardian shall be subjected to criminal or civil liability for making a health care decision reasonably and in good faith pursuant to this section.

§ 4. Section 1751 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1751. Petition for appointment; by whom [made] and where made

1. A petition for the appointment of a guardian of the person or property, or both, [of a person who is intellectually disabled or a person who is developmentally disabled] may be made by a parent of a person asserted to have a developmental disability or traumatic brain injury, any [interested] person eighteen years of age or older on behalf of the [person who is intellectually disabled or a person who is developmentally disabled] respondent, including a corporation authorized to serve as a guardian as provided for by this article, or by the person who is [intellectually disabled or a person who is developmentally disabled] asserted to have a developmental disability or traumatic brain injury when such person is eighteen years of age or older.

2. A proceeding under this article shall be brought in the surrogate's court within the county in which the respondent resides. If the respondent is a resident in a residential facility, the residence of the respondent shall be deemed to be in the county where that facility is located.

§ 5. Section 1752 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1752. Petition for appointment; contents

The petition for the appointment of a guardian shall be filed with the court on forms to be prescribed by the [state] chief administrator of the courts. Such petition for a guardian of a [person who is intellectually disabled or a person who is developmentally disabled] respondent shall include, but not be limited to, the following information:

1. the full name, date of birth and residence of the [person who is intellectually disabled or a person who is developmentally disabled] respondent;

2. the name, age, address and relationship or interest of the petitioner to the [person who is intellectually disabled or a person who is developmentally disabled] respondent;

3. the names of the [father, the mother] parents, children, adult siblings [if eighteen years of age or older], the spouse [and primary care physician if other than a physician having submitted a certification with the petition, if any, of the person who is intellectually disabled or a person who is developmentally disabled], if any, of the respondent, and whether or not they are living, and if living, their addresses and the names and addresses of the nearest [distributees] family members of full age who are domiciliaries, if both parents are [dead] deceased;

4. the name and address of the person with whom the [person who is intellectually disabled or a person who is developmentally disabled] respondent resides if other than the parents or spouse. If the respondent resides in a facility, the name and address of the facility;

5. the name, age, address, education and other qualifications, and consent of the proposed guardian, standby and alternate guardian[, if]. If petitioner is someone other than the parent, spouse, adult child [if eighteen years of age or older] or adult sibling [if eighteen years of age or older], and if such parent, spouse [or], adult child or adult sibling be living, why any of them should not be appointed guardian;

6. the estimated value of real and personal property and the annual income therefrom and any other income including governmental entitle-

ments to which the [person who is intellectually disabled or person who is developmentally disabled] respondent is entitled; [and]

7. any circumstances which the court should consider in determining whether [it is in the best interests of the person who is intellectually disabled or person who is developmentally disabled to] the respondent should not be present at the hearing [if conducted];

8. a statement that the respondent has a developmental disability or traumatic brain injury, including the basis for same, and the nature and extent of the respondent's functional abilities; and

9. a statement of the alternatives to guardianship considered, including but not limited to the execution of a health care proxy, power of attorney, representative payee, care coordination and/or other social support services, or other supported or shared decision-making, and reasons for the declination of such alternatives.

§ 6. Section 1753 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1753. Persons to be served

1. Upon presentation of the petition, process shall issue to:

(a) the spouse, the parent or parents, and adult children and adult siblings, if the petitioner is other than a parent[, adult siblings, if the petitioner is other than a parent, and if the person who is intellectually disabled or person who is developmentally disabled is married, to the spouse, if their residences are known];

(b) the person [having] providing care [and custody of] to the [person who is intellectually disabled or person who is developmentally disabled] respondent, or with whom such person resides if other than the parents or spouse; and

(c) the [person who is intellectually disabled or person who is developmentally disabled if fourteen years of age or older for whom an application has been made in such person's behalf] respondent.

2. Upon presentation of the petition, notice of such petition shall be served by certified mail to:

(a) the adult siblings if the petitioner is a parent, and adult children if the petitioner is a parent;

(b) [the mental hygiene legal service in the judicial department where the facility, as defined in subdivision (a) of section 47.01 of the mental hygiene law, is located if the person who is intellectually disabled or person who is developmentally disabled resides in such a facility;

(c)] in all cases, to the director in charge of a facility licensed or operated by an agency of the state of New York, if the [person who is intellectually disabled or person who is developmentally disabled] respondent resides in such facility;

[(d) one other person] (c) any other person or persons if designated in writing by the [person who is intellectually disabled or person who is developmentally disabled] respondent; and

[(e)] (d) such other persons as the court may deem proper.

3. [No process or notice shall be necessary to a parent, adult child, adult sibling, or spouse of the person who is intellectually disabled or person who is developmentally disabled who has been declared by a court as being incompetent. In addition, no process or notice shall be necessary to a spouse who is divorced from the person who is intellectually disabled or person who is developmentally disabled, and to a parent, adult child, adult sibling when it shall appear to the satisfaction of the court that such person or persons have abandoned the person who is

intellectually disabled or person who is developmentally disabled] The court shall upon the issuance of a citation assign counsel for the respondent and shall provide said counsel with a copy of the petition and any supporting papers filed therein. Process or notice may be dispensed with in the court's discretion.

§ 7. Section 1754 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1754. Hearing and trial

1. Upon a petition for the appointment of a guardian of a [person who is intellectually disabled or person who is developmentally disabled eighteen years of age or older] respondent, the court shall conduct a hearing at which [such person] the respondent shall have the right to jury trial. The right to a jury trial shall be deemed waived by failure to make a demand therefor. [The court may in its discretion dispense with a hearing for the appointment of a guardian, and may in its discretion appoint a guardian ad litem, or the mental hygiene legal service if such person is a resident of a mental hygiene facility as defined in subdivision (a) of section 47.01 of the mental hygiene law, to recommend whether the appointment of a guardian as proposed in the application is in the best interest of the person who is intellectually disabled or person who is developmentally disabled, provided however, that such application has been made by:

(a) both parents or the survivor; or

(b) one parent and the consent of the other parent; or

(c) any interested party and the consent of each parent.

2. When it shall appear to the satisfaction of the court that a parent or parents not joining in or consenting to the application have abandoned the person who is intellectually disabled or person who is devel-

opmentally disabled or are not otherwise required to receive notice, the court may dispense with such parent's consent in determining the need to conduct a hearing for a person under the age of eighteen. However, if the consent of both parents or the surviving parent is dispensed with by the court, a hearing shall be held on the application.

3. If a hearing is conducted, the person who is intellectually disabled or person who is developmentally disabled]

2. (a) The court shall appoint mental hygiene legal services as counsel for the respondent unless it appoints other counsel. The court may also appoint a guardian ad litem for the respondent. Such assignments of counsel or guardian ad litem shall be implemented as provided in section four hundred seven of this act.

(b) If the respondent objects to having counsel, the respondent may proceed self-represented only with leave of the court. The court may appoint counsel or guardian ad litem at its discretion, over the respondent's objection.

3. Counsel for the respondent or the guardian ad litem may:

(a) apply to the court for an order to inspect the clinical records pertaining to the respondent in accordance with state and federal laws;

(b) be allowed access to the respondent's clinical records without a court order as otherwise limited by law; and

(c) request that the court issue such orders to permit access.

4. At the scheduled hearing, the respondent shall be present unless it shall appear to the satisfaction of the court [on the certification of the certifying physician that the person who is intellectually disabled or person who is developmentally disabled is medically incapable of being present to the extent that attendance is likely to result in physical harm to such person who is intellectually disabled or person who is

developmentally disabled, or under such other circumstances which the court finds would not be in the best interest of the person who is intellectually disabled or person who is developmentally disabled.

4. If either a hearing is dispensed with pursuant to subdivisions one and two of this section or the person who is intellectually disabled or person who is developmentally disabled is not present at the hearing pursuant to subdivision three of this section, the court may appoint a guardian ad litem if no mental hygiene legal service attorney is authorized to act on behalf of the person who is intellectually disabled or person who is developmentally disabled. The guardian ad litem or mental hygiene legal service attorney, if appointed, shall personally interview the person who is intellectually disabled or person who is developmentally disabled and shall submit a written report to the court] that the respondent's presence would result in harm to such person.

5. If, upon conclusion of [such hearing or jury trial or if none be held upon the application] the proceeding, the court is satisfied [that the best interests of the person who is intellectually disabled or person who is developmentally disabled will be promoted by the appointment of a guardian of the person or property, or both, it shall make a decree naming such person or persons to serve as such guardians] based on clear and convincing evidence that the respondent is incapable of managing her or his affairs, it shall make a decree appointing a guardian provided that guardianship shall be imposed only if necessary and in the least restrictive manner specifically considering the respondent's functional abilities.

6. Where the court has determined that the respondent has certain decision-making capacity, the court shall appropriately limit the scope or duration of the guardianship it decrees.

§ 8. The surrogate's court procedure act is amended by adding a new section 1754-a to read as follows:

§ 1754-a. Decision-making standard

Decisions made by a guardian appointed hereunder shall be made in accordance with the following standards:

1. A guardian shall exercise authority only as necessary and shall encourage the person with a developmental disability or traumatic brain injury to participate in making decisions and to act on his or her own behalf.

2. A guardian shall consider the expressed desires and personal values of the person with a developmental disability or traumatic brain injury to the extent known when making decisions and shall consult such person.

3. If the person's wishes are unknown and remain unknown after reasonable efforts are made to discern them, the decision shall be made on the basis of the best interests of such person as determined by the guardian. In determining the best interests of such person, the guardian shall weigh the reason for and nature of the proposed action; the benefit or necessity of the action; the possible risks and other consequences of the proposed action; and any available alternatives and their risks, consequences and benefits. The guardian shall take into account any other information, including the views of family and friends that the guardian believes said person would have considered if able to act for herself or himself.

§ 9. Section 1755 of the surrogate's court procedure act is REPEALED and a new section 1755 is added to read as follows:

§ 1755. Duration, modification and revocation

1. Such guardianship shall remain in effect until modified or revoked by the court.

2. Any person for whom a guardian has been appointed pursuant to this article, or anyone, including the guardian, on behalf of such person may petition to the court to discharge the guardian and appoint a successor, to designate the guardian of the property as a limited guardian of the property, to appoint a spouse as stand-by guardian, or to otherwise modify or revoke the guardianship order. Upon such a petition, the court shall conduct a hearing and such review pursuant to section seventeen hundred fifty-four of this article. The court may modify or revoke an order if it deems that the circumstances or needs of the person with a developmental disability or traumatic brain injury have changed and the provisions of the order are no longer appropriate or necessary.

3. Any proceeding to modify or revoke a prior guardianship order may be brought in the surrogate's court which granted the prior order, unless at the time of the application to modify or revoke the order the person with a developmental disability or traumatic brain injury resides elsewhere, in which case the proceeding may be brought in the county where the person with a developmental disability or traumatic brain injury resides.

§ 10. Section 1756 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1756. Limited guardian of the property

When it shall appear to the satisfaction of the court that [such person who is intellectually disabled or person who is developmentally disabled for whom an application for guardianship is made is eighteen years of age or older and] the respondent is wholly or substantially self-supporting by means of [his or her] wages or earnings from employment, the court is authorized and empowered to appoint a limited guardian of the property of [such person who is intellectually disabled or

person who is developmentally disabled] the respondent who shall receive, manage, disburse and account for only such property of said person [who is intellectually disabled or person who is developmentally disabled] as shall be received from other than the wages or earnings of said person.

[The] Said person [who is intellectually disabled or person who is developmentally disabled] for whom a limited guardian of the property has been appointed shall have the right to receive and expend any and all wages or other earnings of [his or her] employment and shall have the power to contract or legally bind himself or herself for such sum of money not exceeding one month's wages or earnings from such employment or three hundred dollars, whichever is greater, or as otherwise authorized by the court.

§ 11. Section 1757 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1757. Standby guardian of a person [who is intellectually disabled or person who is developmentally disabled] with a developmental disability or traumatic brain injury

1. Upon application, a standby guardian of the person or property or both of a person [who is intellectually disabled or person who is developmentally disabled] with a developmental disability or traumatic brain injury may be appointed by the court. The court may also, upon application, appoint an alternate and/or successive alternates to such standby guardian, to act if such standby guardian shall die, or become incapacitated, or shall renounce. Such appointments by the court shall be made in accordance with the provisions of this article.

2. Such standby guardian, or alternate in the event of such standby guardian's death, incapacity or renunciation, shall without further

proceedings be empowered to assume the duties of [his or her] office immediately upon death, renunciation or adjudication of incompetency of the guardian or standby guardian appointed pursuant to this article, subject only to confirmation of [his or her] the appointment by the court within one hundred eighty days following assumption of [his or her] the standby or alternate guardian's duties of such office. Before confirming the appointment of the standby guardian or alternate guardian, the court may conduct a hearing pursuant to section seventeen hundred fifty-four of this article upon petition by anyone on behalf of the person [who is intellectually disabled or person who is developmentally disabled] with a developmental disability or traumatic brain injury or the person [who is intellectually disabled or person who is developmentally disabled if such person is eighteen years of age or older] with a developmental disability or traumatic brain injury, or upon its discretion.

3. Failure of a standby or alternate standby guardian to assume the duties of guardian, seek court confirmation or to renounce the guardianship within sixty days of written notice by certified mail or personal delivery given by or on behalf of the person [who is intellectually disabled or person who is developmentally disabled] with a developmental disability or traumatic brain injury of a prior guardian's inability to serve and the standby or alternate standby guardian's duty to serve, seek court confirmation or renounce such role shall allow the court to:

(a) deem the failure an implied renunciation of guardianship, and

(b) authorize, notwithstanding the time period provided for in subdivision two of this section to seek court confirmation, any remaining standby or alternate standby guardian to serve in such capacity provided (i) an application for confirmation and appropriate notices pursuant to

subdivision one of section seventeen hundred fifty-three of this article are filed, or (ii) an application for modification of the guardianship order pursuant to section seventeen hundred fifty-five of this article is filed.

§ 12. Subdivision 2 of section 1758 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

2. After the appointment of a guardian, standby guardian or alternate guardians, the court shall have and retain general jurisdiction over the person [who is intellectually disabled or person who is developmentally disabled] with a developmental disability or traumatic brain injury for whom such guardian shall have been appointed, to take of its own motion or to entertain and adjudicate such steps and proceedings relating to such guardian, standby, or alternate guardianship as may be deemed necessary or proper for the welfare of such person [who is intellectually disabled or person who is developmentally disabled].

§ 13. Section 1759 of the surrogate's court procedure act is REPEALED.

§ 14. Section 1760 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1760. Corporate guardianship

No corporation may be appointed guardian of the person under the provisions of this article, except that a non-profit corporation organized and existing under the laws of the state of New York and having the corporate power to so act [as guardian of a person who is intellectually disabled or person who is developmentally disabled may be appointed as the guardian of the person only of such person who is intellectually disabled or person who is developmentally disabled] may be appointed.

§ 15. Section 1761 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1761. Application of other provisions

To the extent that the context thereof shall admit, the provisions of article seventeen of this act shall apply to all proceedings under this article [with the same force and effect as if an "infant", as therein referred to, were a "person who is intellectually disabled" or "person who is developmentally disabled" as herein defined, and a "guardian" as therein referred to were a "guardian of the person who is intellectually disabled" or a "guardian of a person who is developmentally disabled" as herein provided for].

§ 16. This act shall take effect on the first of January next succeeding the date on which it shall have become a law.

OCA 2019-30

IN SUPPORT OF

S.

A.

AN ACT to amend the surrogate's court procedure act, in relation to guardians of persons who are intellectually and developmentally disabled

This is one in a series of measures being introduced at the request of the Chief Administrative Judge upon the recommendation of his Surrogate's Court Committee.

This measure would amend Article 17-A of the Surrogate's Court Procedure Act to better reflect the rights of individuals with developmental disabilities and traumatic brain injuries by removing obsolete language and addressing current legal standards of due process.

Article 17-A serves the vital purpose of ensuring that family members, or other individuals, interested in the welfare of persons who were born with intellectual disabilities or who suffered traumatic brain injuries at a young age, can be appointed guardians of the person and/or property in an inexpensive and generally more efficient manner than if they had to obtain such relief by proceeding under Article 81 of the Mental Hygiene Law.

Given the statute's significance, it is imperative that it be amended not only to modernize its clinical terminology to conform with current usage, but also to reflect today's medical knowledge regarding the capabilities of persons with intellectual disabilities. Additionally, it is critical that the statute be amended to more clearly define existing procedural requirements, while establishing new provisions that eliminate any perceived violations of due process alleged to exist under the current Federal or State statutory framework.

This measure ensures that a respondent will be represented by counsel with the right to a hearing or jury trial prior to the issuance of a guardianship order; imposes a "clear and convincing" standard as the burden of proof; and provides that a guardianship of the person will be imposed in the least restrictive means possible. In the same vein, the measure clarifies any ambiguity existing in the current statute regarding a court's authority to tailor a guardianship to specific areas of responsibility, as the evidence presented focuses on the respondent's functional abilities or limitations instead of on a simple diagnosis of a medical condition. In so doing, the amendment relieves petitioners of the burden of acquiring formulistic medical affidavits from health care providers.

Importantly, the new statutory scheme ensures that persons with intellectual disabilities may exercise the independence and self-determination of which they are capable by establishing

a new standard of guardianship decision making, which promotes self-reliance to the fullest extent possible.

Finally, this measure does not place any additional administrative burdens on Surrogate's Court personnel, while providing for the uniform application of Article 17-A throughout the State by clearly defining the proper procedural framework within which these proceedings must operate.

The following will summarize key provisions of this measure:

- Section 1750 is repealed, and a new section 1750 is added to set forth new definitions of developmental disability and traumatic brain injury.

- Section 1750-a is amended to establish that the court may grant guardianship of individuals with developmental disabilities and traumatic brain injuries pursuant to Article 17-A. This section also establishes a clear and convincing standard as the proof required and provides that a guardianship shall be imposed in the least restrictive manner considering the individual's functional abilities.

- Section 1750-b is amended to add new language setting forth its applicability to health care decisions for individuals with developmental disabilities or traumatic brain injuries.

- Section 1751 is amended to add new language and to add a new section pertaining to venue.

- Section 1752 is amended to add new language and sets forth additional requirements for the contents of the petition seeking guardianship. It adds new provisions requiring the petition to contain a statement regarding the nature and extent of the individual's functional abilities, and a statement of the alternatives to guardianship considered.

- Section 1753 is amended to add new requirements regarding service of process and notice. It requires the court to assign counsel for the respondent upon the issuance of a citation.

- Section 1754 is amended to reflect new language and provides that the court shall appoint the Mental Hygiene Legal Service or other counsel to represent the respondent. It would also provide the court with discretion to appoint a guardian *ad litem* for the respondent; and that counsel assignments shall be implemented for indigent persons as provided in section 407 of the SCPA.

- Section 1754-a is added to set forth a decision-making standard for guardians. It requires that a guardian shall encourage self-determination and follow the expressed desires and personal values of the individual and requires the guardian to consult with the individual. If the individual's wishes are unknown, the amended statute would require the guardian to make decisions based on the best interests of the individual.

- Section 1755 is repealed, and a new section 1755 is added to set forth guidelines for the duration, modification and revocation of guardianship, and to set forth provisions for venue of proceedings to modify or revoke a guardianship.

- Sections 1756, 1757, 1758, 1760 and 1761 are amended to add new language; and section 1759 is repealed.

This measure, which would have no fiscal impact, would take effect January first after becoming law.

Legislative History: None. New proposal.

An act to amend the surrogate's court procedure act in relation to guardianship for individuals with developmental disabilities.

The People of the State of New York, represented in the Senate and Assembly, do enact as follows:

Section 1. Section 1750 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1750. POWER ~~Guardianship of persons who are intellectually disabled.~~. When it shall appear to the satisfaction of the court that ~~a person~~ AN INDIVIDUAL WITH A DEVELOPMENTAL DISABILITY is a person ~~who is~~ IN NEED OF A GUARDIAN AS DETERMINED BY THE COURT IN ACCORDANCE WITH THE STANDARD SET FORTH IN SECTION 1756 ~~intellectually disabled~~, the court is authorized to appoint a guardian of the person or of the property or of both. ~~if such appointment of a guardian or guardian is in the best interest of the mentally retarded person.~~ NEITHER THE ALLEGED DEVELOPMENTAL DISABILITY NOR THE AGE OF THE INDIVIDUAL ALLEGED TO HAVE A DEVELOPMENTAL DISABILITY CAN BE THE SOLE BASIS FOR THE APPOINTMENT OF A GUARDIAN. THE APPOINTMENT OF A GUARDIAN SHALL BE DESIGNED TO ENCOURAGE THE DEVELOPMENT OF MAXIMUM SELF-RELIANCE AND INDEPENDENCE IN THE INDIVIDUAL. THE APPOINTMENT SHALL BE ORDERED ONLY AS A LAST RESORT AND ONLY TO THE EXTENT A GUARDIAN IS NEEDED BECAUSE OF THE ACTUAL IMPAIRMENT OF AN INDIVIDUAL'S GENERAL OR SPECIFIC AREAS OF INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS WHEN EITHER 1) THE INDIVIDUAL CONSENTS TO THE APPOINTMENT OF THE GUARDIAN, OR 2) THERE IS CLEAR AND CONVINCING EVIDENCE THAT THE INDIVIDUAL IS LIKELY TO SUFFER HARM BECAUSE THEY ARE UNABLE TO PROVIDE FOR PERSONAL NEEDS AND/OR PROPERTY MANAGEMENT, AND CANNOT ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND CONSEQUENCES OF SUCH INABILITY EVEN WITH APPROPRIATE SUPPORTIVE SERVICES, TECHNOLOGICAL ASSISTANCE, OR SUPPORTED DECISION MAKING THAT ALLOWS THEM TO EXERCISE THEIR LEGAL CAPACITY. ~~Such appointment shall be made pursuant to the provisions of this article; provided however that the provisions of section seventeen hundred fifty-a of this article shall not apply to the appointment of a guardian or guardians of a mentally retarded person. 1. For the purposes of this article, a mentally retarded person is a person who has been certified by one licensed physician and one licensed psychologist, or by two licensed physicians at least one of whom is familiar with or has professional knowledge in the care and treatment of persons with mental retardation, having qualifications to make such certification, as being incapable to manage him or herself and/or his or her affairs by reason of mental retardation and that such condition is permanent in nature or likely to continue indefinitely. 2. Every such certification pursuant to subdivision one of this section, made on or after the effective date of this subdivision, shall include a specific determination by such physician and psychologist, or by such physicians, as to whether the mentally retarded person has the capacity to make health care~~

~~decisions, as defined by subdivision three of section twenty-nine hundred eighty of the public health law, for himself or herself. A determination that the mentally retarded person has the capacity to make health care decisions shall not preclude the appointment of a guardian pursuant to this section to make other decisions on behalf of the mentally retarded person. The absence of this determination in the case of guardians appointed prior to the effective date of this subdivision shall not preclude such guardians from making health care decisions.~~

§ 2. Section 1750-a of the surrogate's court procedure act is REPEALED.

