

Report and Recommendations of the New York State Bar Association Committee on Disability Rights

Guardianship for People with Developmental Disabilities: Examination and Reform of Surrogate's Court Procedure Act Article 17-A is a Constitutional Imperative.

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Executive Summary

The New York State Bar Association Committee on Disability Rights argues that there is an urgent need to reform Article 17-A of the SCPA. As a Committee, we set forth the following general principles which a guardianship statute for adults with intellectual and developmental disabilities should contain. The report will further explain the underpinnings of the principles we articulate.

- 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.
- 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 their 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. 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 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.

Report of the Disability Rights Committee -New York State Bar Association¹

Guardianship for People with Developmental Disabilities: Examination and Reform of Surrogate's Court Procedure Act Article 17-A is a Constitutional Imperative.

Introduction

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 their 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 their 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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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-Torok, 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]).

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*

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 incapacity³ 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:

By appointing a guardian, the court entrusts to someone else the power to choose where [they] will live, what medical treatment [they] will get and, in rare cases, when [they] will die. It is in one short sentence, the most punitive civil penalty that can be

Decisions Act for Persons with Developmental Disabilities and Patients In or 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.

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 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 their 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).

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.

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 their 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 none 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 Act⁸ 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." 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.

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. Adopted in 2006, the CRPD is the first international human rights treaty drafted specifically to protect the rights of people with disabilities. Even though the United States Senate has not

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.

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)

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-Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship in New York*, 75 Alb. L. Rev. 807, 813, n. 36).

See Bailly & Nick-Torok, supra note 6, Should We Be Talking, pp. 813-14 and the authorities cited therein.
 Id.

Id. at 814, citing ABA Commission on the Mentally Disabled, Guardianship & Conservatorship 1-2 (1979);
Model Guardianship and Conservatorship Act.

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

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 Committee on Disability Rights argues that there is an urgent need to reform article 17-A. 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.
- 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.¹⁵
- 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.

Rights, Routledge (2015).

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).

See also Principle 11.

- 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. 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 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.

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]).

- 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.¹⁷ 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. ¹⁸ 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 embraced assumption that "mentally retarded" people were perpetual children. ¹⁹ 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.²⁰

¹⁷ MHL § 81.01.

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]).

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 (see 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 their person or of their 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).

See Shea and Pressman, supra note 2, Guardianship a Civil Rights Perspective, at 21.

Article 81 of the Mental Hygiene Law 21

Article 81 of the MHL, proceedings for appointment of a guardian for personal needs or property management, became effective on April 1, 1993.²² Article 81 replaced the former dual structure conservatorship and committee statutes that operated in New York.²³ 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.²⁴ 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.²⁵ In 1972, the conservatorship statute (former article 77 of the MHL) was enacted into law as a less restrictive alternative to the committee procedure.²⁶ 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:

[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.²⁷

However, by design, the statute limited the power of the conservator to property and financial matters.²⁸ 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.²⁹ 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.³⁰ Cast as reform measures, the amendments actually contributed to the "legal blurring" between articles 77 and 78.³¹ 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*,³² 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.³³ However,

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.

²² 1992 N.Y. Laws c. 698.

²³ *Id*.

²⁴ *Id*.

²⁵ In re Fisher, 147 Misc. 2d 329, 332 (Sup. Ct. N.Y. County 1989).

²⁶ 1972 N.Y. Laws, c. 251

²⁷ MHL § 77.01 (repealed 1992 N. Y. Laws c. 698).

²⁸ Id

²⁹ MHL 77.04 & 70.02 (repeated 1992 N. Y. Laws c. 698).

³⁰ 1974 N. Y. Laws c. 623 § 3.

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 Koppell & Kenneth J. Munnelly, The New Guardian Statute: Article 81 of the Mental Hygiene Law, N. Y. St. B. J., Feb. 1993, at 16.

³² 77 N.Y.2d 703 (1991).

Solinski, *supra* note 27 at 450.

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." ³⁴

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.³⁵ 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.³⁶

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 their best interests would be promoted by the appointment.³⁷ 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. ³⁸ 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.³⁹ 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.⁴⁰ In contrast, article 81 proceedings can be very complex and

³⁴ **I**d

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).