§ 3. Section 1750-b of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is amended to read as follows:

§ 1750-b. Health care decisions for persons ~~who are intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY

1. Scope of authority. Unless specifically prohibited by the court after consideration of the determination, if any, regarding ~~a person who is intellectually disabled's~~ capacity OF A PERSON ALLEGED TO HAVE A DEVELOPMENTAL DISABILITY to make health care decisions, ~~which is required by section seventeen hundred fifty of this article,~~ the guardian of such person appointed pursuant to ~~section seventeen hundred fifty of~~ this article shall have the authority to make any and all health care decisions, as defined by subdivision six of section twenty-nine hundred eighty of the public health law, on behalf of ~~the~~ SUCH person ~~who is intellectually disabled~~ that such person could make if such person had capacity. Such decisions may include decisions to withhold or withdraw life-sustaining treatment. For purposes of this section, "life-sustaining treatment" means medical treatment, including cardiopulmonary resuscitation and nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period. Cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician. The provisions of this article are not intended to permit or promote suicide, assisted suicide or euthanasia; accordingly, nothing in this section shall be construed to permit a guardian to consent to any act or omission to which ~~the~~ SUCH person ~~who is intellectually disabled~~ could not consent if such person had capacity.

(a) For the purposes of making a decision to withhold or withdraw life-sustaining treatment pursuant to this section, in the case of a person for whom no guardian has been appointed pursuant to ~~section seventeen hundred fifty or seventeen hundred fifty-a of~~ this article, a "guardian" shall also mean a family member of a person who (i) has intellectual disability, or (ii) has a developmental disability, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability. Qualified family members shall be included in a prioritized list of said family members pursuant to regulations established by the commissioner of the office for people with developmental disabilities. Such family members must have a significant and ongoing involvement in a person's life so as to have sufficient knowledge of their needs and, when reasonably known or ascertainable, the person's wishes, including moral and religious beliefs. In the case of a person who was a resident of the former Willowbrook state school on March seventeenth, nineteen hundred seventy-two and those

individuals who were in community care status on that date and subsequently returned to Willowbrook or a related facility, who are fully represented by the consumer advisory board and who have no guardians appointed pursuant to this article or have no qualified family members to make such a decision, then a "guardian" shall also mean the Willowbrook consumer advisory board. A decision of such family member or the Willowbrook consumer advisory board to withhold or withdraw life-sustaining treatment shall be subject to all of the protections, procedures and safeguards which apply to the decision of a guardian to withhold or withdraw life-sustaining treatment pursuant to this section.

In the case of a person for whom no guardian has been appointed pursuant to this article or for whom there is no qualified family member or the Willowbrook consumer advisory board available to make such a decision, a "guardian" shall also mean, notwithstanding the definitions in section 80.03 of the mental hygiene law, a surrogate decision-making committee, as defined in article eighty of the mental hygiene law. All declarations and procedures, including expedited procedures, to comply with this section shall be established by regulations promulgated by the ~~commission on quality of care and advocacy for persons with disabilities~~ JUSTICE CENTER FOR THE PROTECTION OF PEOPLE WITH SPECIAL NEEDS, AS ESTABLISHED BY ARTICLE TWENTY OF THE EXECUTIVE LAW.

(b) Regulations establishing the prioritized list of qualified family members required by paragraph (a) of this subdivision shall be developed by the commissioner of the office for people with developmental disabilities in conjunction with parents, advocates and family members of persons ~~who are intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY. Regulations to implement the authority of the Willowbrook consumer advisory board pursuant to paragraph (a) of this subdivision may be promulgated by the commissioner of the office for people with developmental disabilities with advice from the Willowbrook consumer advisory board.

(c) Notwithstanding any provision of law to the contrary, the formal determinations required pursuant to section seventeen hundred fifty-SIX of this article shall only apply to guardians appointed pursuant to section seventeen hundred fifty ~~or seventeen hundred fifty-a~~ of this article.

2. Decision-making standard. (a) The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY and, when reasonably known or ascertainable with reasonable diligence, on the WISHES OF THE person ~~who is intellectually disabled's wishes~~ WITH A DEVELOPMENTAL DISABILITY, including moral and religious beliefs.

(b) An assessment of the BEST INTERESTS OF THE person WITH A DEVELOPMENTAL DISABILITY ~~who is intellectually disabled's best interests~~ shall include consideration of:

(i) the dignity and uniqueness of every person;

(ii) the preservation, improvement or restoration of the HEALTH OF THE person ~~who is intellectually disabled's health~~ WITH A DEVELOPMENTAL DISABILITY;

(iii) the relief of the SUFFERING OF THE person ~~who is intellectually disabled's suffering~~ WITH A DEVELOPMENTAL DISABILITY by means of palliative care and pain management;

(iv) the unique nature of artificially provided nutrition or hydration, and the effect it may have on the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY; and

(v) the entire medical condition of the person.

(c) No health care decision shall be influenced in any way by:

(i) a presumption that persons ~~who are intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY are not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to persons without ~~an intellectual disability or~~ a developmental disability; or

(ii) financial considerations of the guardian, as such considerations affect the guardian, a health care provider or any other party.

3. Right to receive information. Subject to the provisions of sections 33.13 and 33.16 of the mental hygiene law, the guardian shall have the right to receive all medical information and medical and clinical records necessary to make informed decisions regarding the HEALTH CARE OF A person ~~who is intellectually disabled's health care~~ WITH A DEVELOPMENTAL DISABILITY.

4. Life-sustaining treatment. The guardian shall have the affirmative obligation to advocate for the full and efficacious provision of health care, including life-sustaining treatment. In the event that a guardian makes a decision to withdraw or withhold life-sustaining treatment from a person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY:

(a) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, must confirm to a reasonable degree of medical certainty that the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY lacks capacity to make health care decisions. The determination thereof shall be included in the MEDICAL RECORD OF THE person ~~who is intellectually disabled's medical record~~ WITH A DEVELOPMENTAL DISABILITY, and shall contain such attending physician's opinion regarding the cause and nature of the LACK OF CAPACITY OF A person ~~who is intellectually disabled's incapacity~~ WITH A DEVELOPMENTAL DISABILITY as well as its extent and probable duration. The attending physician who makes the confirmation shall consult with another physician, or a licensed psychologist, to further confirm the LACK OF CAPACITY OF THE person ~~who is intellectually disabled's lack of capacity~~ WITH A DEVELOPMENTAL DISABILITY. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, must (i) be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or (ii) have been employed for a minimum of two years to render care and service in a facility or program operated, licensed or authorized by the office for people with developmental disabilities, or (iii) have been approved by the commissioner of the office for people with developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three-years experience in treating intellectual disability. A record of such consultation shall be included in the MEDICAL RECORD OF THE person WITH A DEVELOPMENTAL DISABILITY ~~who is intellectually disabled's medical record~~.

(b) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, with the concurrence of another physician with whom such attending physician shall consult, must determine to a reasonable degree of medical certainty and note on the CHART OF THE person ~~who is intellectually disabled's chart~~ WITH A DEVELOPMENTAL DISABILITY that:

(i) the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY has a medical condition as follows:

A. a terminal condition, as defined in subdivision twenty-three of section twenty-nine hundred sixty-one of the public health law; or
B. permanent unconsciousness; or
C. a medical condition other than THE DEVELOPMENTAL DISABILITY OF such ~~person's intellectual disability~~ which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and
(ii) the life-sustaining treatment would impose an extraordinary burden on such person, in light of:
A. such person's medical condition, other than THE DEVELOPMENTAL DISABILITY OF such person~~'s intellectual disability~~; and
B. the expected outcome of the life-sustaining treatment, notwithstanding THE DEVELOPMENTAL DISABILITY OF such person~~'s intellectual disability~~; and
(iii) in the case of a decision to withdraw or withhold artificially provided nutrition or hydration:
A. there is no reasonable hope of maintaining life; or
B. the artificially provided nutrition or hydration poses an extraordinary burden.
(c) The guardian shall express a decision to withhold or withdraw life-sustaining treatment either:
(i) in writing, dated and signed in the presence of one witness eighteen years of age or older who shall sign the decision, and presented to the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or
(ii) orally, to two persons eighteen years of age or older, at least one of whom is the ATTENDING PHYSICIAN OF THE person ~~who is intellectually disabled's attending physician~~ WITH A DEVELOPMENTAL DISABILITY, as defined in subdivision two of section twenty-nine hundred eighty of the public health law.
(d) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, who is provided with the decision of a guardian shall include the decision in the MEDICAL CHART OF THE person ~~who is intellectually disabled's medical chart~~ WITH A DEVELOPMENTAL DISABILITY, and shall either:
(i) promptly issue an order to withhold or withdraw life-sustaining treatment from the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, and inform the staff responsible for such person's care, if any, of the order; or
(ii) promptly object to such decision, in accordance with subdivision five of this section.
(e) At least forty-eight hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining treatment, the attending physician shall notify:
(i) the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, except if the attending physician determines, in writing and in consultation with another physician or a licensed psychologist, that, to a reasonable degree of medical certainty, the person would suffer immediate and severe injury from such notification. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, shall:
A. be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or
B. have been employed for a minimum of two years to render care and service in a facility operated, licensed or authorized by the office for people with developmental disabilities, or

C. have been approved by the commissioner of the office for people with developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three years experience in treating intellectual disability. A record of such consultation shall be included in the person who is intellectually disabled's medical record;

(ii) if the person is in or was transferred from a residential facility operated, licensed or authorized by the office for people with developmental disabilities, the chief executive officer of the agency or organization operating such facility and the mental hygiene legal service; and

(iii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.

5. Objection to health care decision. (a) Suspension. A health care decision made pursuant to subdivision four of this section shall be suspended, pending judicial review, except if the suspension would in reasonable medical judgment be likely to result in the death of the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, in the event of an objection to that decision at any time by:

(i) the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY on whose behalf such decision was made; or

(ii) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY; or

(iii) the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or

(iv) any other health care practitioner providing services to the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, who is licensed pursuant to article one hundred thirty-one, one hundred thirty-one-B, one hundred thirty-two, one hundred thirty-three, one hundred thirty-six, one hundred thirty-nine, one hundred forty-one, one hundred forty-three, one hundred forty-four, one hundred fifty-three, one hundred fifty-four, one hundred fifty-six, one hundred fifty-nine or one hundred sixty-four of the education law; or

(v) the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section; or

(vi) if the person is in or was transferred from a residential facility or program operated, approved or licensed by the office for people with developmental disabilities, the mental hygiene legal service; or

(vii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.

(b) Form of objection. Such objection shall occur orally or in writing.

(c) Notification. In the event of the suspension of a health care decision pursuant to this subdivision, the objecting party shall promptly notify the guardian and the other parties identified in paragraph (a) of this subdivision, and the attending physician shall record such suspension in the MEDICAL CHART OF THE person WITH THE DEVELOPMENTAL DISABILITY ~~who is intellectually disabled's medical chart~~.

(d) Dispute mediation. In the event of an objection pursuant to this subdivision, at the request of the objecting party or person or entity authorized to act as a guardian under this section, except a surrogate decision making committee established pursuant to article eighty of the mental hygiene law, such objection shall be referred to a dispute mediation system, established pursuant to section two thousand nine hundred seventy-two of the public health law or similar entity for

mediating disputes in a hospice, such as a patient's advocate's office, hospital chaplain's office or ethics committee, as described in writing and adopted by the governing authority of such hospice, for non-binding mediation. In the event that such dispute cannot be resolved within seventy-two hours or no such mediation entity exists or is reasonably available for mediation of a dispute, the objection shall proceed to judicial review pursuant to this subdivision. The party requesting mediation shall provide notification to those parties entitled to notice pursuant to paragraph (a) of this subdivision.

6. Special proceeding authorized. The guardian, the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section, the mental hygiene legal service (if the person is in or was transferred from a residential facility or program operated, approved or licensed by the office for people with developmental disabilities) or the commissioner of the office for people with developmental disabilities or his or her designee (if the person is not in and was not transferred from such a facility or program) may commence a special proceeding in a court of competent jurisdiction with respect to any dispute arising under this section, including objecting to the withdrawal or withholding of life-sustaining treatment because such withdrawal or withholding is not in accord with the criteria set forth in this section.

7. Provider's obligations. (a) A health care provider shall comply with the health care decisions made by a guardian in good faith pursuant to this section, to the same extent as if such decisions had been made by the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, if such person had capacity.

(b) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require a private hospital to honor a guardian's health care decision that the hospital would not honor if the decision had been made by the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, if such person had capacity, because the decision is contrary to a formally adopted written policy of the hospital expressly based on religious beliefs or sincerely held moral convictions central to the hospital's operating principles, and the hospital would be permitted by law to refuse to honor the decision if made by such person, provided:

(i) the hospital has informed the guardian of such policy prior to or upon admission, if reasonably possible; and

(ii) the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY is transferred promptly to another hospital that is reasonably accessible under the circumstances and is willing to honor the guardian's decision. If the guardian is unable or unwilling to arrange such a transfer, the hospital's refusal to honor the decision of the guardian shall constitute an objection pursuant to subdivision five of this section.

(c) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require an individual health care provider to honor a guardian's health care decision that the individual would not honor if the decision had been made by the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, if such person had capacity, because the decision is contrary to the individual's religious beliefs or sincerely held moral convictions, provided the individual health care provider promptly informs the guardian and the facility, if any, of his or her refusal to honor the guardian's decision. In such event, the facility shall promptly transfer responsibility for the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY to another individual health care provider willing to honor

the guardian's decision. The individual health care provider shall cooperate in facilitating such transfer of the patient.

(d) Notwithstanding the provisions of any other paragraph of this subdivision, if a guardian directs the provision of life-sustaining treatment, the denial of which in reasonable medical judgment would be likely to result in the death of the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY, a hospital or individual health care provider that does not wish to provide such treatment shall nonetheless comply with the guardian's decision pending either transfer of the person ~~who is intellectually disabled~~ WITH A DEVELOPMENTAL DISABILITY to a willing hospital or individual health care provider, or judicial review.

(e) Nothing in this section shall affect or diminish the authority of a surrogate decision-making panel to render decisions regarding major medical treatment pursuant to article eighty of the mental hygiene law.

8. Immunity. (a) Provider immunity. No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring reasonably and in good faith a health care decision by a guardian, or for other actions taken reasonably and in good faith pursuant to this section.

(b) Guardian immunity. No guardian shall be subjected to criminal or civil liability for making a health care decision reasonably and in good faith pursuant to this section.

§ 4. Article 17A of the surrogate's court procedure act is amended by adding a new section 1751 to read as follows:

§ 1751. DEFINITIONS

WHEN USED IN THIS ARTICLE,

(1) "ADAPTIVE BEHAVIOR" SHALL MEAN THE COLLECTION OF CONCEPTURAL, SOCIAL AND PRACTICAL SKILLS LEARNED BY INDIVIDUALS TO ENABLE THEM TO FUNCTION IN THEIR EVERYDAY LIVES.

(2) "AVAILABLE RESOURCES AND ALTERNATIVES TO GUARDIANSHIP" SHALL MEAN EXISTING HEALTH CARE AND OTHER SURROGATE DECISIONMAKING STATUTES AND REGULATIONS, AND RESOURCES, SUPPORTS, AND ALTERNATIVES, SUCH AS, BUT NOT LIMITED TO, HEALTH CARE PROXY, JOINT BANK ACCOUNT, POWER OF ATTORNEY, REPRESENTATIVE PAYEE, SPECIAL NEEDS TRUSTS, HEALTH CARE SURROGATE DECISIONMAKING COMMITTEE, CASE MANAGEMENT SERVICES, DAY SERVICES, IN-HOME CARE SERVICES, MONEY MANAGEMENT PROGRAMS, CARE COORDINATION, SOCIAL SUPPORTS, SERVICES AND NETWORKS, SUPPORTED DECISION MAKING, AND AVAILABLE SHARED DECISION MAKING.

(3) "DEVELOPMENTAL DISABILITY" SHALL MEAN A DEVELOPMENTAL DISABILITY WITHIN THE MEANING OF SUBDIVISION TWENTY-TWO OF SECTION 1.03 OF THE MENTAL HYGIENE LAW.

(4) “FUNCTIONAL LEVEL” SHALL MEAN THE MEASUREMENT OF THE ABILITY TO LIVE INDEPENDENTLY, PROVIDE FOR PERSONAL NEEDS, FUNCTION SAFELY, AND/OR THE ABILITY TO MANAGE PROPERTY, WITH APPROPRIATE SUPPORTIVE SERVICES, TECHNOLOGICAL ASSISTANCE, OR SUPPORTED DECISIONMAKING.

(5) “FUNCTIONAL LIMITATIONS” SHALL MEAN BEHAVIOR OR CONDITIONS OF A PERSON WHICH IMPAIR THE ABILITY TO LIVE INDEPENDENTLY, PROVIDE FOR PERSONAL NEEDS, FUNCTION SAFELY, AND/OR THE ABILITY TO MANAGE PROPERTY, EVEN WITH APPROPRIATE SUPPORTIVE SERVICES, TECHNOLOGICAL ASSISTANCE, OR SUPPORTED DECISIONMAKING.

(6) “DEVELOPMENTAL DISABILITY INDIVIDUAL SUPPORT AND CARE COORDINATION ORGANIZATION” SHALL MEAN AN ENTITY THAT HAS RECEIVED A CERTIFICATE OF AUTHORITY PURSUANT TO THE PUBLIC HEALTH LAW TO PROVIDE, OR ARRANGE FOR, HEALTH AND LONG TERM CARE SERVICES, AS DETERMINED BY THE COMMISSIONER AND THE COMMISSIONER OF THE OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES.

(7) "PERSONAL NEEDS" SHALL MEAN NEEDS SUCH AS, BUT NOT LIMITED TO, FOOD, CLOTHING, SHELTER, HEALTH CARE, AND SAFETY.

(8) "PROPERTY MANAGEMENT" SHALL MEAN TAKING ACTIONS TO OBTAIN, ADMINISTER, PROTECT, AND DISPOSE OF REAL AND PERSONAL PROPERTY, INTANGIBLE PROPERTY, BUSINESS PROPERTY, BENEFITS, AND INCOME, AND TO DEAL WITH FINANCIAL AFFAIRS.

(9) “RESPONDENT” SHALL MEAN THE INDIVIDUAL WHO IS ALLEGED TO HAVE A DEVELOPMENTAL DISABILITY.

(10) “SUPPORTED DECISION MAKING” SHALL MEAN ASSISTANCE FROM ONE OR MORE PERSONS OF AN INDIVIDUAL’S CHOOSING IN UNDERSTANDING THE NATURE AND CONSEQUENCES OF POTENTIAL PERSONAL AND FINANCIAL DECISIONS, WHICH ENABLE THE INDIVIDUAL TO MAKE DECISIONS, AND IN COMMUNICATING A DECISION ONCE MADE IF CONSISTENT WITH AN INDIVIDUAL’S WISHES.

§ 5. Section 1751 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1752 and amended to read as follows:

§ ~~1751~~ 1752. Petition for appointment; by whom made. A petition for the appointment of a guardian of the person or property, or both, of ~~a person who is intellectually disabled or a person who is developmentally disabled~~ THE RESPONDENT may be made by
(1) a parent, any interested person eighteen years of age or older on behalf of the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT including a corporation authorized to serve as a guardian as provided for by this article, or by,

(2) the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT when such person is eighteen years of age or older.

§ 6. Section 1752 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1753 and amended to read as follows:

§ ~~1752~~ 1753. Petition for appointment; contents.
The petition for the appointment of a guardian shall be filed with the court on forms to be prescribed by the state chief administrator of the courts. Such petition for a guardian of a person who is ~~intellectually disabled or a person who is developmentally disabledmentally~~ ALLEGED TO HAVE A DEVELOPMENTAL DISABILITY shall include, but not be limited to, the following information:

1. the full name, date of birth and residence of the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT;

2. A STATEMENT THAT THE RESPONDENT HAS A DEVELOPMENTAL DISABILITY; THE NATURE AND EXTENT OF THE DISABILITY AND THE AGE AT WHICH THE DISABILITY ORIGINATED;

~~2~~.3. the name, age, address, and relationship or interest of the petitioner to the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT;

~~3~~. 4. the names of the father, the mother, children, adult siblings ~~if eighteen years of age or older~~, the spouse ~~and primary care physician if other than a physician having submitted a certification with the petition~~, if any, of the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT and, whether or not they are living, and if living, their addresses and, IF BOTH PARENTS ARE DEAD, the names and addresses of the nearest distributees of full age who are domiciliaries ~~if both parents are dead~~;

~~4~~.5. the name and address of the person with whom the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT resides ~~if other than the parents or spouse~~;

6. THE NAME AND ADDRESS OF THE DEVELOPMENTAL DISABILITY INDIVIDUAL SUPPORT AND CARE COORDINATION ORGANIZATION AND ANY OTHER PERSONS PROVIDING SERVICES RELATED TO THE ALLEGED DEVELOPMENTAL DISABILITY OF THE RESPONDENT, OR ARRANGING FOR THE PROVISION OF SUCH SERVICES TO THE RESPONDENT, IF SUCH PERSONS ARE KNOWN TO THE PETITIONER;

~~5.~~ 7. the name, age, address, education and other qualifications, and consent of the proposed guardian, standby and alternate guardian, if other than the parent, spouse, adult child ~~if eighteen years of age or older~~ or adult sibling ~~if eighteen years of age or older~~, and if such parent, spouse, or adult child, OR ADULT SIBLING be living, why any of them should not be appointed guardian;

~~6.~~ 8. the estimated value of real and personal property and the annual income therefrom and any other income including governmental entitlements to which ~~the person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT is entitled; ~~and~~

~~7. any circumstances which the court should consider in determining whether it is in the best interests of the mentally retarded or developmentally disabled person not be be present at the hearing if conducted;~~

9. A DESCRIPTION OF THE RESPONDENT'S FUNCTIONAL LEVEL, ADAPTIVE BEHAVIORS, AND FUNCTIONAL LIMITATIONS INCLUDING THE RESPONDENT'S ABILITY TO MANAGE THE ACTIVITIES OF DAILY LIVING, AND ANY SUPPORTIVE SERVICES, TECHNOLOGICAL ASSISTANCE OR SUPPORTED DECISION MAKING THE INDIVIDUAL USES;

10. A STATEMENT OF THE AVAILABLE RESOURCES AND ALTERNATIVES TO GUARDIANSHIP WHICH HAVE BEEN CONSIDERED OR IMPLEMENTED BY THE PETITIONER, AND IF THEY HAVE NOT BEEN CONSIDERED OR IMPLEMENTED, THE REASON THEY HAVE NOT BEEN CONSIDERED OR IMPLEMENTED;

11. THE PARTICULAR POWERS BEING SOUGHT, THEIR RELATIONSHIP TO THE FUNCTIONAL LEVEL, ADAPTIVE BEHAVIORS, AND FUNCTIONAL LIMITATIONS DESCRIBED IN PARAGRAPH NINE, AND DURATION OF THE POWERS BEING SOUGHT;

12. THE APPROXIMATE VALUE AND DESCRIPTION OF THE PROPERTY AND FINANCIAL RESOURCES OF THE RESPONDENT, TO THE BEST OF THE PETITIONER'S KNOWLEDGE;

13. THE NATURE AND AMOUNT OF ANY CLAIM, DEBT, OR OBLIGATIONS OF THE RESPONDENT, TO THE BEST OF THE PETITIONER'S KNOWLEDGE**;**

14. AN EXPLANATION OF THE REASONS WHY THE FORM OF GUARDIANSHIP SOUGHT IS THE LEAST RESTRICTIVE RELIEF WHICH WILL MEET THE NEEDS OF THE RESPONDENT;

15. ANY OTHER INFORMATION WHICH THE PETITIONER ALLEGES WILL ASSIST THE COURT.

§ 7. Section 1753 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1754 and amended to read as follows:

§ ~~1753.~~ 1754. Persons to be served AND NOTICE

1. Upon ~~presentation~~ FILING of the petition, process shall issue to:

(a) the parent or parents, adult children, ~~if the petitioner is other than a parent~~, adult siblings, ~~if the petitioner is other than a parent~~, and if the ~~the person who is intellectually disabled or a~~

~~person who is developmentally disabled~~ RESPONDENT is married, to the spouse, if their residences are known;
(b) the person ~~having care and custody of the person who is intellectually disabled or person who is developmentally disabled~~ with whom ~~such person~~ RESPONDENT resides if other than the parents or spouse; and
(c) the ~~person who is intellectually disabled or person who is developmentally disabled~~ RESPONDENT if fourteen years of age or older ~~for whom an application has been made in such person's behalf~~.
PROCESS ISSUED TO RESPONDENT SHALL INCLUDE A STATEMENT IN AN EASILY UNDERSTOOD FORM DEVELOPED BY THE OFFICE OF COURT ADMINISTRATION THAT STATES THE DATE, TIME, AND PLACE OF THE HEARING OF THE PETITION; THE RIGHTS OF THE RESPONDENT IN THE PROCEEDING, INCLUDING THE RIGHT TO BE PRESENT AT THE HEARING; THE RIGHT TO CONTEST THE PROCEEDING; THE RIGHT TO DESIGNATE IN WRITING A PERSON WHO SHOULD RECEIVE NOTICE OF THE PROCEEDING; THE RIGHT TO COUNSEL; THAT THE COURT IS APPOINTING MENTAL HYGIENE LEGAL SERVICE AS COUNSEL FOR THE RESPONDENT, INCLDUING THE NAME, ADDRESS AND TELEPHONE NUMBER OF THE PERSON APPOINTED AS COUNSEL; THAT IF PERSON RETAINS HIS OR HER OWN COUNSEL, THE COURT WILL EXCUSE MENTAL HYGIENE LEGAL SERVICE WHEN RESPONDENT'S RETAINED COUNSEL NOTIFIES THE COURT OF HIS OR HER APPEARANCE.
2. Upon FILING ~~presentation~~ of the petition, notice of such petition shall be served by certified mail to:
(a) ~~the adult siblings if the petitioner is a parent, and adult children if the petitioner is a parent;~~
~~(b)~~ the mental hygiene legal service in the judicial department where ~~the facility, as defined in subdivision (a) of section 47.01 of the mental hygiene law, is located if the person who is intellectually disabled or person who is developmentally disabled~~ THE RESPONDENT resides ~~in such a facility~~.
~~(c)~~ (b) ~~in all cases, to~~ the director in charge of a facility AS DEFINED IN SECTION 47.01 OF THE MENTAL HYGIENE LAW, if the ~~person who is intellectually disabled or a person who is developmentally disabled~~ RESPONDENT resides in such facility; ~~(d)~~
(c) THE DEVELOPMENTAL DISABILITY INDIVIDUAL SUPPORT AND CARE COORDINATION ORGANIZATION AND ANY OTHER PERSONS PROVIDING SERVICES TO THE RESPONDENT;
(d) one other person ~~if~~ designated in writing by the ~~person who is intellectually disabled or person who is developmentally disabled~~ RESPONDENT; and
(e) such other persons as the court may deem proper.

3. No process or notice shall be necessary to a parent, adult child, adult sibling, or spouse of the ~~person who is intellectually disabled or person who is developmentally disabled~~ RESPONDENT who has been declared by a court as being incompetent; ~~In addition, no process or notice shall be necessary~~ to a spouse who is divorced from the ~~person who is intellectually disabled or person who is developmentally disabled~~ RESPONDENT; and to a parent, adult child, adult sibling when it shall appear to the satisfaction of the court that such person or persons have abandoned the ~~person who is intellectually disabled or person who is developmentally disabled~~ RESPONDENT.

§ 8. Article 17A of the surrogate's court procedure act is amended by adding a new section 1755 to read as follows:

§ 1755. COUNSEL; GUARDIAN AD LITEM

1. THE RESPONDENT SHALL BE ENTITLED TO BE REPRESENTED BY LEGAL COUNSEL. THE COURT SHALL APPOINT AS COUNSEL THE MENTAL HYGIENE LEGAL SERVICE. IF THE COURT DETERMINES THAT MENTAL HYGIENE LEGAL SERVICE CANNOT ACCEPT AN APPOINTMENT BECAUSE OF A CONFLICT OF INTEREST, THE COURT SHALL APPOINT AN ATTORNEY WITH APPROPRIATE EXPERTISE ELIGIBLE FOR APPOINTMENT PURSUANT TO SECTION THIRTY-FIVE OF THE JUDICIARY LAW. IN THE EVENT THAT THE COURT DETERMINES THAT THE RESPONDENT HAS RETAINED COUNSEL, THE COURT SHALL SUBSTITUTE RETAINED COUNSEL FOR APPOINTED COUNSEL UPON THE COURT'S DETERMINATION THAT RETAINED COUNSEL HAS BEEN CHOSEN FREELY AND INDEPENDENTLY BY THE RESPONDENT. THE COURT APPOINTED COUNSEL SHALL BE AT NO COST TO THE PETITIONER OR RESPONDENT. COUNSEL FOR THE RESPONDENT SHALL BE PROVIDED WITH COPIES OF THE PETITION AND THE SERVICE OF PROCESS AND NOTICE COMPLETED PURSUANT TO SECTION SEVENTEEN FIFTY-FOUR. COUNSEL SHALL BE AFFORDED ACCESS TO THE RESPONDENT'S CLINICAL RECORDS WITHOUT A COURT ORDER TO THE EXTENT ACCESS IS OTHERWISE AUTHORIZED BY STATE AND FEDERAL LAWS, AND MAY APPLY TO THE COURT FOR PERMISSION TO INSPECT THE CLINICAL RECORDS PERTAINING TO THE RESPONDENT IN ACCORDANCE WITH STATE AND FEDERAL LAWS. COUNSEL SHALL ADVOCATE FOR THE RESPONDENT'S EXPRESSED WISHES, IF KNOWN. IF THE RESPONDENT'S WISHES ARE NOT KNOWN AND CANNOT BE ASCERTAINED AFTER INVESTIGATION, COUNSEL SHALL SAFEGUARD THE RESPONDENT'S PROCEDURAL RIGHTS THROUGHOUT THE PROCEEDING TOWARD ACHIEVING THE LEAST RESTRICTIVE DISPOSITION CONSISTENT WITH THE RESPONDENT'S NEEDS.
2. THE COURT IN ITS DISCRETION MAY APPOINT A GUARDIAN AD LITEM AS PROVIDED IN ARTICLE FOUR OF THIS ACT.

§ 9. Section 1754 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1756 and amended to read as follows:

§ ~~1754~~. 1756. Hearing and trial; STANDARD OF APPOINTMENT OF A GUARDIAN; DISPOSITIONAL ALTERNATIVES.

1. Upon a petition for the appointment of a guardian ~~of a person who is intellectually disabled or person who is developmentally disabled~~ FOR A RESPONDENT eighteen years of age or older, the court shall conduct a hearing ON ANY CONTESTED ISSUE OF FACT at which such person shall have the right to jury trial AND THE RIGHT TO PRESENT EVIDENCE AND CONFRONT AND CROSS-EXAMINE WITNESSES. The right to a jury trial shall be deemed waived by failure to make a demand therefor. EXCEPT AS OTHERWISE PRESCRIBED BY LAW, ALLEGATIONS CONTAINED IN A PETITION, UNLESS DENIED BY ANSWER, OBJECTION OR OTHER PROOF, ARE DUE PROOF OF THE FACTS STATED THEREIN.

~~The court may in its discretion dispense with a hearing for the appointment of a guardian, and may in its discretion appoint a guardian ad litem, or the mental hygiene legal service if such person is a resident of a mental hygiene facility as defined in subdivision (a) of section 47.01 of the mental hygiene law, to recommend whether the appointment of a guardian as proposed in the application is in the best interest of the person who is intellectually disabled or a person who is developmentally disabled, provided however, that such application has been made by: (a) both parents or the survivor; or (b) one parent and the consent of the other parent; or (c) any interested party and the consent of each parent.~~

2. ~~When it shall appear to the satisfaction of the court that a parent or parents not joining in or consenting to the application have abandoned the person who is intellectually disabled or person who is developmentally disabled or are not otherwise required to receive notice, the court may dispense with such parent's consent in determining the need to conduct a hearing for a person under the age of eighteen. However, if the consent of both parents or the surviving parent is dispensed with by the court, a hearing shall be held on the application~~.

~~3. If a hearing is conducted, the person who is intellectually disabled or a person who is developmentally disabled shall be present unless it shall appear to the satisfaction of the court on the certification of the certifying~~ physician that the person who is intellectually disabled or ~~person who is developmentally disabled is medically incapable of being present to the extent that attendance is likely to result in physical harm to such person who is intellectually disabled or person who is developmentally disabled, or under such other circumstances which the court finds would not be in the best interest of the person who is intellectually disabled or person who is developmentally disabled~~ THE RESPONDENT SHALL BE PRESENT AT THE HEARING UNLESS SUCH PRESENCE IS EXCUSED BY THE COURT, TAKING INTO CONSIDERATION THE RECOMMENDATION OF RESPONDENT'S COUNSEL.

~~4. If either a hearing is dispensed with pursuant to subdivisions one and two of this section or the person who is intellectually disabled or person who is developmentally disabled is not present at the hearing pursuant to subdivision three of this section, the court may appoint a guardian ad litem if no mental hygiene legal service attorney is authorized to act on behalf of the person who is intellectually disabled or person who is developmentally disabled. The guardian ad litem or mental hygiene legal service attorney, if appointed, shall personally interview the person who is intellectually disabled or person who is developmentally disabled and shall submit a written report to the court. 5.~~

3.THE COURT, UPON THE PLEADINGS, OR AFTER A HEARING ON ANY CONTESTED ISSUES OF FACT, SHALL MAKE FINDINGS REGARDING:

(a) WHETHER THE RESPONDENT HAS A DEVELOPMENTAL DISABILITY;

(b) THE EXTENT OF THE FUNCTIONAL LEVEL, THE FUNCTIONAL LIMITATIONS AND THE LEVEL OF THE IMPAIRMENT IN THE RESPONDENT'S INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS;

(c) THE RESPONDENT'S LACK OF UNDERSTANDING AND APPRECIATION OF THE NATURE AND CONSEQUENCES OF THEIR FUNCTIONAL LIMITATIONS AND IMPAIRMENT IN INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS;

(d) THE SUFFICIENCY AND RELIABILITY OF AVAILABLE RESOURCES AND ALTERNATIVES TO GUARDIANSHIP;

(e) THE LIKELIHOOD THAT THE RESPONDENT WILL SUFFER HARM BECAUSE OF THE RESPONDENT'S FUNCTIONAL LIMITATIONS AND IMPAIRMENT IN INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS AND INABILITY TO ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND CONSEQUENCES OF SUCH FUNCTIONAL LIMITATIONS AND IMPAIRMENT;

(f) THE NECESSITY OF THE APPOINTMENT OF A GUARDIAN TO PREVENT SUCH HARM;

(g) THE SPECIFIC POWERS OF THE GUARDIAN WHICH CONSTITUTE THE LEAST RESTRICTIVE FORM OF INTERVENTION CONSISTENT WITH THE FINDINGS OF THIS SUBDIVISION.

4. (a) IF IT IS DETERMINED THAT THE RESPONDENT DOES NOT HAVE A DEVELOPMENTAL DISABILITY, THE COURT SHALL DISMISS THE PETITION.

(b) IF IT IS DETERMINED THAT THE RESPONDENT CAN PROVIDE FOR PERSONAL NEEDS AND/OR PROPERTY MANAGEMENT, THE COURT SHALL DISMISS THE PETITION.

(c) IF IT IS FOUND THAT THE RESPONDENT IS A PERSON WITH A DEVELOPMENTAL DISABILITY AND IT IS DETERMINED BY CLEAR AND CONVINCING EVIDENCE THAT RESPONDENT IS LIKELY TO SUFFER HARM BECAUSE OF THE RESPONDENT'S FUNCTIONAL LIMITATIONS AND IMPAIRMENT IN INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS AND INABILITY TO ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND CONSEQUENCES OF SUCH FUNCTIONAL LIMITATIONS AND IMPAIRMENTS, EVEN WITH THE SUPPORTS THEY MAY REQUIRE, THE COURT WITHOUT APPOINTING A GUARDIAN, MAY AUTHORIZE, DIRECT, OR RATIFY ANY TRANSACTION OR SERIES OF TRANSACTIONS NECESSARY TO ACHIEVE ANY SECURITY, SERVICE, OR CARE ARRANGEMENT MEETING THE FORESEEABLE NEEDS OF THE RESPONDENT, OR MAY AUTHORIZE, DIRECT, OR RATIFY ANY CONTRACT, TRUST, OR OTHER TRANSACTION RELATING TO THE RESPONDENT'S PROPERTY AND FINANCIAL AFFAIRS IF THE COURT DETERMINES THAT THE TRANSACTION IS NECESSARY AS A MEANS OF PROVIDING FOR PERSONAL NEEDS AND/OR PROPERTY MANAGEMENT FOR THE RESPONDENT. BEFORE APPROVING A PROTECTIVE ARRANGEMENT OR OTHER TRANSACTION UNDER THIS SUBDIVISION, THE COURT SHALL CONSIDER THE INTERESTS OF DEPENDENTS AND CREDITORS OF THE RESPONDENT, AND IN VIEW OF THE RESPONDENT'S FUNCTIONAL LEVEL, WHETHER THE RESPONDENT NEEDS THE CONTINUING PROTECTION OF A GUARDIAN. THE COURT MAY APPOINT A SPECIAL GUARDIAN TO ASSIST IN THE ACCOMPLISHMENT OF ANY PROTECTIVE ARRANGEMENT OR OTHER TRANSACTION AUTHORIZED UNDER THIS SUBDIVISION. THE SPECIAL GUARDIAN SHALL HAVE THE AUTHORITY CONFERRED BY THE ORDER OF APPOINTMENT, SHALL REPORT TO THE COURT ON ALL MATTERS DONE PURSUANT TO THE

ORDER OF APPOINTMENT, AND SHALL SERVE UNTIL DISCHARGED BY ORDER OF THE COURT.

(d) IF IT IS FOUND THAT RESPONDENT IS A PERSON WITH A DEVELOPMENTAL DISABILITY AND IT IS DETERMINED BY CLEAR AND CONVINCING EVIDENCE THAT THE RESPONDENT IS LIKELY TO SUFFER HARM BECAUSE THEY ARE UNABLE TO PROVIDE FOR SOME BUT NOT ALL OF THEIR PERSONAL NEEDS AND/OR PROPERTY MANAGEMENT AND CANNOT ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND CONSEQUENCES OF SUCH INABILITY, EVEN WITH THE SUPPORTS THEY MAY REQUIRE, THE COURT SHALL APPOINT A LIMITED GUARDIAN WITH AUTHORITY TAILORED TO ACT ON BEHALF OF THE RESPONDENT WITH RESPECT TO SPECIFIC FUNCTIONAL LIMITATIONS OF THE RESPONDENT, SHALL ESTABLISH THE DURATION OF THE GUARDIANSHIP, AND SHALL DISPOSE OF ANY REMAINING ISSUES IN THE PROCEEDING.

(e) IF IT IS FOUND THAT THE RESPONDENT IS A PERSON WITH A DEVELOPMENTAL DISABILITY AND IT IS DETERMINED BY CLEAR AND CONVINCING EVIDENCE THAT THE RESPONDENT IS LIKELY TO SUFFER HARM BECAUSE THEY ARE TOTALLY UNABLE TO PROVIDE FOR THEIR PERSONAL NEEDS AND/OR PROPERTY MANAGEMENT AND CANNOT ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND CONSEQUENCES OF SUCH INABILITY, EVEN WITH THE SUPPORTS THEY MAY REQUIRE, THE COURT SHALL APPOINT A PLENARY GUARDIAN OF THE PERSON OR OF THE ESTATE OR BOTH FOR THE RESPONDENT, SHALL ESTABLISH THE DURATION OF THE GUARDIANSHIP, AND SHALL DISPOSE OF ANY REMAINING ISSUES IN THE PROCEEDING.

(f) THE ORDER APPOINTING A GUARDIAN SHALL PROVIDE THAT THE MENTAL HYGIENE LEGAL SERVICE IN THE JUDICIAL DEPARTMENT WHERE THE RESPONDENT RESIDES, AND ALL PERSONS INDENTIFIED IN THE ORDER SHALL BE ENTITLED TO NOTICE OF ALL FURTHER PROCEEDINGS.

§ 10. Section 1755 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1757 and amended to read as follows:

§ ~~1755~~ 1757. REMOVAL, DISCHARGE OR Modification order.