³⁶ MHL § 81.01.

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]).

³⁸ *Id*.

See Bailly & Nick-Torok, supra note 6, Should We Be Talking, 821-825.

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.

expensive to prosecute.⁴¹ 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.⁴²

Given the many substantive and procedural variations between article 17-A and article 81, the Governor's *Olmstead* Cabinet⁴³ and commentators have called for reform or "modernization" of article 17-A. 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. Further, a lawsuit was commenced on February 7, 2024 in Supreme Court of New York, Albany County, by Disability Rights New York seeking, among other relief, to enjoin the appointment of guardians pursuant to article 17-A. The complaint alleges 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. The complaint names as defendants New York State, The Unified Court System of the State of New York, Honorable Rowan D. Wilson, as Chief Judge of the New York State Unified Court System, and Honorable Joseph A. Zayas, as Chief Administrative Judge of the New York State Unified Court System.

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

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).

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.

See Bailly & Nick-Torok, supra note 6; Andreasian et al., supra note 36.

⁴⁵ See In re D.D., 50 Misc. 3d 666 (Sur Ct., Kings Co. 2015).

Illegal and Discriminatory Guardianships in New York State, https://www.drny.org/page/news--press-3.html. A 2016 federal lawsuit alleging similar claims by Disability Rights New York, Inc. was subsequently dismissed on *Younger* abstention grounds. *See Disability Rights New York v. New York*, 916 F. 3d 129 (2d Cir. 2019). The federal court's decision to abstain does not prejudice the right of the plaintiffs to challenge the statute in state court. 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]).

⁴⁷ See Jennifer Monthie, The Myth of Liberty and Justice for All: Guardianship in New York State, 80 Alb. L. Rev. 947 (2016-2017).

Illegal and Discriminatory Guardianships in New York State, https://www.drny.org/page/news--press-3.html.

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." 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. 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. ⁵¹

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. New York courts have described guardianship as "calculated to deprive a citizen not only of the possession of his property, but also of his personal liberty." 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.⁵⁴

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

⁵⁰ See U. S. Const. amend. XIV § 1; Reno v. Flores, 507 U.S. 292, 301-02 (1993).

U.S. Const. amend V.

See Monthie, supra note 47 at 961 and the authorities cited therein.

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 (see Sadie Ishee and Sheila Shea, Make Every Vote Count: Reform of New York's Election Law to Protect the Franchise for People with Disabilities, 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.

⁵³ *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).

In re Mark C.H., 28 Misc. 3d 765, 776 (Sur. Ct. New York Co., Glen, J.).

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.⁵⁵ 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; ⁵⁶
- 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.

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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"

The certifications are often entirely conclusory, hearsay and/or are not subject to cross-examination.

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.⁵⁷

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." 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 arbitrary, wrongful government actions regardless of the fairness of the procedures used to implement them." ⁵⁹ 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. ⁶⁰

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.⁶¹ 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.⁶² The best interest standard has been described as "amorphous"⁶³ 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."⁶⁴ 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

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).

⁵⁸ See U. S. Const. amend. XIV.

⁵⁹ Zinermon v. Burch, 494 U.S. 113 (1990).

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]).

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."

⁶² SCPA 1754

⁶³ Koppenhoefer v. Koppenhoefer, 159 A.D.2d 113 (2d Dept. 1990).

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).

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."

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 scrutinized and carefully confined." 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.⁶⁷

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.⁶⁸

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

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See, Monthie, supra note 47 at 988.

⁶⁶ Harper v. Va. State Bd. Of Elections, 383 U.S. 663, 670 (1966).

⁶⁷ Skinner v. Oklahoma, 316 U.S. 535, 541 (1942).

⁶⁸ See Monthie, supra note 47, 968-970.

clear and convincing evidence standard of proof, whereas article 17-A uses a best interest standard.⁶⁹

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. On the 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.

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."⁷² 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.⁷³ In *Matter of Derek*,⁷⁴ 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."⁷⁵ 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.⁷⁶

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-

⁶⁹ See Monthie, supra note 47, 980-983.

See Matter of Joshua J.K., 71 Misc. 3d 843 (Sur. Ct., Westchester Co. 2021).

⁷¹ See Monthie, supra note 47, 987-988.

See Monthie, supra note 47, at 990.

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."

⁷⁴ 12 Misc. 3d 1132 (Sur. Ct., Broome County 2006).

⁷⁵ *Id.*, at 1134-1135

⁷⁶ 527 U.S. 581 (1999).

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.

The Olmstead Cabinet examined New York's compliance with Olmstead, and issued a thirty-one-page report with recommendations in October 2013.⁷⁷ 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

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.

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 designate a health care agent unless they have a guardian appointed for them. OPWDD regulations encourage the execution of health care proxies for people with developmental disabilities. 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.

A 2008 chapter amendment to article 33 of the MHL authorized the creation of a simplified advance directive for persons with developmental disabilities. 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. 82

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

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.

⁷⁹ See 14 N.Y.C.R.R. 633.20

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]).

L. 2008, c. 210; MHL 33.03[e]).

⁸² *Id*.

services from such providers. A workgroup was formed to implement the chapter amendment shortly after its enactment. Regrettably, a form has yet 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.⁸³ 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.⁸⁴ There is no health care decision making authority attached to a Power of Attorney.⁸⁵

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. ⁸⁶

Representative payment, supplemental needs trusts, ABLE accounts

A person with a disability who is receiving public benefits but who may be unable to manage their 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.⁸⁷ As a matter of policy, SSA states that every beneficiary has the right to manage their 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.⁸⁸

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.⁸⁹ Such means-tested public benefits can make a significant positive impact on the quality of life available to the person with disabilities, permitting them to live successfully in

The New York State Power of Attorney statute was recently amended, effective June 13, 2021. *See*, L. 2020, c. 323.

See, definitions at General Obligations Law (GOL) § 5-1501.

However, an agent may make financial decisions relative to health care (see GOL§ 5-1502k).

⁸⁶ 14 N.Y.C.R.R. 22.3 - when a patient may sign a legal instrument.

⁸⁷ 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 their 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).

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]).

See Cricchio v. Pennisi, 90 N.Y.2d 296 (1997); In re Abraham XX., 11 N.Y. 3d 429 (2008).

their home communities, while the trust funds can pay for supplemental needs and wants of the beneficiary which the public funds do not provide.⁹⁰

In contrast, an ABLE account (Achieving a Better Life Experience [ABLE] Act)⁹¹ 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.⁹²

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:

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

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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).

⁹¹ 26 U.S.C. 529A

⁹² See MHL art. 84; State Finance Law 99-x.

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.⁹³

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.⁹⁴ 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. 95

SDM was legally recognized in New York when Article 82 of the Mental Hygiene Law was enacted in 2022. 96 The statute, as those of other states have done, requires acceptance by third parties of SDMA agreements and relieves those third parties from liability for good faith reliance. 97

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,

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).

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).

⁹⁴ https://sdmny.hunter.cuny.edu/

L. 2022, c. 481, adding Article 82 of the Mental Hygiene Law.

OPWDD is 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. L. 2022, c. 481 §1. Until OPWDD promulgates its implementing regulations, however, SDMAs have no binding legal effect, and third parties – health care professionals, financial institutions, landlords, for example – are under no legal obligation to honor it. OPWDD is also funding an expanded pilot program, focusing on facilitation of SDMA's, including to "implement facilitation training materials, identify and equip providers of facilitation services, develop a supported decision-making facilitation resource center model...." (see https://opwdd.ny.gov/news/supported-decision-making-pilot-program).

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 2025 legislative session.

VII. 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- (S. 7107) L. 2022, c. 481, adding Article 82 of the Mental Hygiene Law.
- e. Stakeholder Comments on OPWDD program bill

Dated: May 17, 2024

Appendix A

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An act to amend the surrogate's court procedure act in relation to guardianship for individuals with developmental disabilities.

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The People of the State of New York, represented in the Senate and Assembly, do enact as follows:

8 9 10

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:

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§ 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.

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§ 2. Section 1750-a of the surrogate's court procedure act is REPEALED.