(a) Any person ~~who is intellectually disabled or person who is developmentally disabled~~, eighteen years of age or older WITH A DEVELOPMENTAL DISABILITY FOR WHOM A GUARDIAN HAS BEEN APPOINTED BY THIS COURT, or any person on behalf of any person ~~who is intellectually disabled or person who is developmentall disabled~~ WITH A DEVELOPMENTAL DISABILITY for whom a guardian has been appointed BY THIS COURT, may apply to the court having jurisdiction over the guardianship ~~order~~ requesting REMOVAL OR DISCHARGE OF THE GUARDIAN OR modification of THE GUARDIANSHIP ORDER ~~such order in order to protect the person who is intellectually disabled's, or person who is developmentally disabled's financial situation and/or his or her~~

~~personal interests~~. A REQUEST FOR REMOVAL, DISCHARGE OR MODIFICATION UNDER THIS SECTION, IF MADE BY THE INDIVIDUAL FOR WHOM A GUARDIAN HAS BEEN APPOINTED, MAY BE COMMUNICATED TO THE COURT BY ANY MEANS, INCLUDING, BUT NOT LIMITED TO, ORAL COMMUNICATION OR LETTER.
(b)The court ~~may~~ SHALL, upon receipt of any such request to REMOVE OR DISCHARGE THE GUARDIAN, OR modify the guardianship order, appoint MENTAL HYGIENE LEGAL SERVICE AS COUNSEL FOR THE PERSON WITH A DEVELOPMENTAL DISABILITY UNLESS IT APPEARS TO THE COURT THAT THE PERSON WITH A DEVELOPMENTAL DISABILITY HAS RETAINED COUNSEL, AND IF THE REQUEST HAS BEEN MADE BY MEANS OTHER THAN A MOTION, REQUIRE COUNSEL TO PREPARE A WRITTEN MOTION FOR REMOVAL, DISCHARGE OR MODIFICATION TO BE SUBMITTED TO THE COURT**.** ~~a guardian ad litem. The court shall so modify the guardianship order if in its judgment the interests of the guardian are adverse to those of the person who is intellectually disabled or person who is developmentally disabled or if the interests of justice will be best served including, but not limited to, facts showing the necessity for protecting the personal and/or financial interests of the person who is intellectually disabled or person who is developmentally disabled~~
(c) THE COURT WHICH APPOINTED THE GUARDIAN SHALL REMOVE THE GUARDIAN WHEN THE GUARDIAN FAILS TO COMPLY WITH AN ORDER, IS GUILTY OF MISCONDUCT, OR FOR ANY OTHER CAUSE WHICH TO THE COURT SHALL APPEAR JUST.
(d) THE COURT WHICH APPOINTED THE GUARDIAN SHALL DISCHARGE THE GUARDIAN OR MODIFY THE POWERS OF THE GUARDIAN WHERE APPROPRIATE, IF IT APPEARS TO THE SATISFACTION OF THE COURT THAT:
(1) PERSON HAS BECOME ABLE TO EXERCISE SOME OR ALL OF THE POWERS NECESSARY TO PROVIDE FOR PERSONAL NEEDS OR PROPERTY MANAGEMENT WHICH THE GUARDIAN IS AUTHORIZED TO EXERCISE;
(2) THE PERSON HAS BECOME UNABLE TO EXERCISE POWERS NECESSARY TO PROVIDE FOR PERSONAL NEEDS OR PROPERTY MANAGEMENT WHICH THE GUARDIAN IS NOT AUTHORIZED TO EXERCISE;
(3) THE PERSON HAS DIED; OR
(4) FOR SOME OTHER REASON, THE APPOINTMENT OF THE GUARDIAN IS NO LONGER NECESSARY FOR THE PERSON WITH A DEVELOPMENTAL DISABILITY, OR THE POWERS OF THE GUARDIAN SHOULD BE MODIFIED BASED UPON CHANGES IN THE CIRCUMSTANCES OF THE PERSON.
(e) THE COURT SHALL CONDUCT A HEARING ON THE APPLICATION UPON NOTICE TO THE PERSONS ENTITLED TO NOTICE UNDER SUBDIVISION (f) OF SECTION 1756. THE COURT MAY FOR GOOD CAUSE SHOWN DISPENSE WITH THE HEARING PROVIDED THAT AN ORDER OF MODIFICATION INCREASING THE POWERS OF THE GUARDIAN SHALL SET FORTH THE FACTUAL BASIS FOR DISPENSING WITH THE HEARING. IF THE PERSON OR THEIR COUNSEL RAISES AN ISSUE OF FACT AS TO THE ABILITY OF THE PERSON TO PROVIDE FOR THEIR PERSONAL NEEDS OR PROPERTY MANAGEMENT AND DEMANDS A JURY TRIAL OF SUCH ISSUE, THE COURT SHALL ORDER A TRIAL BY JURY THEREOF.
(f). TO THE EXTENT THAT RELIEF SOUGHT UNDER THIS SECTION WOULD TERMINATE THE GUARDIANSHIP OR RESTORE CERTAIN POWERS TO THE PERSON

WITH A DEVELOPMENTAL DISABILITY THE BURDEN OF PROOF SHALL BE ON THE PERSON OBJECTING TO SUCH RELIEF. TO THE EXTENT THAT RELIEF SOUGHT UNDER THIS SECTION WOULD FURTHER LIMIT THE POWERS OF THE PERSON WITH A DEVELOPMENTAL DISABILITY, THE BURDEN OF PROOF SHALL BE ON THE PERSON SEEKING SUCH RELIEF.

(g). IF THE GUARDIAN IS DISCHARGED BECAUSE THE PERSON WITH A DEVELOPMENTAL DISABILITY BECOMES FULLY ABLE TO CARE FOR THEIR PROPERTY, THE COURT SHALL ORDER THAT THE PROPERTY REMAINING IN THE HANDS OF THE GUARDIAN BE RESTORED TO SUCH PERSON. IF THE PERSON WITH A DEVELOPMENTAL DISABILITY HAS DIED, THE GUARDIAN SHALL PROVIDE FOR SUCH PERSON'S BURIAL OR OTHER DISPOSITION THE COST OF WHICH SHALL BE BORNE BY THE ESTATE OF THE PERSON WITH A DEVELOPMENTAL DISABILITY.

§ 11. Section 1756 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is REPEALED.

§12. Section 1757 of the surrogate's court procedure act, as amended by chapter198 of the laws of 2016, is renumbered section 1758 and amended to read as follows:

§ ~~1757~~1758. Standby guardian of a ~~mentally retarded or developmentally disabled~~ person WITH A DEVELOPMENTAL DISABILITY

1. Upon application, a standby guardian of the person or property or both MAY BE APPOINTED BY THE COURT FOR a ~~mentally retarded or developmentally disabled~~ person WITH A DEVELOPMENTAL DISABILITY FOR WHOM A GUARDIAN HAS BEEN APPOINTED ~~may be appointed by the court~~. The court may also, upon application, appoint an alternate and/or successive alternates to such standby guardian, to act if such standby guardian shall die, or become incapacitated, or shall renounce. Such appointments by the court shall be made in accordance with the provisions of this article.

2. Such standby guardian, or alternate in the event of such standby guardian's death, incapacity or renunciation, shall without further proceedings be empowered to assume the duties of his or her office immediately upon death, renunciation or adjudication of ~~incompetency~~ INCAPACITY of the guardian or standby guardian appointed pursuant to this article, subject only to confirmation of his or her appointment by the court within one hundred eighty days following assumption of his or her duties of such office. Before confirming the appointment of the standby guardian or alternate guardian, the court may conduct a hearing pursuant to section seventeen hundred fifty-~~four~~ SIX of this article upon petition by anyone on behalf of the ~~mentally retarded or developmentally disabled~~ person WITH A DEVELOPMENTAL DISABILITY or the ~~mentally retarded or developmentally disabled~~ person WITH A DEVELOPMENTAL DISABILITY if such person is eighteen years of age or older, or upon its discretion.

§ 13. Section 1758 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1759 and amended to read as follows:

~~1758~~ 1759. Court jurisdiction, VENUE, AND JUDICIAL REVIEW OF GUARDIANSHIP APPOINTMENTS

1. A PROCEEDING UNDER THIS ARTICLE SHALL BE BROUGHT IN THE SURROGATE'S COURT IN THE COUNTY IN WHICH THE RESPONDENT RESIDES, OR IS PHYSICALLY PRESENT AT THE TIME THE PROCEEDING IS COMMENCED, SUBJECT TO AN APPLICATION TO CHANGE VENUE PURSUANT TO THIS SUBDIVISION.

2. After the appointment of a guardian, standby guardian or alternate guardians, the court shall have and retain general jurisdiction over the GUARDIAN AND THE ~~mentally retarded or developmentally disabled~~ person WITH A DEVELOPMENTAL DISABILITY for whom such guardian shall have been appointed, to take of its own motion or to entertain and adjudicate such steps and proceedings relating to such guardian, standby, or alternate guardianship as may be deemed necessary or proper for the welfare of such ~~mentally retarded or developmentally disabled~~ person. ANY PROCEEDING TO REMOVE OR DISCHARGE A GUARDIAN, OR TO MODIFY A PRIOR ORDER SHALL BE BROUGHT IN THE SURROGATE'S COURT WHICH APPOINTED THE GUARDIAN OR GRANTED THE PRIOR ORDER, UNLESS AT THE TIME OF THE APPLICATION, THE RESPONDENT RESIDES ELSEWHERE IN WHICH CASE THE PROCEEDING SHALL BE BROUGHT IN THE COUNTY WHERE THE RESPONDENT IS LOCATED, SUBJECT TO AN APPLICATION BY AN INTERESTED PARTY FOR A CHANGE IN VENUE TO THE COURT WHICH APPOINTED THE GUARDIAN OR GRANTED THE PRIOR ORDER BECAUSE OF THE INCONVENIENCE OF THE PARTIES OR WITNESSES OR THE CONDITION OF THE PERSON.

3. THE GUARDIANSHIP SHALL BE SUBJECT OF REVIEW BY MENTAL HYGIENE LEGAL SERVICE EVERY THREE YEARS AFTER THE APPOINTMENT OF THE GUARDIAN. THE COURT MAY, AT ANY TIME, ON ITS OWN MOTION OR UPON REQUEST BY MENTAL HYGIENE LEGAL SERVICE, OR ANY INTERESTED PERSON, TAKE APPROPRIATE ACTION REGARDING THE GUARDIANSHIP, INCLUDING, BUT NOT LIMITED TO, ORDERING A REVIEW OF THE GUARDIANSHIP.

§ 14. Article 17A of the surrogate's court procedure act is amended by adding a new section 1760 to read as follows:

§ 1760. DECISION MAKING STANDARD

DECISIONS MADE BY A GUARDIAN APPOINTED PURSUANT TO THIS ARTICLE SHALL BE MADE IN ACCORDANCE WITH THE FOLLOWING STANDARDS:

1. A GUARDIAN SHALL EXERCISE AUTHORITY ONLY AS NEEDED BECAUSE OF THE LIMITATIONS OF THE PERSON WITH A DEVELOPMENTAL DISABILITY, AND, TO THE EXTENT POSSIBLE, SHALL ENCOURAGE THE PERSON WITH A DEVELOPMENTAL DISABILITY TO PARTICIPATE IN DECISIONS AND TO ACT ON HIS OR HER OWN BEHALF.

2. A GUARDIAN SHALL ENCOURAGE THE PERSON WITH A DEVELOPMENTAL DISABILITY TO DEVELOP OR REGAIN TO THE MAXIMUM EXTENT POSSIBLE THE CAPACITY TO MEET HIS OR HER NEEDS.

3. A GUARDIAN SHALL CONSIDER THE EXPRESSED DESIRES AND PERSONAL VALUES OF THE PERSON WITH A DEVELOPMENTAL DISABILITY TO THE EXTENT KNOWN WHEN MAKING DECISIONS AND SHALL CONSULT WITH THE PERSON WITH A DEVELOPMENTAL DISABILITY WHENEVER MEANINGFUL COMMUNICATION IS POSSIBLE.

4. IF THE PERSON'S WISHES ARE UNKNOWN AND REMAIN UNKNOWN AFTER REASONABLE EFFORTS TO DISCERN THEM, THE DECISION SHALL BE MADE ON THE BASIS OF THE BEST INTERESTS OF THE PERSON WITH A DEVELOPMENTAL DISABILITY AS DETERMINED BY THE GUARDIAN. IN DETERMINING THE BEST INTERESTS OF THE PERSON WITH A DEVELOPMENTAL DISABILITY, THE GUARDIAN SHALL WEIGH THE REASON FOR, AND NATURE OF, THE PROPOSED ACTION, THE BENEFIT OR NECESSITY OF THE ACTION, THE POSSIBLE RISKS AND OTHER CONSEQUENCES OF THE PROPOSED ACTION, AND ANY AVAILABLE ALTERNATIVES AND THEIR RISKS, CONSEQUENCES, AND BENEFITS. THE GUARDIAN SHALL TAKE INTO ACCOUNT ANY OTHER INFORMATION, INCLUDING THE VIEWS OF FAMILY AND FRIENDS, THAT THE GUARDIAN BELIEVES THE PERSON WITH A DEVELOPMENTAL DISABILITY WOULD HAVE CONSIDERED IF ABLE TO ACT FOR HERSELF OR HIMSELF.

§ 15. Section 1759 of the surrogate's court procedure act is REPEALED.

§ 16. Section 1760 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1761 and amended to read as follows:

~~1760~~1761. Corporate guardianship

No corporation may be appointed guardian of the person under the provisions of this article, except that a non-profit corporation organized and existing under the laws of the state of New York and having the corporate power to act as guardian of THE PERSON OF A PERSON WITH A DEVELOPMENTAL DISABILITY, GUARDIAN OF THE PROPERTY OF ~~mentally retarded or developmentally disabled~~ persons WITH A DEVELOPMENTAL DISABILITY, OR BOTH, may be appointed as the guardian of the person OR THE PROPERTY OR BOTH ~~only of such mentally retarded or developmentally disabled person~~.

§ 17. Section 1761 of the surrogate's court procedure act, as amended by chapter 198 of the laws of 2016, is renumbered section 1764 and amended to read as follows:

§ ~~1761~~ 1762. Application of other provisions.

To the extent that the context thereof shall admit, the provisions of article seventeen of this act shall apply to all proceedings under this article ~~with the same force and affect as if an "infant", as therein referred to, were a "mentally retarded" or "developmentally disabled person" as herein defined, and a "guardian" as therein referred to were a "guardian of the mentally retarded person" or a "guardian of a developmentally disabled person" as herein provided for~~.

§ 18. THE MENTAL HYGIENE LEGAL SERVICE SHALL MAKE A REPORT TO THE LEGISLATURE AND THE GOVERNOR OF ITS FINDINGS, CONCLUSIONS, AND ANY RECOMMENDATIONS REGARDING THE IMPLEMENTATION OF THIS LEGISLATION NOT LATER THAN DECEMBER THIRTY-FIRST, TWO THOUSAND TWENTY-FOUR.

§ 19. (a) CONTINUATION OF GUARDIANS APPOINTED PRIOR TO THE EFFECTIVE DATE OF THIS ACT. ANY ORDERS, DETERMINATIONS OR DECISIONS OF THE APPOINTING OR SUBSEQUENT COURT SHALL CONTINUE IN FORCE AND EFFECT UNTIL DULY MODIFIED OR ABROGATED BY A JUDGE PURSUANT TO ARTICLE 17A AS AMENDED BY THIS ACT. ANY GUARDIAN APPOINTED PRIOR TO THE EFFECTIVE DATE OF THIS ACT SHALL BE GOVERNED BY THE REPORTING REQUIREMENTS OF SECTION 1762, AS OF APRIL 1, 2020.

(b) PRIOR PROCEEDINGS. IN ALL PROCEEDINGS COMMENCED UNDER ARTICLE 17A PRIOR TO APRIL 1, 2020 BUT UNDER WHICH NO DETERMINATION FOR THE APPOINTMENT OF A GUARDIAN HAS BEEN MADE, THE COURT SHALL MAKE THE FINDINGS REQUIRED BY SECTION 1756 OF THE SURROGATE'S COURT PROCEDURE ACT 17A AS AMENDED BY THIS ACT. UNLESS THE COURT DEEMS IT IMPRACTICABLE, SUCH PROCEEDINGS SHALL OTHERWISE BE GOVERNED BY ALL OTHER PROVISIONS OF ARTICLE 17A AS AMENDED BY THIS ACT.

§ 10. THIS ACT SHALL TAKE EFFECT ON THE FIRST OF APRIL NEXT SUCCEEDING THE DATE ON WHICH IT SHALL HAVE BECOME A LAW.

STATE OF NEW YORK

7107

2021-2022 Regular Sessions

IN SENATE

June 1, 2021

Introduced by Sen. MANNION -- (at request of the Office for People with Developmental Disabilities) -- read twice and ordered printed, and when printed to be committed to the Committee on Disabilities

AN ACT to amend the mental hygiene law, in relation to supported decision-making by people with intellectual, developmental, cognitive and psychosocial disabilities

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. The mental hygiene law is amended by adding a new article 82 to read as follows:

ARTICLE 82

SUPPORTED DECISION-MAKING

§ 82.01 Legislative findings and purpose.

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

LBD09657-01-1

(a) The legislature finds that a person's right to make their own decisions is critical to their autonomy and self-determination. People with intellectual, developmental, cognitive and psychosocial disabilities are often denied that right because of stigma and outdated beliefs about their capability. This right is denied, despite the reality that very few people make decisions entirely on their own. Everyone uses supports, as do people with disabilities; who may just need more or different kinds of supports.

(b) The legislature further finds that the, now well recognized, practice of supported decision-making is a way in which people with disabilities can make their own decisions with the support they need from trusted persons in their lives, and that supported decision-making can be a less restrictive alternative to guardianship. Recognizing that supported decision-making can take a variety of forms, the legislature finds that a more formal process, resulting in a supported decision-making agreement between the person with a disability (the decision-maker) and their supporter or supporters, can provide the basis for requiring third parties, who might otherwise question a person's legal capacity because of their disability, to recognize their decisions on the same basis as others, and to grant corresponding immunity to such parties when they do so in good faith. When this more formal process is followed, people with disabilities can make choices confident that they will be respected by others and knowing they will be solely responsible for their own decisions.

(c) The legislature further finds that supported decision-making and supported decision-making agreements should be encouraged for most persons with disabilities, and that the execution of a supported decision-making agreement should not detrimentally impact the eligibility of a person for other services, including adult protective services. At present, the legislature finds there is sufficient evidence of the means of providing support to persons with intellectual and developmental disabilities, as demonstrated, for example, through the recently completed five-year pilot project funded by the New York State Developmental Disability Planning Council, to require third-party recognition of decisions made pursuant to supported decision-making agreements made through a process of facilitation for the decision-maker and their supporters. Where persons with intellectual or developmental disabilities and their supporters receive facilitation and/or education, in accordance with regulations to be drafted by the office for people with developmental disabilities, the legislature will deem them to have legal capacity on a basis equal with all others.

(d) The legislature also strongly urges relevant state agencies and civil society to research and develop appropriate and effective means of support for older persons with cognitive decline, persons with traumatic brain injuries, and persons with psychosocial disabilities, so that full legislative recognition can also be accorded to the decisions made with supported decision-making agreements by persons with such conditions, based on a consensus about what kinds of support are most effective and how they can best be delivered.

§ 82.02 Definitions.

When used in this article, the following terms shall have the following meaning, unless the context or subject matter requires a different interpretation:

(a) "abuse" encompasses physical abuse, sexual abuse, and emotional abuse, as defined in section four hundred seventy-three of the social services law.

(b) "adult" means an individual eighteen years of age or older.

(c) "advance directive" means a legally recognized written or oral instruction by an adult relating to the provision of health care to the adult if and when they become incapacitated, including but not limited to a health care proxy, a consent to the issuance of an order not to resuscitate or other orders for life-sustaining treatment recorded in a patient's medical record, or other legally-recognized statements of wishes or beliefs.

(d) "decision-maker" means an adult who has executed, or seeks to execute, a supported decision-making agreement.

(e) "financial exploitation" has the meaning given in section four hundred seventy-three of the social services law.

(f) "good faith" means honest in fact and in the observance of reasonable standards of fair dealing.

(g) "neglect" has the meaning defined in paragraph (d) of subdivision one of section four hundred seventy-three of the social services law.

(h) "physical coercion" means to place under duress, menace, or threaten physical violence or imprisonment.

(i) "supported decision-making" means a way by which a decision-maker utilizes support from trusted persons in their life, in order to make their own decisions about their life, including, but not limited to, decisions related to where and with whom the decision-maker wants to live; decisions about finances; the services, supports, and health care the decision-maker wants to receive; and where the decision-maker wants to work.

(j) "supported decision-making agreement" is an agreement a decision-maker enters into with one or more supporters under this section that describes how the decision-maker uses supported decision-making to make their own decisions.

(k) "supporter" means an adult who has voluntarily entered into a supported decision-making agreement with a decision-maker, agreeing to assist the decision-maker in making their own decisions as prescribed by the supported decision-making agreement, and who is not ineligible under section 82.08 of this article.

(l) "undue influence" means moral or mental coercion that leads someone to carry out the wishes of another instead of their own because they are unable to refuse or resist.

§ 82.03 Presumption of capacity.

(a) For the purposes of this article, every adult shall be presumed to have the capacity to enter into a supported decision-making agreement, unless that adult has a legal guardian, appointed by a court of competent jurisdiction, whose granted authority is in conflict with the proposed supported decision-making agreement. This presumption may be rebutted only by clear and convincing evidence.

(b) Capacity shall include capacity with decision-making support and/or accommodations.

(c) A diagnosis of intellectual, developmental, or other disability or condition shall not constitute evidence of incapacity.

(d) The manner in which an adult communicates with others shall not constitute evidence of incapacity.

(e) No person or court may use or consider a decision-maker's execution of, or wish to execute, a supported decision-making agreement as evidence that the decision-maker lacks capacity, or to deny the decision-maker benefits to which they are otherwise entitled.

(f) A decision-maker may make, change, or revoke a supported decision-making agreement, if the decision-maker understands that they are

making, changing, or revoking an agreement with their chosen supporters and that they are doing so voluntarily.

§ 82.04 Scope.

(a) If a decision-maker voluntarily enters into a supported decision-making agreement with one or more supporters, the decision-maker may, in the agreement, authorize the supporter to provide support to them in making their own decisions in areas they choose, including, but not limited to: gathering information, understanding and interpreting information, weighing options and alternatives to a decision, considering the consequences of making a decision or not making it, participating in conversations with third parties if the decision-maker is present and requests their participation, communicating the decision-maker's decision to third parties, and providing the decision-maker support in implementing the decision-maker's decision.

(b) Nothing in this article, nor the existence of an executed supported decision-making agreement, shall preclude the decision-maker from acting independently of the supported decision-making agreement or executing, with or without the assistance of supporters under a supported decision-making agreement, a power of attorney under title fifteen of article five of the general obligations law, health care proxy under article twenty-nine-c of the public health law, or other advance directive.

(c) Notwithstanding the existence of a supported decision-making agreement, a decision-maker shall continue to have unrestricted access to their personal information without the assistance of a supporter.

(d) Notwithstanding the existence of a supported decision-making agreement, a decision-maker may request and receive assistance in making any decision that is not covered under the supported decision-making agreement at any time and from any person, regardless of whether that person is designated as a supporter in the supported decision-making agreement.

(e) A supported decision-making agreement made pursuant to this article may be evidence that the decision-maker has a less restrictive alternative to guardianship in place.

(f) The availability of supported decision-making agreements is, in no way, intended to limit the informal use of supported decision-making, or to preclude judicial consideration of such informal arrangements as less restrictive alternatives to guardianship.