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§ 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

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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 1
- 2 Willowbrook or a related facility, who are fully represented by the consumer advisory board and
- 3 who have no guardians appointed pursuant to this article or have no qualified family members to
- 4 make such a decision, then a "guardian" shall also mean the Willowbrook consumer advisory
- 5 board. A decision of such family member or the Willowbrook consumer advisory board to
- 6 withhold or withdraw life-sustaining treatment shall be subject to all of the protections,
- 7 procedures and safeguards which apply to the decision of a guardian to withhold or withdraw
- 8 life-sustaining treatment pursuant to this section.
- 9 In the case of a person for whom no guardian has been appointed pursuant to this article or for
- 10 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 11
- 12 in section 80.03 of the mental hygiene law, a surrogate decision-making committee, as defined in
- 13 article eighty of the mental hygiene law. All declarations and procedures, including expedited
- 14 procedures, to comply with this section shall be established by regulations promulgated by the
- 15 commission on quality of care and advocacy for persons with disabilities JUSTICE CENTER
- FOR THE PROTECTION OF PEOPLE WITH SPECIAL NEEDS, AS ESTABLISHED BY 16
- 17 ARTICLE TWENTY OF THE EXECUTIVE LAW.
- 18 (b) Regulations establishing the prioritized list of qualified family members required by
- 19 paragraph (a) of this subdivision shall be developed by the commissioner of the office for people
- 20 with developmental disabilities in conjunction with parents, advocates and family members of
- 21 persons who are intellectually disabled WITH A DEVELOPMENTAL DISABILITY.
- 22 Regulations to implement the authority of the Willowbrook consumer advisory board pursuant to
- 23 paragraph (a) of this subdivision may be promulgated by the commissioner of the office for
- 24 people with developmental disabilities with advice from the Willowbrook consumer advisory
- 25 board.
- 26 (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 27 28 appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of-this article.
- 29 2. Decision-making standard. (a) The guardian shall base all advocacy and health care decision-
- 30 making solely and exclusively on the best interests of the person who is intellectually disabled
- 31 WITH A DEVELOPMENTAL DISABILITY and, when reasonably known or ascertainable with
- 32 reasonable diligence, on the WISHES OF THE person who is intellectually disabled's wishes
- 33 WITH A DEVELOPMENTAL DISABILITY, including moral and religious beliefs.
- 34 (b) An assessment of the BEST INTERESTS OF THE person WITH A DEVELOPMENTAL
- 35 DISABILITY who is intellectually disabled's best interests shall include consideration of:
- 36 (i) the dignity and uniqueness of every person;
- 37 (ii) the preservation, improvement or restoration of the HEALTH OF THE person who is
- 38 intellectually disabled's health WITH A DEVELOPMENTAL DISABILITY;
- 39 (iii) the relief of the SUFFERING OF THE person who is intellectually disabled's suffering
- 40 WITH A DEVELOPMENTAL DISABILITY by means of palliative care and pain management;
- 41 (iv) the unique nature of artificially provided nutrition or hydration, and the effect it may have on
- 42 the person who is intellectually disabled WITH A DEVELOPMENTAL DISABILITY; and
- 43 (v) the entire medical condition of the person.
- 44 (c) No health care decision shall be influenced in any way by:

- 1 (i) a presumption that persons who are intellectually disabled WITH A DEVELOPMENTAL
- 2 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
- 4 (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
- 7 mental hygiene law, the guardian shall have the right to receive all medical information and
- 8 medical and clinical records necessary to make informed decisions regarding the HEALTH
- 9 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
- 14 who is intellectually disabled WITH A DEVELOPMENTAL DISABILITY:
- 15 (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
- 19 RECORD OF THE person who is intellectually disabled's medical record WITH A
- 20 DEVELOPMENTAL DISABILITY, and shall contain such attending physician's opinion
- 21 regarding the cause and nature of the LACK OF CAPACITY OF A person who is intellectually
- 22 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
- 24 another physician, or a licensed psychologist, to further confirm the LACK OF CAPACITY OF
- 25 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
- 27 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
- 35 licensed psychologist possess specialized training or three-years experience in treating
- intellectual disability. A record of such consultation shall be included in the MEDICAL
- 37 RECORD OF THE person WITH A DEVELOPMENTAL DISABILITY who is intellectually
- 38 disabled's medical record.
- 39 (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
- 41 physician shall consult, must determine to a reasonable degree of medical certainty and note on
- 42 the CHART OF THE person who is intellectually disabled's chart-WITH A
- 43 DEVELOPMENTAL DISABILITY that:
- 44 (i) the person who is intellectually disabled WITH A DEVELOPMENTAL DISABILITY has a
- 45 medical condition as follows:

- 1 A. a terminal condition, as defined in subdivision twenty-three of section twenty-nine hundred
- 2 sixty-one of the public health law; or
- 3 B. permanent unconsciousness; or
- 4 C. a medical condition other than THE DEVELOPMENTAL DISABILITY OF such person's
- 5 intellectual disability which requires life-sustaining treatment, is irreversible and which will
- 6 continue indefinitely; and
- 7 (ii) the life-sustaining treatment would impose an extraordinary burden on such person, in light
- 8 of:
- 9 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
- 13 (iii) in the case of a decision to withdraw or withhold artificially provided nutrition or hydration:
- 14 A. there is no reasonable hope of maintaining life; or
- B. the artificially provided nutrition or hydration poses an extraordinary burden.
- 16 (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
- 21 (ii) orally, to two persons eighteen years of age or older, at least one of whom is the
- 22 ATTENDING PHYSICIAN OF THE person who is intellectually disabled's attending physician
- WITH A DEVELOPMENTAL DISABILITY, as defined in subdivision two of section twenty-
- 24 nine hundred eighty of the public health law.
- 25 (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
- 27 decision in the MEDICAL CHART OF THE person who is intellectually disabled's medical
- 28 chart-WITH A DEVELOPMENTAL DISABILITY, and shall either:
- 29 (i) promptly issue an order to withhold or withdraw life-sustaining treatment from the person
- 30 who is intellectually disabled WITH A DEVELOPMENTAL DISABILITY, and inform the staff
- responsible for such person's care, if any, of the order; or
- 32 (ii) promptly object to such decision, in accordance with subdivision five of this section.
- 33 (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:
- 36 (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
- 40 makes the confirmation, or the physician or licensed psychologist with whom the attending
- 41 physician consults, shall:
- A. be employed by a developmental disabilities services office named in section 13.17 of the
- 43 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