(g) Execution of a supported decision-making agreement may not be a condition of participation in any activity, service, or program.

(h) If a decision-maker seeks from any person professional advice that would be otherwise covered by evidentiary privilege in accordance with sections forty-five hundred three, forty-five hundred four, forty-five hundred seven, forty-five hundred eight and forty-five hundred ten of the civil practice law and rules, the inclusion in the conversation of a supporter authorized by the supported decision-making agreement to provide support in the area in which the decision-maker seeks the professional advice shall not constitute a waiver of that privilege.

(i) Notwithstanding any other provision of law to the contrary, nothing within this article shall be construed to prohibit eligibility of a decision-maker for receipt of services or supports that they would have otherwise been entitled absent entering into a supported decision-making agreement under the provisions of this article.

§ 82.05 Duties, responsibilities, and authority of supporters.

(a) A supporter must:

1. respect the decision-maker's right to make a decision, even when the supporter disagrees with the decision or believes it is not in the decision-maker's best interests;

2. act honestly, diligently, and in good faith;

3. act within the scope set forth in the executed supported decision-making agreement;

4. avoid conflicts of interest; and

5. notify the decision-maker in writing, and in a manner the decision-maker can understand, of the supporter's intent to resign as a supporter.

(b) A supporter is prohibited from:

1. making decisions for the decision-maker, except to the extent otherwise granted in an advance directive;

2. exerting undue influence upon the decision-maker;

3. physically coercing the decision-maker;

4. obtaining, without the consent of the decision-maker, information acquired for a purpose other than assisting the decision-maker in making a decision authorized by the supported decision-making agreement; and

5. obtaining, without the consent of the decision-maker, or as expressly granted by the supported decision-making agreement, and accompanied by an appropriate release, nonpublic personal information as defined in 15 U.S.C. § 6809(4)(A), or clinical records or information under subdivision (c) of section of 33.13 of this chapter.

(c) The relationship between a decision-maker and a supporter is one of trust and confidence and serves to preserve the decision-making authority of the decision-maker.

(d) A supporter shall not be considered a surrogate or substitute decision maker for the decision-maker and shall not have the authority to sign legal documents on behalf of the decision-maker or bind the decision-maker to a legal agreement, but may, if such authority is expressly granted in the supported decision-making agreement, provide co-signature together with the decision-maker acknowledging the receipt of statements of rights and responsibilities in order to permit participation in such programs or activities that the decision-maker has communicated a choice to participate in.

(e) If expressly granted by the supported decision-making agreement, and the decision-maker has signed an appropriate release, the supporter may assist the decision-maker in obtaining educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. § 1232g), protected health information under the Health Insurance Portability and Accountability Act of 1996 (45 CFR §§ 164.502, 164.508), or clinical records and information under subdivision (c) of section 33.13 of this chapter.

(f) A supporter shall ensure the information under this section is kept privileged and confidential, as applicable, and is not subject to unauthorized access, use, or disclosure.

§ 82.06 Formation and term of agreement.

(a) An adult may enter into a supported decision-making agreement at any time if the adult enters into the agreement voluntarily.

(b) A decision-maker may sign a supported decision-making agreement in any manner, including electronic signatures permitted under article three of the state technology law.

(c) A supported decision-making agreement formed under the provisions of this article shall remain in effect unless and until revoked by the decision-maker.

§ 82.07 Revocation and amendment of agreement.

(a) The decision-maker may revoke all or part of a supported decision-making agreement by notifying the supporters orally or in writing, or by any other act evincing a specific intent to revoke the agreement. The failure of the decision-maker to notify supporters shall not invalidate the revocation of all or part of the supported decision-making agreement.

(b) A decision-maker may amend a supported decision-making agreement at any time for any reason, subject to the requirements of this section. The decision-maker shall notify all supporters of any amendment made to the supported decision-making agreement, but the failure to do so shall not invalidate the amendment.

§ 82.08 Eligibility and resignation of supporters.

(a) A supporter shall be any adult chosen by the decision-maker.

(b) An individual who has been chosen by the decision-maker to be a supporter, or who has entered into a supported decision-making agreement as a supporter shall be deemed ineligible to act, continue to serve as supporter upon the occurrence of any of the following:

1. a court authorizes a protective order or restraining order against the supporter on request of or on behalf of the decision-maker; or

2. the local department of social services has found that the supporter has committed abuse, neglect, financial exploitation, or physical coercion against the decision-maker as such terms are defined in section 82.02 of this article.

(c) A supporter may resign as supporter by written or oral notice to the decision-maker and the remaining supporters. If the supported decision-making agreement includes more than one supporter or is amended to replace the supporter who has resigned, the supported decision-making agreement shall survive for supporters who have not resigned as supporters, unless it is otherwise revoked under this section.

(d) If a supporter with whom a decision-maker entered into a supported decision-making agreement becomes ineligible to serve as supporter under subdivision (b) of this section, or resigns as supporter under subdivision (c) of this section, and the decision-maker does not amend the supported decision-making agreement to designate a replacement, the supported decision-making agreement shall be considered terminated as to the role of the ineligible or resigned supporter, but shall continue to have effect as to any other designated supporters.

§ 82.09 Facilitation of agreement.

The provisions of section 82.11 and subdivisions (b) through (d) of section 82.12 of this article shall only apply in circumstances where a decision is made by a decision-maker who receives or is eligible to receive services that are operated, certified, funded or approved by the office for people with developmental disabilities, pursuant to a supported decision-making agreement made in accordance with this article and following a recognized supported decision-making facilitation or education process as defined and prescribed by regulations promulgated by the office for people with developmental disabilities.

§ 82.10 Form of agreement.

(a) A supported decision-making agreement may be in any form consistent with the requirements set forth in this article.

(b) A supported decision-making agreement must:

1. be in writing;

2. be dated;

3. designate the decision-maker, and at least one supporter;

4. list the categories of decisions with which a supporter is authorized to assist the decision-maker;

5. list the kinds of support that each supporter may give for each area in which they are designated as a supporter;

6. contain an attestation that the supporters agree to honor the right of the decision-maker to make their own decisions in the ways and areas specified in the agreement, respect the decision-maker's decisions, and, further, that they will not make decisions for the decision-maker;

7. state that the decision-maker may change, amend, or revoke the supported decision-making agreement at any time for any reason, subject to the requirements of section 82.06 of this article;

8. be signed by all designated supporters; and

9. be executed or endorsed by the decision-maker in the presence of at least two adult witnesses who are not also designated as supporters, or with the attestation of a notary public.

(c) A supported decision-making agreement may:

1. appoint more than one supporter;

2. authorize a supporter to obtain personal information as described in subdivision (e) of section 82.05 of this article;

3. authorize a supporter to share information with any other supporter or others named in the agreement; or

4. detail any other limitations on the scope of a supporter's role that the decision-maker deems important.

(d) In order to be subject to the provisions of section 82.11 and subdivisions (b) through (d) of section 82.12 of this article, a supported decision-making agreement must also:

1. be signed by a facilitator or educator;

2. include a statement that the supported decision-making agreement was made in accordance with a recognized facilitation and/or education process; and

3. include an attached attestation by the decision-maker that a particular decision has been made in accordance with the support described in the supported decision-making agreement.

§ 82.11 Legal effect of decisions made with support and third-party obligations.

(a) This section shall apply only to decisions made by adults who receive or are eligible to receive services that are operated, certified, funded or approved by the office for people with developmental disabilities, and pursuant to supported decision-making agreements made in accordance with this article and following a recognized supported decision-making facilitation or education process, as prescribed by regulations governing the facilitation and education processes promulgated by the office for people with developmental disabilities.

(b) A decision or request made or communicated by a decision-maker with the assistance of a supporter in accordance with the provisions of a supported decision-making agreement must, notwithstanding any other provision of law, be recognized as the decision or request of the decision-maker and may be enforced by the decision-maker in law or equity on the same basis as all others.

(c) A person, entity, or agency required to recognize and honor a decision made pursuant to a supported decision-making agreement authorized by this section may require the decision-maker to execute or endorse an attestation, as provided in paragraph three of subdivision (d) of section 82.10 of this article, as a condition of recognizing and honoring the decision.

(d) A person, entity, or agency that receives a supported decision-making agreement must honor a decision made in accordance with the agreement, unless the person, entity, or agency has substantial cause to

believe the supported decision-making agreement has been revoked, or the decision-maker is being abused, coerced, unduly influenced, or financially exploited by the supporter, or that the decision will cause the decision-maker substantial and imminent physical or financial harm.

§ 82.12 Limitations on liability.

(a) Subdivisions (b), (c) and (d) of this section shall apply only to decisions made by adults who receive or are eligible to receive services that are operated, certified, funded or approved by the office for people with developmental disabilities, and pursuant to supported decision-making agreements made in accordance with this article and following a recognized supported decision-making facilitation or education process, as prescribed by regulations governing the facilitation and education processes promulgated by the office for people with developmental disabilities.

(b) A person shall not be subject to criminal or civil liability and shall not be determined to have engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a decision made by an decision-maker pursuant to a duly executed supported decision-making agreement made in accordance with this article.

(c) Any health care provider that provides health care based on the consent of a decision-maker, given with support or assistance provided through a duly executed supported decision-making agreement, made in accordance with this article, shall be immune from any action alleging that the decision-maker lacked capacity to provide informed consent unless the entity, custodian, or organization had actual knowledge or notice that the decision-maker had revoked the supported decision-making agreement, or that the supporter had committed abuse, physical coercion, undue influence, or financial exploitation with respect to the decision to grant consent.

(d) Any public or private entity, custodian, or organization that discloses personal information about a decision-maker in reliance on the terms of a duly executed supported decision-making agreement made in accordance with this article, to a supporter authorized by the terms of the supported decision-making agreement to assist the decision-maker in accessing, collecting, or obtaining that information under subdivision (e) of section 82.05 of this article shall be immune from any action alleging that it improperly or unlawfully disclosed such information to the supporter unless the entity, custodian, or organization had actual knowledge that decision-maker had revoked such authorization.

(e) This section may not be construed to provide immunity from actions alleging that a health care provider has done any of the following:

1. caused personal injury as a result of a negligent, reckless, or intentional act;

2. acted inconsistently with the expressed wishes of a decision-maker;

3. failed to provide information to either decision-maker or their supporter that would be necessary for informed consent; or

4. otherwise acted inconsistently with applicable law.

(f) The existence or availability of a supported decision-making agreement does not relieve a health care provider of any legal obligation to provide services to individuals with disabilities, including the obligation to provide reasonable accommodations or auxiliary aids and services, including, but not limited to, interpretation services and communication supports to individuals with disabilities under the federal Americans with Disabilities Act (42 U.S.C. § 12101).

§ 82.13 Supporter notice.

(a) If any state or municipal law requires that an agency, entity, or person provide a prescribed notice to a decision-maker, and the agency, entity, or person required to provide such notice has received a supported decision-making agreement from a decision-maker that specifies that a supporter is also to receive a copy of any such notice, then the agency, entity, or person in possession of the supported decision-making agreement shall also provide the specified supporter with a copy of such notice.

(b) Notwithstanding the provisions of this subsection, if any state or municipal law requires that an agency, entity, or person provide a prescribed notice to a decision-maker and such notice includes protected information, including private health information or educational records protected by state or federal law, such notice shall not be provided to the specified supporter unless the supported decision-making agreement is accompanied by a release authorizing the specified supporter to obtain the protected information.

§ 82.14 Reporting abuse, coercion, undue influence, or financial exploitation.

(a) Any person who receives a copy of or an original supported decision-making agreement and has cause to believe the decision-maker is being abused, physically coerced, or financially exploited by a supporter, may report the alleged abuse, physical coercion, or financial exploitation to adult protective services pursuant to section four hundred seventy-three of the social services law.

(b) Nothing in this section may be construed as eliminating or limiting a person's duty or requirement to report under any other statute or regulation.

§ 82.15 Rules and regulations.

(a) The commissioner of the office for people with developmental disabilities shall promulgate within one year of the passage of this act the rules and regulations necessary to implement this article for adults who receive or are eligible to receive services that are operated, certified, funded or approved by the office for people with developmental disabilities.

(b) Further regulations related to this article may be promulgated by state agencies whose service populations may benefit from the implementation of supported decision-making.

§ 2. This act shall take effect ninety days from the date that the regulations issued in accordance with section one of this act appear in the New York State Register, or the date such regulations are adopted, whichever is later; and provided that the commissioner of mental hygiene shall notify the legislative bill drafting commission upon the occurrence of the appearance of the regulations in the New York State Register or the date such regulations are adopted, whichever is later, in order that the commission may maintain an accurate and timely effective data base of the official text of laws of the state of New York in furtherance of effecting the provisions of section 44 of the legislative law and section 70-b of the public officers law.

REPORT ON LEGISLATION BY THE MENTAL HEALTH LAW COMMITTEE

A.XXXX-X

An act to amend the mental hygiene law, in relation to supported decision-making by people with intellectual, developmental, cognitive and psycho-social disabilities.

THIS BILL IS APPROVED WITH MODIFICATION

Supported decision-making (SDM) is an emerging practice by which persons with intellectual, developmental, cognitive and psychosocial disabilities can make their own decisions with the support of trusted persons in their lives. SDM can take many forms, from entirely informal to a more formal process resulting in a signed supported decision-making agreement (SDMA) between the person with a disability, often referred to as the "Decision-Maker" and their supporters. SDM is now widely recognized as a constitutionally required "less restrictive alternative to guardianship;[1] the Uniform Law Commission has explicitly included SDM as such in its recently revised Uniform Guardianship, Conservatorship and Other Protective Proceedings Act, [2] and several states have followed suit.[3]

At the same time, a growing number of U.S. states—ten as of this writing—and the District of Columbia, have adopted legislation to legally recognize decisions made pursuant to supported decision-making agreements (SDMAs).[4] SDMA statutes have a number of purposes, including encouraging and incentivizing the use of SDM and SDMAs, empowering people with disabilities to become more self-determined and autonomous, and ending unwarranted

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[1] Supported decision-making has been recognized as a "less restrictive alternative" to guardianship by, *e.g.,* the American Bar Association, the National Guardianship Association, ARC of the U.S., the National Council on Disability, and, most recently, the Fourth National guardianship Summit. The constitutional imperative of least restrictive alternative derives from *O'Connor v. Donaldson*, 422 U.S. 563 (1975) and has been embraced by New York courts. *See, e.g.*, *Kesselbrenner v. Anonymous* 33 N.Y. 2d 161,165 (1973); *Manhattan Psychiatric Center v. Anonymous*, 285 A.D. 2d 189, 197-98 (1st Dept. 2001).

[2] NAT'L CONFERENCE OF COMMISSIONERS ON UNIF. STATE LAWS, UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT (UNIF. L. COMM'N 2017), https://www.uniformlaws. org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=de9bae9e-0b4e-0781-12b5-f5305569bf19&forceDialog=0.

[3] *See, e.g.*, Maine Revised Probate Code, 18-C M.R.S. Sec. 5-401.

[4] TEX. EST. CODE ANN. §§ 1357.001 - 1357.102 (West 2019); WIS. STAT. ANN. §§ 52.01-52.32 (West 2018); ALASKA STAT. ANN. §§ 13.56.010-13.56.195 (West 2018); DEL. CODE ANN. tit. 16, §§ 9401A-9410A (West 2016); D.C. CODE ANN. §§ 7-2131 – 7-2134 (West 2018); IND. CODE ANN. §§ 29-3-14-1 - 29-3-14-13 (West 2019); N.D. CENT. CODE ANN. §§ 30.1-36-01 - 30.1-36-08 (West 2019); 42 R.I. GEN. LAWS ANN. §§ 42-66.13-1 - 42-66.13-10 (West 2020); NEV. REV. STAT. ANN. §§ 162C.010 - 162C.330 (West 2020); WASH. REV. CODE ANN. §§ 11.130.700 et. seq. (West 2020) (effective Jan. 1 2022); 2020 Wash. Legis. Serv. Ch. 312 (S.S.B. 6287) Part VI § 601-612 (West 2020); LA. STAT. ANN. § 13:4261.101- 13:4261.302 (West 2020).

discrimination against persons with disabilities whose decisions are often questioned or disregarded because third parties believe that they "lack capacity." SDMA statutes, like the instant bill, draw on the non-discrimination principles of the Americans with Disabilities Act to require equal treatment of persons with disabilities who make decisions pursuant to a legislatively recognized SDMA by requiring third parties to accept those decisions and, in return, conferring immunity for their good faith acceptance.[5] As the Legal Director for the Autism Self-Advocacy Network has written, "It is critical that states adopt legislation through which people with significant decision-making support needs can make legally enforceable decisions with the assistance of a chosen support network."[6]

The New York City Bar Association ("City Bar") was founded in 1870 and is a private, non-profit organization of more than 23,000 attorneys, judges and law professors. With over 23,000 members, the City Bar has long supported the vigorous and fair enforcement of civil rights law. In January 2016, the City Bar's Mental Health Law Committee in conjunction with the Disability Law Committee issued a report, *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual Disabilities* which addressed how, if at all, the state should provide substituted decision-making for this vulnerable population and specifically noted the emergence of SDM as "a new model of autonomy and self-determination."[7] The Mental Health Law Committee respectfully urges the Legislature to consider the adoption of the A.XXXX-X ("the bill") with the modification proposed, in order to ensure that the rights of people with intellectual, developmental, cognitive and psychosocial disabilities are properly protected.

1. The Bill is the Consequence of Significant Involvement and Investment by the State.

New York has played a significant and thoughtful role in the formulation and development of SDM and SMDAs in theory and in practice. In 2012, the American Bar Association Commissions on Law and Aging, and Disability Rights, convened the first national, interdisciplinary Roundtable to explore SDM in New York City.[8] The convening received funding from the New York Community Trust and support from the federal government's Administration for Community Living.[9] Three years later, as efforts to enact SDMA legislation grew around the country, the New York State Developmental Disability Planning Council (DDPC), awarded a $1.5 million, five-year grant to Supported Decision-Making New York (SDMNY) to educate stakeholders about SDM, to develop and pilot a model utilizing SDM to

[5] Americans with Disabilities Act, 42 U.S.C. Sec. 12101 *et seq*. As one commentator has written, "Just as we recognize that the law–and common principles of human decency–generally require that we build a ramp so that an individual with a physical impairment can enter a building without being carried up the steps, we should also recognize a legal obligation to provide decision-making support to an individual with limitations in mental capabilities rather than assign a guardian to make decisions *for* that person." Rachel Mattingly Phillips, *Note: Model Language for Supported Decision-Making Statutes,* 98 Wash. U. L. Rev 615, 624 (2020).
[6] Samantha Alexandra Crane, *Is Guardianship Reform Enough? Next Steps in Policy Reforms to Promote Self-Determination Among People with Disabilities*, 8 J. Compar. & Int'l Aging L. & Pol'y 177, 180 (2015)
[7] 18 CUNY L. Rev. 287 (2015); also available at http://www2.nycbar.org/.
[8] Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, 39 Cardozo L. Rev. 495, 501 (2017).
[9] Kristin Booth Glen, *Supported Decision-Making From Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 Alb. Gov't L. Rev. 94, 101 n.36 (2019-2020).

divert persons at risk of guardianship or restore rights to persons currently under guardianship, and to develop an evidentiary base for prospective SDMA legislation in New York.[10] Over the last five years, SDMNY has enrolled more than 140 Decision-Makers, developed a three-phase model that facilitates Decision-Makers and their supporters in making an agreement reflecting the process by which the Decision-Maker will make decisions and the supporters will provide support going forward.[11] Unlike the other jurisdictions that have enacted SDMA statutes with no empirical, "on the ground" evidence, New York's prescient decision to first thoroughly explore how SDM actually works for people with intellectual and developmental disability (I/DD) positions it as a leader in fostering the rights of people with intellectual, cognitive and psychosocial disabilities through an authentic practice of SDM.

2. By Recognizing SDM as an Alternative to Guardianship the Bill Will Clarify Existing Law and Provide Guidance to Courts, Litigants and Counsel.

Although New York has recognized the constitutional imperative of "least restrictive alternative" in case law, [12] and provided that other decisional supports must be considered before guardianship is imposed pursuant to Article 81 of the Mental Health Law (MHL),[13] SDM is nowhere specifically named.[14] Article 17-A of the Surrogate's Court Procedure Act (SCPA) lacks any reference to consideration of alternatives whatsoever. By naming the process of SDM as "a way by which a decision-maker utilizes support from trusted persons in their life, in order to make their own decisions about their life,"[15] stating explicitly that SDM can be "a less restrictive alternative to guardianship,"[16] and recognizing that SDM may take a variety of forms,[17] all of which, including informal arrangements may be considered by courts as "less restrictive alternatives,"[18] the bill fills the existing lacuna, providing clear guidance to courts and litigants.

[10] SDMNY is a consortium of Hunter/CUNY, the NY Alliance for Inclusion and Innovation, a statewide association of provider agencies (formerly NYSACRA) and the Arc of Westchester, a large, parent-led provider agency, with New York's federally funded Protection & Advocacy Agency, Disability Rights New York (DRNY) as its legal partner.

[11] The SDMNY model, including the 3-phase facilitation process, facilitator training and oversight by trained mentors, and the U.S. and the international pilots from which it was derived is described in detail in Glen, *supra* n. 9, and on the SDMNY website, www.sdmny.org.

[12] *Supra*. n.1.

[13] MHL Sec. 81.01; *see, e.g. In re Isadora R.*, 5 A.D.3d 494 (2d Dept. 2004); *In re Janczak*, 167 Misc. 2d 766 (S. Ct. Ontario Co. 1995).

[14] This is not deliberate; the concept of SDM did not yet exist when Article 81 was enacted.

[15] The bill defines "decision-maker" is defined as "an adult who has executed or seeks to execute a supported decision-making agreement." Sec. 82.02(i).

[16] *Id.*

[17] Sec. 82.01(b).

[18] Sec.82.04(f).