- 1 C. have been approved by the commissioner of the office for people with developmental
- 2 disabilities in accordance with regulations promulgated by such commissioner. Such regulations
- 3 shall require that a physician or licensed psychologist possess specialized training or three years
- 4 experience in treating intellectual disability. A record of such consultation shall be included in
- 5 the person who is intellectually disabled's medical record;
- 6 (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
- 8 the agency or organization operating such facility and the mental hygiene legal service; and
- 9 (iii) if the person is not in and was not transferred from such a facility or program, the
- 10 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
- 14 who is intellectually disabled WITH A DEVELOPMENTAL DISABILITY, in the event of an
- objection to that decision at any time by:
- 16 (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
- 20 DISABILITY; or
- 21 (iii) the attending physician, as defined in subdivision two of section twenty-nine hundred eighty
- of the public health law; or
- 23 (iv) any other health care practitioner providing services to the person-who is intellectually
- 24 disabled-WITH A DEVELOPMENTAL DISABILITY, who is licensed pursuant to article one
- 25 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
- 29 (v) the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four
- of this section; or
- 31 (vi) if the person is in or was transferred from a residential facility or program operated,
- 32 approved or licensed by the office for people with developmental disabilities, the mental hygiene
- 33 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.
- 36 (b) Form of objection. Such objection shall occur orally or in writing.
- 37 (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
- 40 the MEDICAL CHART OF THE person WITH THE DEVELOPMENTAL DISABILITY who
- 41 <u>is intellectually disabled's medical chart.</u>
- 42 (d) Dispute mediation. In the event of an objection pursuant to this subdivision, at the request of
- 43 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 1
- 2 ethics committee, as described in writing and adopted by the governing authority of such
- 3 hospice, for non-binding mediation. In the event that such dispute cannot be resolved within
- 4 seventy-two hours or no such mediation entity exists or is reasonably available for mediation of a
- 5 dispute, the objection shall proceed to judicial review pursuant to this subdivision. The party
- 6 requesting mediation shall provide notification to those parties entitled to notice pursuant to 7 paragraph (a) of this subdivision.
- 8 6. Special proceeding authorized. The guardian, the attending physician, as defined in
- 9 subdivision two of section twenty-nine hundred eighty of the public health law, the chief
- 10 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 11
- 12 facility or program operated, approved or licensed by the office for people with developmental
- 13 disabilities) or the commissioner of the office for people with developmental disabilities or his or
- 14 her designee (if the person is not in and was not transferred from such a facility or program) may
- 15 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 16
- 17 treatment because such withdrawal or withholding is not in accord with the criteria set forth in
- 18 this section.
- 19 7. Provider's obligations. (a) A health care provider shall comply with the health care decisions
- 20 made by a guardian in good faith pursuant to this section, to the same extent as if such decisions
- 21 had been made by the person who is intellectually disabled WITH A DEVELOPMENTAL
- 22 DISABILITY, if such person had capacity.
- 23 (b) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed
- 24 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 25
- 26 DEVELOPMENTAL DISABILITY, if such person had capacity, because the decision is
- 27 contrary to a formally adopted written policy of the hospital expressly based on religious beliefs
- 28 or sincerely held moral convictions central to the hospital's operating principles, and the hospital 29
- would be permitted by law to refuse to honor the decision if made by such person, provided: 30 (i) the hospital has informed the guardian of such policy prior to or upon admission, if
- 31 reasonably possible; and
- 32 (ii) the person who is intellectually disabled WITH A DEVELOPMENTAL DISABILITY is
- 33 transferred promptly to another hospital that is reasonably accessible under the circumstances
- 34 and is willing to honor the guardian's decision. If the guardian is unable or unwilling to arrange
- 35 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. 36
- 37 (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 38
- 39 individual would not honor if the decision had been made by the person who is intellectually
- 40 disabled WITH A DEVELOPMENTAL DISABILITY, if such person had capacity, because the
- 41 decision is contrary to the individual's religious beliefs or sincerely held moral convictions,
- 42 provided the individual health care provider promptly informs the guardian and the facility, if
- 43 any, of his or her refusal to honor the guardian's decision. In such event, the facility shall
- 44 promptly transfer responsibility for the person who is intellectually disabled WITH A
- 45 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.
- 3 (d) Notwithstanding the provisions of any other paragraph of this subdivision, if a guardian
- 4 directs the provision of life-sustaining treatment, the denial of which in reasonable medical
- 5 judgment would be likely to result in the death of the person who is intellectually disabled WITH
- 6 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
- 8 either transfer of the person who is intellectually disabled WITH A DEVELOPMENTAL
- 9 DISABILITY to a willing hospital or individual health care provider, or judicial review.
- 10 (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.

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- 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.
- 17 (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
- 25 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.
- 31 (2) "AVAILABLE RESOURCES AND ALTERNATIVES TO GUARDIANSHIP" SHALL
- 32 MEAN EXISTING HEALTH CARE AND OTHER SURROGATE DECISIONMAKING
- 33 STATUTES AND REGULATIONS, AND RESOURCES, SUPPORTS, AND
- 34 ALTERNATIVES, SUCH AS, BUT NOT LIMITED TO, HEALTH CARE PROXY, JOINT
- 35 BANK ACCOUNT, POWER OF ATTORNEY, REPRESENTATIVE PAYEE, SPECIAL
- 36 NEEDS TRUSTS, HEALTH CARE SURROGATE DECISIONMAKING COMMITTEE.
- 37 CASE MANAGEMENT SERVICES, DAY SERVICES, IN-HOME CARE SERVICES,
- 38 MONEY MANAGEMENT PROGRAMS, CARE COORDINATION, SOCIAL SUPPORTS,
- 39 SERVICES AND NETWORKS, SUPPORTED DECISION MAKING, AND AVAILABLE
- 40 SHARED DECISION MAKING.
- 42 (3) "DEVELOPMENTAL DISABILITY" SHALL MEAN A DEVELOPMENTAL
- 43 DISABILITY WITHIN THE MEANING OF SUBDIVISION TWENTY-TWO OF SECTION
- 44 1.03 OF THE MENTAL HYGIENE LAW.