3. By recognizing SDM, and Prescribing a More Formalized Process for Making SDMAs, the Bill Will Provide Families an Alternative to Guardianship While Leaving Existing Guardianship Statutes in Place and Available When Appropriate.

The bill does nothing to change existing guardianship law which has, in any event, proven relatively impervious to alteration.[19] No one is, or can be required to use SDM or enter into an SDMA.[20] Nor does the use of SDM or the existence of an SDMA necessarily result in denial of a proposed guardianship, or termination of an existing guardianship; a factual inquiry into the need for the guardianship, and whether SDM or the SDMA actually constitutes a less restrictive alternative is always required. SDM or an SDMA does not preclude parents or other potential petitioners from seeking—and obtaining—guardianship if the process is not effectively meeting the needs that guardianship is statutorily prescribed to fill. Studies consistently demonstrate that many parents who want to continue promoting the autonomy and self-determination of their adult children with I/DD believe they have no alternative other than to seek guardianship and are unaware of alternatives.[21] The bill provides an alternative that families are free to try and which may prove a beneficial and less restrictive alternative, preserving the civil and legal rights of persons with I/DD.

At the same time, the bill will incentivize the use of SDM by families seeking to promote self-determination of their adult children with I/DD. One learning from the DDPC-supported pilot project is particularly salient. Many parents and their adult children with I/DD are anxious to try SDM, but fear that, in the absence of legal recognition, they will inevitably find themselves in a situation where a third party (generally perceived to be a health-care provider) refuses to provide services to the Decision-Maker because of her/his perceived lack of capacity, insisting instead on a guardianship order. Many other families face pressure—whether intentional or through the well-intentioned recommendations of professionals—to seek guardianship.[22]

Those parents, facing what they understand to be the likely "inevitability" of guardianship, may say that the time and work that goes into creating an SDMA is simply not worth it—unless and until there is legal recognition of decisions made pursuant to the SDMA. Parents who have been surveyed are virtually unanimous in supporting legislation that "solves" this problem by providing for legislative recognition, and report that it would positively impact their decision to try SDM.[23] That is precisely what the bill will provide.

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[19] This is particularly true of SCPA Article 17-A, which was recognized as needing significant reform as early as 1990, as reflected in the Committees' earlier Report, *supra* n. 7. Despite a federal civil rights law suit challenging the law, *Disability Rights N.Y. v. New York*, 916 F.3d 129, 133–37 (2d Cir. 2019); Glen, *supra* n. 9 at 100-101, and numerous other calls for change, remains unchanged to this day.

[20] A specific provision of the bill prohibits conditioning of services on the execution of an SDMA, Sec. 82.04(g).

[21] *See, e.g.,* NATIONAL COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION, at 92 (2018).

[22] Carrie E. Rood et al., *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*, 39 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 319 (2015).

[23] *See, e.g.*, ELIZABETH PELL, SUPPORTED DECISION-MAKING NEW YORK: EVALUATION REPORT OF AN INTENTIONAL PILOT (Aug. 2019), https://sdmny.org/wp-content/uploads /2019/12/Pell-SDMNY-Report-2019.pdf., Report of Parent-to-Parent Convened Focus Groups on SDMA Legislation, (May, 2021) (on file with Committee).

4. The Bill Will Prevent Discrimination Against People with Intellectual and Developmental, Cognitive and Psychosocial Disabilities Based on Stigma, Prejudice of Fear of Liability.

For many reasons, third parties, both private and public, question the ability of persons with disabilities to make decisions and often refuse to accept their decisions. [24] In practice, this means individuals with disabilities are frequently deprived of the right to legal capacity.[25] Although existing law presumes that all adults have legal capacity,[26] a diagnosis of intellectual, developmental, cognitive or psychosocial disability, or belief that a person has such disability often results in discriminatory treatment, including refusal to recognize their decisions.[27] The bill, similar to existing SDMA legislation in other jurisdictions, avoids such discrimination by removing the ability of third parties to make their own "determinations" of a person's legal capacity based on their disability. Instead, the bill provides that a decision made pursuant to a recognized SDMA is presumptively made with legal capacity.[28] In this respect, the bill reflects the principles and requirements of the Americans with Disabilities Act by recognizing SDM, through a prescribed process reflected in an SDMA, as an accommodation that enables people with disabilities equal access to contractual relationships.[29]

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[24] These include stigma and prejudice against people with intellectual, developmental, cognitive and psychosocial disabilities, but also fear of liability if a transaction to which a person with such disability was a party is ultimately voided for "lack of capacity." As to the latter, the bill, and other SDMA statutes, avoid the problem by conferring immunity for the acceptance of a decision made pursuant to an authorized SDMA "in good faith." Sec. 82.12(b)

[25] The "right of legal capacity" is derived from the UN Convention on the Rights of Persons with Disabilities which requires recognition of the right to make one's own decisions, and to have those decisions legally recognized, without regard to disability. Committee on the Rights of Persons with Disabilities, General Comment No. 1, Article 12: Equal Recognition Before the Law, ¶ 12, *U.N. Doc. CRPD/C/GC/1* (May 19, 2014).

[26] Robert Dinerstein, "*Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making,"* Human Rights Brief 19, no. 2 (2012): 9.

[27] *See, e.g.,* Crane, *supra* n. 6, noting that "individuals and businesses [may be] unwilling to enter into major contracts—such as lease agreements or automobile loans—with individuals with disabilities who do not have guardians, as a court may at some later point determine that the individual lacked capacity to enter into such contracts and therefore declare them invalid. Similarly, health care providers may be unwilling to provide treatment requested by a disabled individual, for fear that a court will later determine that the individual lacked capacity to consent to treatment."

[28] *See, e.g.,* Rachel Mattingly Phillips, *Note: Model Language for Supported Decision-Making Statutes,* 98 Wash. U. L. Rev. 615, 637 (2020) (proposing that a "statute should make it clear that any decision made or action taken by the principal with the aid of a supporter is legally valid and binding (absent the sort of extenuating circumstances that could void any decision). To this end, the statute should acknowledge that an individual using a supporter is considered to be competent to the same degree as if they had the same capability acting alone.").

[29] Considering the ADA, one commentator has noted that "[t]he statute itself specifies that entering into contracts is a strategy that can be used to ensure the full participation and inclusion of those with disabilities. The ADA provides that the refusal of covered entities, including a broad swath of private actors, to enter into contracts with the disabled is an act of discrimination." Sean M. Scott, *Contractual Incapacity and the Americans with Disabilities Act,* 124 Dick. L. Rev. 253, 288 (2020). The National Guardianship Summit, a convocation of experts and stakeholders, convened approximately every decade, that makes influential recommendations in the field. The Fourth National Guardianship Summit, which met from May 12-16, 2021, just adopted a resolution calling on the Department of Justice to explicitly recognize SDM as an accommodation under the ADA. Fourth National Guardianship Summit, Recommendation VII (on file with Committee).

5. The Bill Provides Protection Against Possible Abuse or Exploitation of Decision-Makers.

Families are often concerned about possible exploitation of their vulnerable adult children with I/DD, and seek guardianship as "protection," relying on supposed court oversight. In fact, Article 17-A of the SCPA has no provision for reporting once a guardian has been appointed, or for any periodic review.[30] In contrast, the bill provides significant protection by essentially creating "on-the-spot," "point-of-transaction" monitoring, by permitting a third party to refuse to accept a decision if there is substantial cause to believe it is the product of abuse, coercion, undue influence or financial exploitation by a supporter,[31] and to report the alleged abuse, coercion, undue influence or exploitation to the appropriate protective agency, in real time, without fear of any penalty.[32]

In addition, existing SDMA statutes have been subject to criticism that by creating a "legal status" for supporters, unrelated to any court proceeding or oversight, people with disabilities entering into SDMAs could be easily exploited through a kind of "guardianship on the cheap." If a supporter had the right to "communicate" and/or enforce (or "implement") the alleged decision of a person with a disability, they would essentially have all the powers of a guardian, but with none of the protections of court-imposed guardianship.[33] The bill protect against this in several ways. First, it explicitly states that a supporter may not make decisions for the Decision-Maker,[34] be considered a substitute decision-maker, or legally bind the Decision-Maker to any legal agreement.[35] Second, where other SMDA laws have accorded legislative recognition to decisions made pursuant to SDMAs that are simply signed forms, with no requirement of any education or facilitation process to ensure that both the Decision-Maker and supporters understand and have committed to a process of trust and respectful support, the Bill draws on the experience of the DDPC-funded project and requires completion of a meaningful facilitation process for Decision-Makers and their supporters for SDMAs in order to require recognition.[36] Finally, as noted below, the bill also draws on empirical evidence—and the lack thereof—to initially limit recognition to SDMAs made by people with I/DD for whom there is consensus on what constitutes appropriate decision-making support.

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[30] *See* the Mental Health Law Committee's prior Report, *supra* n. 7 at 313-31. One court has required periodic reporting and review as constitutionally compelled. *In re Mark C. H.,* 28 Misc. 3d 765 (Surr. Ct. N.Y. Co. 2010).
[31] Sec. 82.11 (d).
[32] Sec. 82.14 (a).
[33] Nina A. Kohn, *Legislating Supported Decision-Making,* __ Harvard J. of Legislation __ (forthcoming 2021). An earlier article by Professor Kohn and others cautioned against embracing SDM and SDMAs in the absence of empirical evidence. Nina A. Kohn et al, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 Penn St. L. Rev.1111 (2013). In response, New York's commitment to developing an adequate evidentiary base is reflected throughout the pending bill.
[34] Sec. 82.05 (b)(1).
[35] Sec. 82.05 (d).
[36] Sec. 82.09. Family members surveyed in focus groups about SDMA legislation believe this to be an important protection against others "taking advantage of" their adult children with I/DD. *See* Parent-to-Parent Report, supra at n. 23. Commentators have called for a training or education requirement. *See, E.g.*, Megan S. Wright, *Dementia, Autonomy and Supported Healthcare Decisionmaking*, 79 Md. L. Rev. 257, 289 (2020).

6. The Bill Encourages SDM and the Use of SDMAs for Everyone While Initially Limiting Legislative Recognition to People with I/DD for Whom Effective and Appropriate Supports Have Been Empirically Demonstrated.

The bill provides that an SDMA can be made by any adult, thus "normalizing"[37] the process, and recognizing that, in making decisions, "everyone uses supports, as do people with disabilities, who may just need more or different kinds of supports."[38] How an SDMA is made, what it may and may not contain, and provisions ensuring that the making of an SDMA can neither be used against the person, or required of them,[39] apply to everyone. To confer legislative recognition, however, there should be some significant level of confidence that the person who has executed the SDMA has appropriate and adequate supports to make decisions. To date, virtually all of the pilot projects and evaluations around the world have involved people with I/DD and have resulted in a general consensus on the use of a process of facilitation for Decision-Makers and their supporters;[40] the DDPC-funded pilot in New York has confirmed that facilitated SDM provides the necessary and appropriate support for legislative recognition of decisions made by persons with I/DD pursuant to an SDMA. There is no corresponding evidentiary base, or the existence of any pilot projects for persons with other disabilities, and no clear understanding of what kinds of support would be necessary for them to achieve or be afforded legal capacity.[41] The bill acknowledges this lacuna while calling on government and civil society "to develop appropriate and effective means of support for older persons with

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[37] WOLF P. WOLFENSBERGER ET AL., THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES (1972).

[38] Sec. 82.01(a); *see also* Committee on the Rights of Persons with Disabilities, General Comment No. 1, Article 12: Equal Recognition Before the Law, ¶ 12, *U.N. Doc. CRPD/C/GC/1* (May 19, 2014) [hereinafter CRPD Committee].

[39] Under the bill, making an SDMA is not evidence of lack of capacity, nor can it be used to deprive a person of benefits to which they are otherwise entitled. Sec. 82.03(e). Conversely, making an SDMA "may not be a condition of participation in any activity, service or program." Sec.82.04(g).

[40] *See, e.g.,* Bigby et. al, *Delivering decision making support to people with cognitive disability — What has been learned from pilot programs in Australia from 2010 to 2015*, 52:3 AUST J SOC ISSUES 222, 244 (Sept. 27, 2017), https://doi.org/10.1002/ajs4.19 (Austrailia); BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS 28 (2015) (Bulgaria); QUIP, *Black and White,* http://www.kvalitavpraxi.cz/en/projects/current-projects/black-and-white/ [https://perma.cc/S6TH-9Q7N] (Czech Republic); *Decision-Making Service for Persons with Disabilities, Service Model* (on file with Committee) (Israel); ZELDA*, "Handbook: FirstSteps in Implementation ofSupported Decision Making in Latvia* (Apr. 26, 2016), http://zelda.org.lv/en/news/rc-zelda-has- published-handbook-first-steps-in-implementation-of-supported-decision-making- in-latvia-2-2446 [https://perma.cc/428C-EZB8] (Latvia).

Significantly, the only jurisdiction that, to date, has enacted an SDMA statute based on a pilot project, Israel, specifically requires a significant amount of training for supporters—though not for Decision-Makers—for the legislative recognition of decisions made pursuant to SDMAs. Glen, *supra* n. 9. For examples in the U.S., see, ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH, PILOT EVALUATION YEAR 1 (Nov. 30, 2015) https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-Supported Decision-Making-HSRI-Evaluation-Year-1-Report-2015.pdf; ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT, https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-SDM-HSRI-Evaluation-Year-2-Report-2016.pdf

[41] For discussion of why there has been so little attention to older persons, and how SDM could be important to that population, *see* Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L. J. 495, 498 (2016). For discussion of legal capacity and persons with psychosocial disabilities, *see generally* PIERS GOODING, A NEW ERA FOR MENTAL HEALTH LAW AND POLICY: SUPPORTED DECISION-MAKING AND THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2017).

cognitive decline, persons with traumatic brain injury, and persons with psychosocial disabilities, so that full legislative recognition can also be accorded to the decisions made with supported decision-making agreements by persons with such conditions."[42]

7. The Bill Should Include a Requirement that Relevant State Entities Provide Accessible Information on SDM and SDMAs as an Alternative to Guardianship.

Few if any of the many benefits of this bill will actually occur unless stakeholders know about SDM and SDMAs. Research consistently shows that parents of transition-age adults with I/DD are routinely and repeatedly informed about, and encouraged to pursue guardianship when their children turn 18.[43] This leads to what the National Council on Disability calls the "school to guardianship pipeline."[44] Similarly, many parents report that they had no idea of available alternatives, and had never heard of SDM.[45] Parents and self-advocates believe that information about SDM should be more readily available, and national organizations have likewise called for information on SDM to be made available in the educational and court systems[46] as well as for professionals and others.[47] This is also a "learning" and recommendation of the DDPC-funded project.[48] To ensure that persons with developmental, intellectual, cognitive and psychosocial disabilities, those who might seek guardianship, and current guardians have access to information about SDM, potentially preventing unnecessary guardianships and protecting the civil and legal rights of persons with disabilities, the bill should include a provision directing the Department of Education to require that schools provide information on SDM and SDMAs as an alternative to guardianship to students and parents during transition planning.[49] Additionally, the bill should require the Office of Court Administration to provide similar information in the appropriate clerks' offices in Surrogates Courts and Supreme Court, Civil Term, and that all such information should be made available in accessible form.

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[42] Sec. 82.01(d).
[43] *See, e.g.*, Rood, *supra* note 23; Crane, *supra* n. 6 at 193, 203.
[44] National Council on Disabilities Report, *supra* n. 21.
[45] *See, e.g.,* Parent-to-Parent Report, *supra* n. 23, Pell, *supra* n. 23; Cathy Constanzo et al, *Supported Decision-Making: Lessons from Pilot Projects,* Syracuse L. Rev. (forthcoming)
[46] Some New York Surrogates Courts are already including information in their clerks' offices, and the Office of Court Administration website has a video on alternatives that mentions SDM. *See, e.g., Guardianship Information Session 17A Alternatives to Guardianship*, https*://www.youtube.com/watch?v=O6Fea1w-LQo*.
[47] *See, e.g.,* NCD Report, *supra* n. 23 at 18-19, Fourth National Guardianship Summit, *supra* n. 30, Recommendations.
[48] Constanzo et al., supra n. 45. *See also* SDMNY, *Principles for Supported Decision-Making Legislation,* Principle IX, https://sdmny.org/supported-decision-making-legislation/principles-for-supported-decision-making-agreements-in-new-york/principles-for-a-supported-decision-making-agreement-sdma-law-long/.
[49] A similar provision can be found in the Wisconsin SDMA Statute, *supra* n. 4 at Sec. 115.807 and the bill currently pending in Massachusetts, S. 124 Section 4, available at https://malegislature.gov/Bills/192/S.124 (requiring the Massachusetts Department of Education to provide information on SDM to parents and students in the transition planning process).

New York City Council Public Hearing
Committee on Public Safety
Mental Health Involuntary Removals and Mayor Adams' Recently Announced Plan

Written Testimony of the New York City Bar Association
February 6, 2023

The New York City Bar Association (City Bar),[1] through its Civil Rights Committee, Disability Law Committee, Mental Health Law Committee, New York City Affairs Committee and Social Welfare Law Committee, urges Mayor Adams to pause implementation of the new directive on "mental health involuntary removals" (the "NYC Removal Directive").[2]

The NYC Removal Directive purports to clarify that the NYPD and other agencies are empowered to forcibly remove from public spaces people who appear to have a mental illness and to be unable to meet their basic needs to an extent that causes them harm. This vague and broad initiative raises significant legal issues that demand careful review to ensure the City's compliance with City, State, and Federal anti-discrimination laws, as well as State laws governing mental health treatment and the U.S. Constitution. Furthermore, as is evidenced by the numerous concerns raised by directly impacted individuals and groups advocating for people with mental illness, the NYC Removal Directive also presents serious policy concerns that deserve thoughtful consideration and would benefit from additional stakeholder input. We call on the City to pause its rushed implementation of the NYC Removal Directive and engage in a transparent and good faith dialogue with service providers, advocates, and directly impacted individuals to design interventions that are evidence-based, consistent with individuals' rights and autonomy, and do

[1] The mission of the New York City Bar Association, which was founded in 1870 and has over 23,000 members, is to equip and mobilize a diverse legal profession to practice with excellence, promote reform of the law, and uphold the rule of law and access to justice in support of a fair society and the public interest in our community, our nation, and throughout the world.

[2] On November 29, 2022, Mayor Adams delivered an "Address on the Mental Health Crisis in New York City" transcript available at: https://www.nyc.gov/office-of-the-mayor/news/871-22/transcript-mayor-eric-adams-delivers-address-mental-health-crisis-new-york-city-holds (all websites last visited February 2, 2023). The 5 page directive that was released with the announcement is captioned *Mental Health Involuntary Removals, as of 11/28/2022*, and is available at: https://www.nyc.gov/assets/home/downloads/pdf/press-releases/2022/Mental-Health-Involuntary-Removals.pdf. Following the announcement, the City has communicated the new policy to its police officers through a FINEST message dated December 6, 2022 (FINEST message). The FINEST message was posted on the docket in the *Baerga et al. v. NYC et al.*, 21-cv-05762 (SDNY) (PAC) litigation, ECF/Docket # 123-1.

About the Association
The mission of the New York City Bar Association, which was founded in 1870 and has over 23,000 members, is to equip and mobilize a diverse legal profession to practice with excellence, promote reform of the law, and uphold the rule of law and access to justice in support of a fair society and the public interest in our community, our nation, and throughout the world.

not violate (on their face or in their implementation) our anti-discrimination laws or the U.S. Constitution.

Below, we highlight our primary legal and policy concerns and reiterate fundamental principles—such as autonomy in decision-making and the "least restrictive alternative"—that we believe should undergird any future City initiative affecting people with mental health conditions.

First, the City's broad language in the NYC Removal Directive would allow removals that are not justified under the U.S. Constitution or State mental health law;

Second, the City's language announcing this initiative both reflects and will exacerbate bias against unhoused people and people with serious mental illness, in violation of anti-discrimination principles, and the NYC Removal Directives will disproportionately burden people of color; and

Third, this initiative directs resources into a failed strategy, at a time when the City has reduced investments in effective strategies that connect people to long term treatment and care.

I. The City's broad language would allow removals that are not justified under the U.S. Constitution or State law.

Summary

Under Mental Hygiene Law (MHL) sections 9.41 and 9.58, the City has the prerogative to remove individuals to a hospital involuntarily under certain circumstances. Indeed, public reporting indicates NYPD effectuated more than 1,000 such removals in 2022 before the issuance of the NYC Removal Directive.[3] This authority which, under section 9.41 is vested in peace officers and law enforcement officers, and under section 9.58 is additionally vested in physicians and certain mental health professionals, is constrained by the Constitution. The New York State Office of Mental Health ("OMH") guidance largely aligns with the caselaw around mental hygiene arrests under MHL § 9.41 with respect to both the probable cause standard and the requirement of an inability to meet basic needs such that a person presents a present risk of harm to self. The mayor's announcement and the accompanying NYC Removal Directive, however, do not.