- 1 (4) "FUNCTIONAL LEVEL" SHALL MEAN THE MEASUREMENT OF THE ABILITY TO
- 2 LIVE INDEPENDENTLY, PROVIDE FOR PERSONAL NEEDS, FUNCTION SAFELY,
- 3 AND/OR THE ABILITY TO MANAGE PROPERTY, WITH APPROPRIATE SUPPORTIVE
 - SERVICES, TECHNOLOGICAL ASSISTANCE, OR SUPPORTED DECISIONMAKING.

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- 6 (5) "FUNCTIONAL LIMITATIONS" SHALL MEAN BEHAVIOR OR CONDITIONS OF A PERSON WHICH IMPAIR THE ABILITY TO LIVE INDEPENDENTLY, PROVIDE FOR
- 8 PERSONAL NEEDS, FUNCTION SAFELY, AND/OR THE ABILITY TO MANAGE
- 9 PROPERTY, EVEN WITH APPROPRIATE SUPPORTIVE SERVICES, TECHNOLOGICAL
- 10 ASSISTANCE, OR SUPPORTED DECISIONMAKING.

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(6) "PERSONAL NEEDS" SHALL MEAN NEEDS SUCH AS, BUT NOT LIMITED TO,
 FOOD, CLOTHING, SHELTER, HEALTH CARE, AND SAFETY.

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- 15 (7) "PROPERTY MANAGEMENT" SHALL MEAN TAKING ACTIONS TO OBTAIN,
- ADMINISTER, PROTECT, AND DISPOSE OF REAL AND PERSONAL PROPERTY,
- 17 INTANGIBLE PROPERTY, BUSINESS PROPERTY, BENEFITS, AND INCOME, AND TO
- 18 DEAL WITH FINANCIAL AFFAIRS.

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- 20 (8) "RESPONDENT" SHALL MEAN THE INDIVIDUAL WHO IS ALLEGED TO HAVE A DEVELOPMENTAL DISABILITY.
- 22 (9) "SUPPORTED DECISION MAKING" SHALL MEAN ASSISTANCE FROM ONE OR
- 23 MORE PERSONS OF AN INDIVIDUAL'S CHOOSING IN UNDERSTANDING THE
- 24 NATURE AND CONSEQUENCES OF POTENTIAL PERSONAL AND FINANCIAL
- 25 DECISIONS, WHICH ENABLE THE INDIVIDUAL TO MAKE DECISIONS, AND IN
- 26 COMMUNICATING A DECISION ONCE MADE IF CONSISTENT WITH AN
- 27 INDIVIDUAL'S WISHES.

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§ 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:

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- § 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
- 34 who is developmentally disabled THE RESPONDENT may be made by
- 35 (1) a parent, any interested person eighteen years of age or older on behalf of the person who is
- 36 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,
- 38 (2) the person who is intellectually disabled or a person who is developmentally disabled
- 39 RESPONDENT when such person is eighteen years of age or older.

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§ 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:

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44 § 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. <u>4.</u> 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.<u>5.</u> 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;

<u>6</u>. THE NAME AND ADDRESS OF ANY 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 1
- 2 BEHAVIORS, AND FUNCTIONAL LIMITATIONS INCLUDING THE RESPONDENT'S
- 3 ABILITY TO MANAGE THE ACTIVITIES OF DAILY LIVING, AND ANY SUPPORTIVE
- 4 SERVICES, TECHNOLOGICAL ASSISTANCE OR SUPPORTED DECISION MAKING
- 5 THE INDIVIDUAL USES;

- 10. A STATEMENT OF THE AVAILABLE RESOURCES AND ALTERNATIVES TO
- 8 GUARDIANSHIP WHICH HAVE BEEN CONSIDERED OR IMPLEMENTED BY THE
- 9 PETITIONER, AND IF THEY HAVE NOT BEEN CONSIDERED OR IMPLEMENTED, THE
- 10 REASON THEY HAVE NOT BEEN CONSIDERED OR IMPLEMENTED;