Background Law and Policy

The Mental Hygiene Law ("MHL") provides authority for peace officers and law enforcement officers to take into custody for the purpose of a psychiatric evaluation those individuals who appear to be mentally ill and are conducting themselves in a manner which is

[3] Ethan Geringer-Sameth, "Police Have Removed Over 1,300 'Emotionally Disturbed People from Transit in 2022; Where Did They Go?" Gotham Gazette, Dec. 13, 2022, https://www.gothamgazette.com/city/11717-adams-nypd-subway-mental-illness-removals-hospitals.

likely to result in serious harm to self or others. MHL § 9.41.[4] Additionally, MHL § 9.58 provides that "a physician or qualified mental health professional who is a member of an approved mobile crisis outreach team shall have the power to remove" someone under the same circumstances.[5]

OMH Commissioner Ann Marie T. Sullivan and Chief Medical Officer Thomas Smith issued interpretive guidance in February 2022 (the "OMH Involuntary Removal Guidance") setting forth the circumstances under which courts have determined that the MHL permits "persons who appear to be mentally ill and who display an inability to meet basic living needs" to be mandated into emergency psychiatric assessments and emergency and involuntary inpatient psychiatric admissions.[6]

Constitutional Considerations

In discussing involuntary confinement, the United States Supreme Court has stated that "a State cannot constitutionally confine, without more, a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends." *O'Connor v. Donaldson*, 422 U.S. 563, 576 (1975). The Court added that "[m]ere

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[4] Like most of the provisions of Article 9 of the MHL relating to involuntary admission and treatment, MHL § 9.41 rests on the definitional construct of "danger" to self or others, permitting what is commonly referred to as a Mental Hygiene "arrest." Section 9.41 provides as follows:

> Any peace officer, when acting pursuant to his special duties, or police officer who is a member of the state police or of an authorized police department or force or of a sheriff's department **may take into custody any person who appears to be mentally ill and is conducting himself in a manner which is likely to result in serious harm to himself or others. "Likelihood to result in serious harm" shall mean (1) substantial risk of physical harm to himself as manifested by threats of or attempts at suicide or serious bodily harm or other conduct demonstrating that he is dangerous to himself, or (2) a substantial risk of physical harm to other persons as manifested by homicidal or other violent behavior by which others are placed in reasonable fear of serious physical harm.** Such officer may direct the removal of such person or remove him to any hospital specified in subdivision (a) of section 9.39 or, pending his examination or admission to any such hospital, temporarily detain any such person in another safe and comfortable place, in which event, such officer shall immediately notify the director of community services or, if there be none, the health officer of the city or county of such action.

N.Y. Mental Hyg. Law § 9.41 (emphasis added).

[5] N.Y. Mental Hyg. Law § 9.58 uses identical language ("any person who appears to be mentally ill and is conducting himself in a manner which is likely to result in serious harm to himself or others") and does not elaborate on the standard for likelihood for serious harm articulated in § 9.41. Though the NYC Removal Directive purports to authorize numerous agencies, including many that employ individuals covered by § 9.58, the City Bar is not aware of any specified guidance that has been provided by any of these agencies. The legal issues presented by the overbroad language of the NYC Removal Directive are not ameliorated depending on whether a peace office or mental health professional makes the determination. That said, arrests pursuant to § 9.41 present a special risk, since peace officers are not trained mental health professionals, are armed, and are authorized to use force in certain instances.

[6] *See* Interpretative Guidance for the Involuntary and Custodial Transportation of Individuals for Emergency Assessments and for Emergency and Involuntary Inpatient Psychiatric Admissions, Date: February 18, 2022, https://omh.ny.gov/omhweb/guidance/interpretative-guidance-involuntary-emergency-admissions.pdf. This document was issued by OMH in connection with Governor Hochul's and New York City Mayor Eric Adams' unveiling of their joint plan to remove people from the New York City subway system. *See* The Subway Safety Plan, https://www1.nyc.gov/assets/home/downloads/pdf/press-releases/2022/the-subway-safety-plan.pdf.

public intolerance or animosity cannot constitutionally justify the deprivation of a person's physical liberty." *Id.* At 575. In a Second Circuit case dealing with the seizure of a woman for a psychiatric evaluation, the Court held that evidence that the woman appeared irrational, annoyed, and very uncooperative was not sufficient to imply that she appeared dangerous and to establish probable cause for arrest. *Myers v. Patterson*, 819 F.3d 625, 632 (2d Cir. 2016).

Federal courts have long read constitutional guarantees of due process into the various provisions of MHL's Article 9 as they relate to involuntary retention and treatment. *See e.g. Project Release v. Prevost*, 722 F.2d 960 (2d Cir. 1983). It is well settled that for involuntary removals under § 9.41 of the MHL, "courts apply the same concepts of probable cause and objective reasonableness as in criminal cases to determine whether the confinement is privileged because the plaintiff's behavior was likely to result in serious harm." *Greenaway v. County of Nassau*, 97 F. Supp. 3d 225, 233 (E.D.N.Y. 2015). In doing so, courts treat involuntary removals as "the functional equivalent of [] arrest[s]," *Disability Advocates., Inc. v. McMahon*, 279 F. Supp. 2d 158, 168-69 (N.D.N.Y. 2003), *aff'd,* 124 F. App'x 674 (2d Cir. 2005). It should be noted that no caselaw specifically assesses whether inability to meet basic needs rises to the level of probable cause to justify a mental hygiene arrest under MHL § 9.41.

Probable cause for an involuntary hospitalization under the mental hygiene laws—a so-called "mental health arrest"—only "exists if there are reasonable grounds for believing that the person seized is dangerous to herself or to others." *Guan v. City of New York*, 2020 WL 6365201, at *2 (S.D.N.Y. Oct. 29, 2020), *aff'd on other grounds*, 37 F.4th 797 (2d Cir. 2022) (internal citation and quotation omitted); *Anthony v. City of New York*, 339 F.3d 129, 142 (2d Cir. 2003) (citation omitted); see *Guan*, 37 F.4th at 805 (addressing probable cause standard for involuntary hospitalization under mental health laws and describing an involuntary hospitalization under said laws as a "mental health arrest").

OMH Involuntary Removal Guidance

Although the OMH Involuntary Removal Guidance does not reference the standards requiring probable cause and danger to self or others that underpin a mental hygiene arrest under MHL § 9.41, the OMH Involuntary Removal Guidance specifies that for purposes of a § 9.41 mental hygiene arrest, "[l]ikelihood of serious harm includes: attempts/threats of suicide or self-injury; threats of physical harm to others; or other conduct demonstrating that the person is dangerous to him or herself, including a person's refusal or inability to meet his or her essential need for food, shelter, clothing or health care, **provided that such refusal or inability is likely to result in serious harm if there is no immediate hospitalization**" (emphasis added).[7]

[7] OMH Involuntary Removals Guidance at 3 (quoting *Matter of Scopes v. Shah*, 59 A.D.2d 203, 398 N.Y.S.2d 911 (3d Dep't 1977)). In *Matter of Scopes*, the Appellate Division's Third Department ruled that in order to satisfy substantive due process requirements, "the continued confinement of an individual must be based upon a finding that the person to be committed poses a real and present threat of substantial harm to himself or others.") *See also Matter of Carl C*., 126 A.D.2d 640 (2d Dept 1987) ("State must prove, by clear and convincing evidence, that the person is mentally ill and that he poses a substantial threat of physical harm to himself (resulting) from a refusal or inability to meet his essential needs for food, clothing or shelter"); *Boggs v. Health Hosps. Corp*., 132 A.D.2d 340, 523 N.Y.S.2d 71 (1st Dept. 1987) (noting that the sole issue before the court is whether, upon clear and convincing evidence, "Ms. Boggs is so severely mentally ill that, unless she continues to receive hospital treatment,

The OMH Involuntary Removal Guidance relies on caselaw describing an individual's inability to meet their essential needs in the context of continued retention or involuntary admission of the person for psychiatric treatment. It notes that in order to satisfy substantive due process requirements, "the continued confinement of an individual must be based upon a finding that the person to be committed poses a real and present threat of substantial harm to himself or others, but that such a finding does not require proof of a recent overtly dangerous act."[8]

The NYC Removal Directive

As demonstrated above, the standard of proof set forth in caselaw and the OMH Involuntary Removal Guidance for what sort of risks rise to the level of "likely to result in serious harm" contemplate imminence ("immediate"), likelihood ("real and present"), and seriousness ("substantial harm" or "dangerousness"), rather than a long-running, speculative risk, or less significant harm.[9] OMH largely aligns with the caselaw when it articulates circumstances in which an "inability to meet essential needs" (also referred to as the "basic needs standard") could rise to that threshold. The NYC Removal Directive deviates significantly, sweeping in circumstances that are not as imminent, risky, or as substantial as those contemplated by caselaw or OMH, and therefore purports to authorize removals that will be legally indefensible.

The NYC Removal Directive notes that "case law does not provide extensive guidance regarding removals for mental health evaluations based on short interactions in the field" and then directs that the following circumstances "could be reasonable indicia": "serious untreated physical injury, unawareness or delusional misapprehension of surroundings, or unawareness or delusional misapprehension of physical condition or health." These are vague, broad, and undefined standards untethered to caselaw or any OMH interpretative guidance, and in particular, they do not incorporate the temporal urgency standard found in the latter source.

The City's December 6, 2022 FINEST message explaining the NYC Removal Directive to its police officers offers slightly more specificity.[10] It bears noting that, while this specificity is an

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she is in danger of doing serious harm to herself"). In the *Boggs* case, the evidence before the court presented a combination of factors that led to the court's conclusion that there was justification for involuntary retention of Ms. Boggs in a psychiatric facility, i.e. Ms. Boggs was homeless and was allegedly living without sufficient clothing on a sidewalk grate in winter, running into traffic, making verbal threats to passersby, tearing up and urinating on money that passersby gave her, and covering herself in her own excrement.

[8] OMH Involuntary Removals Guidance at 2 (internal citation and quotation omitted).

[9] See the discussion of *Matter of Scopes* in note 7, *supra,* and the quoted language from *O'Connor* in the preceding section entitled "Constitutional Considerations" and the OMH Involuntary Removal Guidance in the section bearing that title.

[10] FINEST messages are read to police officers at roll call and are used to announce NYPD policy changes. Unlike the NYC Removal Directive, the instructions provided to officers in the FINEST message reference OMH's standard of temporal urgency (in one of the two relevant passages) and *O'Connor's* language with respect to survival. The FINEST message allows involuntary removal: "when the person appears mentally ill and incapable of meeting basic human needs to such an extent that the person is likely to suffer physical injury or serious harm **without immediate attention**" (emphasis added). The FINEST message provides as examples (without language of imminence of danger): "an incoherent person may be unable to assess and safely navigate their surroundings (e.g.

improvement on the NYC Removal Directive, it is only being distributed to one agency (NYPD), and the NYC Removal Directive purports to empower many city agencies (not just NYPD). Given the broader language found in the NYC Removal Directive and the Mayor's statements (discussed below), we remain concerned about the initiative's implementation across all agencies and future training at NYPD specifically.

These concerns are heightened because of the constitutional right (due process for deprivation of liberty) at stake. In contrast to the standards articulated in caselaw and the OMH Involuntary Removal Guidance, the NYC Removal Directive's basic needs standard is, in and of itself, insufficient to demonstrate immediate dangerousness to self or an incapability of surviving safely in the community. Given *O'Connor* and progeny, application of the basic needs standard absent sufficient indicia of dangerousness raises constitutional concerns. See also *Myers*, 819 F.3d at 632 (holding that a display of irrationality, annoyance, and a lack of cooperation was insufficient to imply dangerousness and to establish that the police acted with probable cause). The NYC Removal Directive's attempt to establish a link between basic needs and conduct likely to result in serious harm is analogous to the police's unsuccessful attempt to establish a link between dangerousness and behaviors unrelated to harm in *Myers.*[11]

II. The City's language announcing this initiative both reflects and will exacerbate bias against unhoused people and people with serious mental illness, in violation of anti-discrimination principles, and the NYC Removal Directive will disproportionately burden people of color.

City, State, and Federal law all prohibit discrimination on the basis of disability. The City Bar is concerned that the statements by key policymakers both accompanying the announcement of the NYC Removal Directive and subsequently explaining it will have a harmful effect in perpetuating negative public attitudes towards people with mental illness. The City Bar is further concerned that the NYC Removal Directive will disproportionately burden people of color who are unhoused or experiencing mental illness.

Anti-Discrimination Laws

City, State, and Federal law prohibit discrimination on the basis of disability, including mental illness, and require the City and other actors to provide reasonable accommodations to

avoiding oncoming traffic or subway tracks), may suffer from a serious untreated injury, or unable to seek out food, shelter or other things **needed for survival**" (emphasis added). A copy of the FINEST message, labeled SER#: 42286935, was posted on the docket in the *Baerga et al. v. NYC et al.*, 21-cv-05762 (SDNY) (PAC) litigation, ECF/Docket # 123-1.

[11] There are, no doubt, legal risks that will be created by implementation of the NYC Removal Directive. Most directly, the NYC Removal Directive allows for seizures that will expose the City to liability for wrongful arrests. *See, e.g. Myers*, 819 F.3d at 633 (denying qualified immunity to a police officer where the record was insufficient to demonstrate arguable probable cause for the seizure and transfer to a psychiatric hospital). Additionally, prior experience has unfortunately but consistently shown that involuntary traumatizing interactions with law enforcement and other first responders have, in numerous instances, resulted in serious harm to both City employees and members of the public. This initiative will prompt incidents that are likely to result in additional City liability to its residents, through worker's compensation and tort litigation.

people with disabilities.[12] The NYC Removal Directive is at odds with the City's obligations under these laws in at least two distinct ways.

First, involuntary removals under the NYC Removal Directive could deny people access to public spaces such as the subway and the streets, based on their mental illness or the perception of it, in a much broader set of circumstances than is allowable under the Americans with Disabilities Act (ADA), and without the provision of reasonable accommodations. The ADA explicitly does not require an entity to include an individual who presents a "direct threat" meaning "a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services." 42 U.S.C. § 12182(3). But the NYC Removal Directive covers a significant range of situations that cannot be categorized as falling within this narrow exception to the ADA's general requirement of inclusion.

Second, this initiative's focus on hospitalization in the absence of adequate and appropriate community-based services is inconsistent with both federal law and aligned state commitments to ensure the availability of community-based treatment options. The Supreme Court ruled in *Olmstead v. L.C.*, 527 U.S. 581 (1999)[13] that unnecessary institutionalization of people with disabilities is discrimination under the ADA. Simply stated, the ADA's "integration mandate" "requires that individuals with disabilities receive services in the most integrated setting appropriate to their needs."[14] OMH has acknowledged that this mandate necessitates a shift in New York's state mental health services towards greater community-based services.[15]

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[12] Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132, provides: "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." The City's Human Rights Law further provides: "it is an unlawful discriminatory practice for any person prohibited by the provisions of this section from discriminating on the basis of disability not to provide a reasonable accommodation to enable a person with a disability to . . . enjoy the right or rights in question provided that the disability is known or should have been known by the covered entity." N.Y.C. Admin. Code § 8-107(15)(a).

[13] The Court in Olmstead was encountering a remarkably similar circumstance to the issue at hand, where the plaintiffs, including Lois Curtis, a passionate self-advocate who recently passed away, cycled in and out of psychiatric hospitalization. "Lois and Elaine found themselves going in and out of the state's mental health hospitals dozens of times. After each stay in the hospital, they would go back home; but then, because they did not have help at home, they would start to struggle again and would have to go back to the hospital to get help again. Lois and Elaine asked the state of Georgia to help them get treatment in the community so that they would not have to go live at the state mental hospital off and on." Disability Integration Project of Atlanta Legal Aid Society, Brief History of Olmstead, https://www.olmsteadrights.org/about-olmstead/.

The Supreme Court stated in *Olmstead* that "unjustified institutional isolation of persons with disabilities is a form of discrimination" in part because "[i]n order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice." *Olmstead v. L.C.*, 527 U.S. at 600, 601.

[14] U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR), https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html.

[15] New York State HCBS [Home and Community-Based Services] Settings Transition Plan (2018) at pg. 195. "The legal system's expansion of civil rights to include people with mental illness, as part of Olmstead Legislation and Americans with Disabilities Act, has begun to move policy from the concept of least restrictive setting to full community inclusion. However, New York currently exceeds both the national average inpatient

Even assuming a person requires and would benefit from acute inpatient psychiatric services, there is a shortage of inpatient psychiatric beds in New York City, meaning that many people simply languish in psychiatric emergency rooms for longer. Some inpatient psychiatric wards take few Medicaid patients, which can make it harder to find beds for homeless people. The fundamental systemic issue, however, is that there are inadequate services and support for patients following their discharge from a hospital.[16] To that end, the City Bar welcomes Governor Hochul's recent announcement that hospitals and other inpatient providers will be required to develop a discharge plan that involves immediate wraparound services.

Disproportionate Effects on Communities of Color

The NYC Removal Directive may also implicate the City's obligations to refrain from engaging in practices that have a disparate effect on people of color. Data suggests policies like the NYC Removal Directive are likely to disproportionately impact Black and brown people.

People of color with disabilities are overrepresented in the population of individuals experiencing homelessness.[17] Black New Yorkers already make up 44% of the people currently receiving court-mandated treatment under one state law, though they're less than a quarter of the city's population. In New York City, "44% of current assisted outpatient treatment (AOT) recipients are Black and 32% are Latinx, according to state data."[18] This data suggest that Black and brown New Yorkers are much more likely to be subjected to forced removals from public spaces than white New Yorkers.

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utilization rate at state-operated Psychiatric Centers (PCs), and per capita inpatient census levels at state-operated PCs in other urban states and all Mid-Atlantic States. . . . The OMH is in the process of creating the mental health system that New York needs in the 21st Century—a system focused on prevention, early identification and intervention, and evidence-based clinical services and recovery supports. OMH is rebalancing the agency's institutional resources to further develop and enhance community-based mental health services which are also consistent with the Americans with Disabilities Act (ADA). The US Supreme Court's 1999 Olmstead decision held that the ADA mandates that the State's services, programs, and activities for people with disabilities must be administered in the most integrated setting appropriate to a person's needs." Available at: https://www.health.ny.gov/health_care/medicaid/redesign/hcbs/docs/2018-05-18_hcbs_final_rule.pdf.

[16] Andy Newman and Joseph Goldstein, *Can New York's Plan for Mentally Ill Homeless People Make a Difference?,* New York Times, December 15, 2022, https://www.nytimes.com/article/nyc-homeless-mental-health-plan.html.

[17] Basic Facts about Homelessness, Coalition for the Homeless, updated December 2022, https://www.coalitionforthehomeless.org/basic-facts-about-homelessness-new-york-city/. *See also* Stacy M. Brown, *Blacks Hit Hardest as NYC's Homeless Population Grows Amid Mental Health Crisis* (Mar. 23, 2022), https://www.washingtoninformer.com/blacks-hit-hardest-as-nycs-homeless-population-grows-amid-mental-health-crisis/.

[18] *See* Ethan Geringer-Sameth, *What's Behind the Increased Use of Kendra's Law in New York City?*, Gotham Gazette, September 27, 2022, https://www.gothamgazette.com/state/11599-increase-kendras-law-new-york-city?utm_source=The+Marshall+Project+Newsletter&utm_campaign=703deaa159-EMAIL_CAMPAIGN_2022_12_16_05_14&utm_medium=email&utm_term=0_5e02cdad9d-703deaa159-%5BLIST_EMAIL_ID%5D.

Bias and Stereotyping

In their public explanations of this initiative, the mayor and public entities have focused on two primary justifications. The first is, according to the mayor, the "moral obligation" to connect severely mentally ill New Yorkers to appropriate care and housing. We support the removal of barriers to accessing care and stable housing for those who need them. The second justification, however, has included the repeated use of stigmatizing language that relies upon stereotypes and exacerbates bias. These statements, quoted below, reflect a shared and fundamentally flawed premise, which is an erroneous belief that those experiencing mental illness definitionally constitute a threat to the personal safety of others.

Inability to meet *one's own* basic needs is not indicative of dangerousness *to others*. As noted above, both the MHL and caselaw provide for distinct lanes of analysis for whether someone constitutes a threat to *themselves* and whether someone constitutes a threat to *others*, and do not countenance unjustified slippage between these concepts.[19] The OMH Involuntary Removal Guidance explicitly identifies inability to meet one's needs as potential evidence of a risk of danger to oneself, rather than as evidence of a danger to others: "conduct demonstrating that the person is dangerous to him or herself, including a person's refusal or inability to meet his or her essential need for food, shelter, clothing or health care, . . ."[20] Despite popular perceptions and fears, empirical data connecting even severe mental illness with an increased risk of perpetrating interpersonal violence is inconclusive, and an appropriate assessment of dangerousness is necessarily highly individualized.[21]

The mayor's statements at the press conference announcing this new initiative present a fundamental misconception and improperly conflate mental illness and interpersonal violence: "There's nothing dignified about using a corner of a tent as a restroom or having month-old food sitting there or talking to yourself, being delusional, or waiting until you carry out a dangerous act before we respond. That is just so irresponsible that **we know that this person is about to probably go off the edge and harm someone** but we're going to wait until it happened."[22]

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[19] *See supra* note 4 quoting MHL § 9.41: "'Likelihood to result in serious harm' shall mean (1) substantial risk of physical harm to himself as manifested by threats of or attempts at suicide or serious bodily harm or other conduct demonstrating that he is **dangerous to himself, or** (2) a substantial risk of physical harm **to other persons** as manifested by homicidal or other violent behavior by which others are placed in reasonable fear of serious physical harm" (emphasis added).

Though both the FINEST message and the NYC Removal Directive repeat the MHL's general language of "harm to themselves or others" there is nothing in either document suggesting that self-neglect would indicate a risk of harm to others, and in fact the FINEST message is quite clear that the risk of harm contemplated by the initiative is "to that person."

[20] OMH Involuntary Removals Guidance at 3.

[21] *See, e.g.,* Varshney M, Mahapatra A, Krishnan V, et al. *Violence and Mental Illness: What is the True Story?* J Epidemiology & Community Health 2016; 70:223-225, https://jech.bmj.com/content/70/3/223.

[22] "Address on the Mental Health Crisis in New York City" transcript available at: https://www.nyc.gov/office-of-the-mayor/news/871-22/transcript-mayor-eric-adams-delivers-address-mental-health-crisis-new-york-city-holds (cited *supra*, n. 2) (emphasis added).

Governor Hochul, in announcing funding for mental health services, similarly conflated general public discomfort with individualized assessments of danger, describing "a public safety crisis" stemming from underfunding of mental health services, and pointing to the public feeling "anxious" about encountering people with mental health conditions while on the subway as evidence thereof.[23]

Unfortunately, these descriptions of the initiative by elected officials -- as well as others that have appeared in both City and State published documents[24] -- have the effect of perpetuating bias. The Mayor, the Governor, and the *Making New York Work for Everyone* report, which was the culmination of months of collaboration among a panel "of civic leaders and industry experts"[25] (although the list of panel contributors does not include experts in mental health treatment or leaders of disability advocacy organizations) have repeated harmful stereotypes about people with mental illness. As the New York City Bar Association has stated in other contexts, "Words matter because they reflect thought and drive action."[26] The disability rights community has a motto: "nothing about us without us," which calls for the meaningful involvement of people with disabilities in the development of policy that impacts them. We call on City leaders to repudiate bias and commit to inclusive decision-making in its future efforts relating to mental illness.

As discussed further below, this new initiative arrives in the context of the City's inadequate provision of voluntary, community-based mental health treatment options, which has resulted in the inaccessibility of low-cost care and long waiting lists. Governor Hochul's State of

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[23] Destra, Shantel, "Lawmakers welcome Hochul's $1 billion to address mental health," City & State NY, Jan. 11, 2023, https://www.cityandstateny.com/policy/2023/01/lawmakers-welcome-hochuls-1-billion-address-mental-health/381708/.

[24] Similarly, the City's Subway Safety Plan notes as an impetus for this initiative the perceptions of the public: "Second, our subways must be safe and feel safe for every person who enters them . . . . Our city's prosperity depends on everyone feeling confident and secure when they enter a station." Subway Safety Plan at 4, https://www1.nyc.gov/assets/home/downloads/pdf/press-releases/2022/the-subway-safety-plan.pdf (cited *supra*, n. 6).

A joint City and State report *Making New York Work for Everyone* released this month similarly states: "Concerns about safety and quality of life can stymie economic prosperity in terms of investment, revenue, and overall economic activity. We must acknowledge that many residents, commuters, and business owners have been increasingly concerned for their safety and that of their employees as they move around the city." *Making New York Work for Everyone*, December 2022, at pg. 42, https://edc.nyc/sites/default/files/2022-12/New-NY-Action-Plan-Making_New_York_Work_for_Everyone.pdf. Conflating again the concepts of risk of harm to self and harm to others, the report states: "As part of the [NYC Removal Directive] plan, the Mayor issued a directive to outreach workers, City-operated hospitals, and first responders clarifying that they have the legal authority to provide care to New Yorkers when severe mental illness prevents them from meeting their own basic human needs to the extent that they are a danger to themselves **or others**" (emphasis added). *Id*. at 44.

[25] *Making New York Work for Everyone* at 4.

[26] President's Column (Winter 2021) by former City Bar President Sheila Boston, https://digital.nycbar.org/44thstreetnotes/winter-2021/launch-of-the-six-priorities/. *See also* Statement of New York City Bar Association on Reckless Statements and Their Impact in the Charged Environment Surrounding the Mar-A-Lago Search (August 24, 2022) ("words matter and have consequences") *and* Statement of New York City Bar Association on The Disturbing Trend of Threats and Violence Against Judges and the Vital Importance of Judicial Security (June 24, 2022) ("today we urge all Americans, particularly public officials and members of the legal profession, to remember that in public discourse our words matter.").

the State included an announcement of new funding for inpatient and outpatient mental health services, as well as funding for affordable housing.[27] These investments are welcome and will, in time, reduce barriers to treatment and stable housing; at the same time, the effects of decades of underfunding for these services will require time and sustained investment to reverse.

III. This initiative directs resources into a failed strategy, at a time when the City has reduced investments in effective strategies that connect people to long term treatment and care.

Numerous groups and individuals with lived experience, both people with mental illness or those with experience providing treatment, have cautioned that increasing involuntary commitments will hinder, rather than improve, our ability to successfully connect people with care.[28]

Fortunately, there are alternative approaches that will remove barriers to accessing care and stable housing for people experiencing mental illness. As the Bazelon Center has noted,[29] research indicates that high-quality engagement of homeless people with mental health conditions, such as that provided through New York's Street Homeless Advocacy Project,[30] which sends people with lived experience with homelessness back to the streets to help others, helps individuals see the value of and agree to participate in supportive services.[31] Safe, stable, and affordable housing, provided with voluntary supports, has been shown to help homeless New Yorkers and

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[27] Press Release, "Governor Hochul Announces Comprehensive Plan to Fix New York State's Continuum of Mental Health Care," Jan. 10, 2023, https://www.governor.ny.gov/news/governor-hochul-announces-comprehensive-plan-fix-new-york-states-continuum-mental-health-care.

[28] *See, e.g.* Fountain House Calls for Comprehensive Mental Health Care in Response to Mayor Adams' Directive on Involuntary Removals, December 1, 2022. "[T]he approaches announced this week will not address the revolving doors to hospitals and jails, and can further stigmatize and isolate people living with serious mental illness." Available at https://www.fountainhouse.org/news/fountain-house-statement-on-mayor-adams-directive-to-expand-involuntary-removals; Anthony Almojera, *I'm an N.Y.C. Paramedic. I've Never Witnessed a Mental Health Crisis Like This One*, The New York Times (guest essay), December 7, 2022. "I'm not opposed to taking mentally ill people in distress to the hospital; our ambulances do this all the time. But I know it's unlikely to solve their problems . . . . While I don't know how forcing people into care will help, I do see how it will hurt. Trust between a medical responder and the patient is crucial. Without it, we wouldn't be able to get patients to talk to us, to let us touch them or stick needles filled with medications into their arms. But if we bundle people into our ambulances against their will, that trust will break." Available at: https://www.nytimes.com/2022/12/07/opinion/nyc-paramedic-mental-health-crisis.html?smid=nytcore-ios-share&referringSource=articleShare.

[29] Judge David L. Bazelon Center for Mental Health Law, *Mayor Adams' Plan Will Not Help New Yorkers With Mental Disabilities*, December 22, 2022, http://www.bazelon.org/wp-content/uploads/2022/12/BC-NYC-Statement-12-2-22.pdf.

[30] *See* Forum Staff, *City Launches Homeless Advocacy Project*, The Forum (Jul. 21, 2022), http://theforumnewsgroup.com/2022/07/21/city-launches-homeless-advocacy-project/.

[31] *See, e.g.,* Center for Court Innovation, *The Myth of Legal Leverage?* ("Studies of therapeutic intervention strongly suggest that the quality of the human interaction outweighs the importance of any particular protocol or approach…." "factors like goal consensus, empathy, alliance, and positive regard are significantly greater than, say, model fidelity," and "a robust therapeutic relationship is less a matter of dosage and more a matter of engagement."), https://www.courtinnovation.org/sites/default/files/media/documents/2020-04/report_the_myth_of_legal_leverage_04232020.pdf.

others stabilize and avoid hospitalization and incarceration.[32] And longer-term services, such as assertive community treatment (ACT), supported employment, and peer support services—delivered not in the hospital, but in the person's own home and community—have been shown to break the cycle of institutionalization.[33]

Yet a report issued by New York City's Public Advocate in November 2022 indicated that the city has reduced the scope of effective evidence-based strategies that would better address mental health crises. There are now only four community- and peer-led Respite Care Centers in the five boroughs of the city, down from eight such centers in 2019.[34] There are only 19 behavioral health mobile crisis teams (MCTs) that can respond to calls for help instead of the police, serving the entire city in 2022, down from 24 teams in 2019.[35]

While the City has a pilot program to send teams of alternative first responders to 911 calls related to mental health crises, these "B-HEARD" teams have a limited scope and capacity. They only responded to 16 percent of 911 calls related to mental health crises in the few Manhattan neighborhoods where they are being piloted, and they have a response time that is not comparable with that of the police.[36]

The Public Advocate's report found that the city is "lagging behind in providing supportive housing, with an often-delayed application process,"[37] and "lagging in the inclusion of peers with lived-in experiences into the city's mental health programs."[38] The Correct Crisis Intervention Today - New York City (CCIT-NYC) coalition, which is made up of civil rights and human service organizations, people with lived experience with mental health crises, family members, and other advocates, has advocated for a decade to increase the availability of evidence-based, peer-led responses to mental health crises.[39] "The City has the power to provide onsite treatment, as well as treatment in homeless shelters or supported housing, but has chosen not to."[40] We note that

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[32] S. Tsemberis & R.F. Eisenberg, *Pathways to Housing: Supported Housing for Street-dwelling Homeless Individuals with Psychiatric Disabilities,* Psychiatric Services Vol. 51, Issue 4, 487-93, https://doi.org/10.1176/appi.ps.51.4.487.

[33] Bazelon Center for Mental Health Law, *Diversion to What? Evidence-Based Mental Health Services that Prevent Needless Incarceration* (September 2019), http://www.bazelon.org/wp-content/uploads/2019/09/Bazelon-Diversion-to-What-Essential-Services-Publication_September-2019.pdf.

[34] Office of the Public Advocate, *Improving New York City's Response to Individuals in Mental Health Crisis 2022 Update 3* (November 2022) at pg. 3, https://advocate.nyc.gov/static/assets/Mental_Health_Updates_2022c.pdf.

[35] *Id*. at 5.

[36] *Id*. at 7-8.

[37] *Id*. at 5.

[38] *Id*. at 10.

[39] https://www.ccitnyc.org/.

[40] National Alliance on Mental Illness – NYC, NAMI-NYC Calls for Comprehensive, Person-Centered Behavioral Health Care for People Living with Serious Mental Illness, November 29, 2022, https://naminycmetro.org/involuntaryremoval/.

these shortcomings may be addressed by Governor Hochul's recent announcement of significant funding for community-based mental health services and supportive housing.

Just last month, the United States Interagency Council on Homelessness released a comprehensive report entitled *All In: The Federal Strategic Plan to Prevent and End Homelessness* (the *All In* report).[41] It notes that local officials have responded to a rise in the number of people living in unsheltered locations "not always in the most effective ways" through "out of sight, out of mind" policies that displace people without successfully connecting them to evidence-based services.[42] The mayor's initiative fits broadly within the parameters of effectively criminalizing homelessness, which the *All In* report identifies as counterproductive. Such policies take away resources from constructive solutions to homelessness, create trauma, can erect financial and criminal legal barriers for people seeking pathways out of housing insecurity and homelessness, and disproportionately burden already-marginalized communities including people of color, LGBTQI+ people and people with disabilities.

* * *

In conclusion, we ask for a commitment from the City to pause its rushed implementation of this initiative, and take seriously the concerns raised by individuals with lived experience of mental illness and/or homelessness following the announcement. In the coming months, our committees, like many interested New Yorkers, will carefully evaluate the City's proposed legislative and operational changes, and would welcome the opportunity to meet with city attorneys to discuss these legal issues. There are evidence-based solutions available to the City to better support people accessing care and housing. We call on the City to halt this removal initiative and instead pursue effective strategies within its legal authority.

Civil Rights Committee
Kevin Eli Jason and Kathleen Rubenstein, Co-Chairs

Disability Law Committee
Katherine Rose Carroll, Chair

Mental Health Law Committee
Mikila J. Thompson, Chair

New York City Affairs Committee
Erik Rubinstein, Secretary[43]

Social Welfare Committee
Lindsay Funk and Sandra Gresl, Co-Chairs

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[41] United States Interagency Council on Homelessness, *All In: The Federal Strategic Plan to Prevent and End Homelessness* (December 2022), https://www.usich.gov/All_In_The_Federal_Strategic_Plan_to_Prevent_and_End_Homelessness.pdf.

[42] *Id*. at 20.

[43] The Chair and a number of members of the New York City Affairs Committee recused themselves from discussion and voting on this letter.

NEW YORK STATE
Unified Court System
OFFICE OF COURT ADMINISTRATION

LAWRENCE K. MARKS
CHIEF ADMINISTRATIVE JUDGE

JOHN W. MCCONNELL, ESQ.
EXECUTIVE DIRECTOR

NANCY J. BARRY, ESQ.
CHIEF OF OPERATIONS

MEMORANDUM

June 17, 2020

To: Hon. George J. Silver
Hon. Vito C. Caruso

From: John W. McConnell
Nancy Barry

Subject: New Procedures for ADA Accommodation Requests

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Chief Administrative Judge Lawrence K. Marks recently approved for distribution a set of revised procedures for handling requests for accommodations of disabilities made by parties, attorneys, witnesses, and other court visitors in the trial courts of the Unified Court System (Exh. A). Developed under the supervision of the Chief Judge's Advisory Committee on Access for People with Disabilities, these procedures are intended to simplify the application process and facilitate swifter provision of appropriate accommodations to court users. In short, the revised guidelines provide that

- Accommodation requests, whether made in advance of, or on the day of a court appearance, and whether in-person, oral or written, should be forwarded to the Chief Clerk (in New York City) or the District Executive (outside New York City) for handling.

  (An optional, online accommodation request form will be available for use by requestors later this year to facilitate advance notice requests.)

- Following receipt of an accommodation request, the Chief Clerk/District Executive will assess whether it addresses a judicial issue (e.g., an adjournment, additional time to submit papers, appearance by phone, trial breaks, etc.) or administrative accommodation (e.g., provision of assistive listening devices, use of Sign language interpreter, or relocation to a physically accessible courtroom, etc.). Judicial accommodations will be forwarded to the appropriate judge for resolution; administrative accommodations will be handled by the Chief Clerk/District Executive or their designee.

- If a judge receives an accommodation request by a court user appearing before her, and the request addresses a purely judicial accommodation, the judge should determine the request without referring it to the Chief Clerk or District Executive. Any aspect of a request made directly to the judge that involves an administrative accommodation should be referred to the Chief Clerk/District Executive for consideration and appropriate action.

- Chief Clerks and District Executives **must** consult with the Statewide ADA Coordinator before denying an accommodation request. When denying a request, a written Denial of Accommodation Form (web link) must be issued, with a copy sent to the Statewide ADA Coordinator. An administrative denial is subject to review within 10 days by the Statewide ADA Coordinator.

Further information on this procedure, as well as substantial additional information about the court system's commitment to assuring access to all, may be found at http://ww2.nycourts.gov/Accessibility/index.shtml.

Please note that each courthouse should have informational ADA posters, prominently displayed near courthouse entrances and on each floor, directing court users seeking accommodations to the Chief Clerk's office for assistance. If a courthouse within your jurisdiction does not have such signage, please notify the ADA Office.

Please distribute this memorandum and attachment to all persons who interact with the public and may be called upon to assist or provide information about accommodation procedures. Questions about the new procedure may be addressed to John Sullivan, Statewide ADA Coordinator (jjsulliv@nycourts.gov). And as always, thank you for your kind assistance in implementing this important court policy.

Attachment

c: Administrative Judges
Hon. Rosalyn Richter
Scott Murphy
Linda Dunlap-Miller
District Executives
NYC Chief Clerks
Chief Michael Magliano
Carolyn Grimaldi
Lucian Chalfen
John Sullivan
Barbara Zahler-Gringer

Guidelines for Handling Requests for Disability Accommodations
(June 2020)

I. Categories of Disability Accommodation Requests

Requests for disability accommodations fall into three categories: judicial, administrative, or a combination of judicial and administrative. Identifying the type of request is important in order to determine how the request should be handled.

A. *Judicial requests* are for accommodations that only a judge – not a court manager – can grant or deny. Judicial requests typically seek an accommodation that involves the judge exercising authority over:

- the parties (e.g., to adjourn a case, or to appear by phone or video, or for more time to submit motion papers), or
- courtroom practices (e.g., to have someone other than an attorney sit beside a party; to take frequent breaks during the proceeding; to schedule the matter in the afternoon, rather than the morning), or
- the substance of the proceedings (e.g., a motion to be permitted to forego cross-examination, or to re-write a jury instruction).

B. *Administrative requests* are for accommodations that <u>don't</u> involve the judge's authority over the case and the parties. These types of requests usually involve:

- providing auxiliary equipment or services (e.g., sign language interpreters; assistive listening devices; CART reporting; or large print or Braille format documents), or
- asking court managers to vary usual court procedures (e.g., relocate a proceeding from an inaccessible courtroom to an accessible courtroom; permit the entry of a service animal into the courthouse; or assist with filling out forms).

C. In some cases, a person may be asking for a *combination of judicial <u>and</u> administrative accommodations*. In those instances, the judge (and only the judge) can determine whether to grant or deny the judicial accommodation requests, but the judge should not be asked to address the administrative accommodation request portion. In other words, responsibility for addressing these types of hybrid requests will be divided between the judge and non-judicial personnel.

II. Receipt of Disability Accommodation Requests

An accommodation request can be made orally or in writing. It can be communicated via e-mail, fax, phone, or in person. Although we ask people to bring their requests to our attention in advance of their court dates, sometimes the request isn't received until the person appears in court. Sometimes, non-judicial personnel are the first to receive the request, and sometimes the request isn't made until the court user is in front of the judge.

III. Process for Handling Disability Accommodation Requests

With one exception – see III (C), below – Chief Clerks (in New York City) and District Executives (outside New York City) are responsible for managing the court system's response to disability accommodation requests. The Chief Clerk or District Executive determines whether the request requires a judicial or administrative response (or both), and addresses the request accordingly, as set forth in III (A) and (B), below.

A. Requests Made in Advance of a Court Appearance

All *advance notice* accommodation requests are made:

- In courts within New York City, to the Chief Clerk of the Court;
- In courts outside New York City, to the District Executive.

Upon receipt, the Chief Clerk or District Executive determines whether the disability request is administrative, judicial, or both. The Statewide ADA Office is available for consultation if the answer isn't clear. If it appears that any delay will be involved, the requestor should be so notified – it is important that court users be kept informed of the status of their requests.)

If the request solely concerns a judicial accommodation:

1. The request is forwarded immediately to the chambers of the judge presiding over the proceeding, indicating to chambers staff that the type of accommodation sought can only be granted or denied by the judge, not administrative personnel.

2. The requestor is informed that the request must be addressed by the judge, and that it has been forwarded to the judge for determination.

If a request is for both administrative and judicial accommodations, that portion that seeks judicial accommodations is referred to the judge, and the requestor so informed. The remaining administrative portion of the request is handled by the court manager, as described below.

If the request is solely administrative in nature, the court manager ensures that it is addressed promptly. The District Executive or Chief Clerk:

1. Handles it on their own, or

2. Designates someone else in their office, or the court involved, to be the point person for ADA requests.

B. Requests Made Without Advance Notice

In some cases, individuals may not request an accommodation until they appear in court. Such no-advance notice, in-person accommodation requests might be directed, in the first instance, to front-facing non-judicial personnel (i.e., the clerk of the court, court officers, counter clerks, part clerks, etc). *Those requests also need to be determined by Chief Clerks and District Executives, as follows.*

All non-judicial court personnel should direct "in-person, day-of" requestors to the court's Chief Clerk's Office.

In NYC Supreme and Surrogate's Courts, the Chief Clerk determines if a judicial response is required and, if so, forwards it to the appropriate judge and informs the requestor that the judge will determine it. If an administrative response is called for, the Chief Clerk (or a designee) provides the appropriate accommodation, if any.

In NYC Civil, Criminal, and Family Courts, the court's Borough Chief Clerk or Clerk of Court immediately advises the court's Chief Clerk (citywide) of the accommodation request; the Chief Clerk (citywide) responds as above.

In courts outside NYC, the court's Chief Clerk immediately advises the District Executive of the accommodation request, and the District Executive determines if a judicial response is required and, if so, forwards it to the appropriate judge and informs the requestor that the judge will determine it. If an administrative response is called for, the District Executive (or a designee) provides the appropriate accommodation, if any.

In all cases, it is important for Chief Clerks and District Executives to follow up to ensure that an accommodation has been provided (if it is appropriate to do so), and that the accommodation is proving effective.

To ensure that requests are addressed in a timely and efficient manner, it is essential that all court personnel who interact with the public know that people with day-of, in-person ADA accommodation requests are to be immediately directed, or escorted, to the Clerk's Office. (However, in those rare courts that do not have a Clerk's Office on the premises, the Clerk's Office should be contacted by phone – the requestor should not be directed to report to another location).

C. Requests Made to Judges

Judges who are asked for *purely judicial* accommodations determine the request, without referring it to the District Executive (outside NYC) or Chief Clerk (inside NYC). Judges who are asked for *administrative* accommodations should refer the request to the District

Executive or Chief Clerk, who will consider the request and make any necessary arrangements, directly or via a designee.

IV. Resolving Accommodation Requests

Granting accommodation Requests: Many requests can be resolved quickly. In some instances, the District Executive or Chief Clerk may need *further conversation* with the requestor if:

1. It is not clear that the individual qualifies for an ADA accommodation, or

2. A better understanding of the individual's limitations and how they might affect participation in court proceedings is needed, or

3. There is uncertainty about the best and most reasonable means of accommodating the individual's disability. Consult with the ADA Office if assistance is needed.

It is important to remember that court managers and staff should never make overly intrusive inquiries or request medical information that is not relevant to the need for an accommodation. Dialogue about a person's disabilities should always be handled in a sensitive and confidential manner that protects individual privacy as much as possible.

When the District Executive or the Chief Clerk, is *granting* an accommodation request, it does not have to be done in writing. However, it might be a best practice to keep a record of the types of accommodations being requested, as that may help ensure an adequate distribution of resources.

Ongoing Accommodation Requests: Where an administrative accommodation is needed on an ongoing basis (e.g. a sign language interpreter, or the relocation of a proceeding to an accessible courtroom), a separate request is not necessary for each court appearance. Court personnel should ensure that the accommodation is in place and ready to go at each anticipated future appearance. Judicial accommodation requests must be renewed whenever the requestor appears before a different judge.

Denial of Accommodation Requests: Chief Clerks and District Executives must consult with the Statewide ADA Coordinator before *denying* an accommodation request. If a request is denied, the Chief Clerk or District Executive must issue a written Denial of Accommodation Form and give it to the requestor, with a copy to the Statewide ADA Coordinator. An administrative denial is subject to review, within 10 days, by the Statewide ADA Coordinator.