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- 12 11. THE PARTICULAR POWERS BEING SOUGHT, THEIR RELATIONSHIP TO THE
- 13 FUNCTIONAL LEVEL, ADAPTIVE BEHAVIORS, AND FUNCTIONAL LIMITATIONS
- 14 DESCRIBED IN PARAGRAPH NINE, AND DURATION OF THE POWERS BEING
- 15 SOUGHT;

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- 12. THE APPROXIMATE VALUE AND DESCRIPTION OF THE PROPERTY AND
- 18 FINANCIAL RESOURCES OF THE RESPONDENT, TO THE BEST OF THE
- 19 PETITIONER'S KNOWLEDGE;

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- 21 13. THE NATURE AND AMOUNT OF ANY CLAIM, DEBT, OR OBLIGATIONS OF THE 22
 - RESPONDENT, TO THE BEST OF THE PETITIONER'S KNOWLEDGE;
- 23 24
 - 14. AN EXPLANATION OF THE REASONS WHY THE FORM OF GUARDIANSHIP SOUGHT IS THE LEAST RESTRICTIVE RELIEF WHICH WILL MEET THE NEEDS OF
 - 26 THE RESPONDENT:

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- 15. ANY OTHER INFORMATION WHICH THE PETITIONER ALLEGES WILL ASSIST
- 29 THE COURT.

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§ 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
- 35 1. Upon presentation-FILING of the petition, process shall issue to:
- 36 (a) the parent or parents, adult children, if the petitioner is other than a parent, adult siblings, if
- 37 the petitioner is other than a parent, and if the the person who is intellectually disabled or a
- 38 person who is developmentally disabled RESPONDENT is married, to the spouse, if their
- 39 residences are known;
- 40 (b) the person having care and custody of the person who is intellectually disabled or person who
- 41 is developmentally disabled with whom such person RESPONDENT resides if other than the
- 42 parents or spouse; and
- 43 (c) the person who is intellectually disabled or person who is developmentally disabled
- 44 RESPONDENT if fourteen years of age or older for whom an application has been made in such
- 45 person's behalf.

- PROCESS ISSUED TO RESPONDENT SHALL INCLUDE A STATEMENT IN AN EASILY 1
- 2 UNDERSTOOD FORM DEVELOPED BY THE OFFICE OF COURT ADMINISTRATION
- 3 THAT STATES THE DATE, TIME, AND PLACE OF THE HEARING OF THE PETITION;
- 4 THE RIGHTS OF THE RESPONDENT IN THE PROCEEDING, INCLUDING THE RIGHT
- 5 TO BE PRESENT AT THE HEARING; THE RIGHT TO CONTEST THE PROCEEDING;
- 6 THE RIGHT TO DESIGNATE IN WRITING A PERSON WHO SHOULD RECEIVE NOTICE
- 7 OF THE PROCEEDING; THE RIGHT TO COUNSEL; THAT THE COURT IS APPOINTING
- 8 MENTAL HYGIENE LEGAL SERVICE AS COUNSEL FOR THE RESPONDENT,
- 9 INCLDUING THE NAME, ADDRESS AND TELEPHONE NUMBER OF THE PERSON
- 10 APPOINTED AS COUNSEL; THAT IF PERSON RETAINS HIS OR HER OWN COUNSEL,
- 11 THE COURT WILL EXCUSE MENTAL HYGIENE LEGAL SERVICE WHEN
- 12 RESPONDENT'S RETAINED COUNSEL NOTIFIES THE COURT OF HIS OR HER
- 13 APPEARANCE.
- 14 2. Upon FILING presentation of the petition, notice of such petition shall be served by certified 15
- 16 (a) the adult siblings if the petitioner is a parent, and adult children if the petitioner is a parent;
- 17 (b) the mental hygiene legal service in the judicial department where the facility, as defined in
- 18 subdivision (a) of section 47.01 of the mental hygiene law, is located if the person who is
- 19 intellectually disabled or person who is developmentally disabled THE RESPONDENT resides 20 in such a facility.
- 21 (c) (b) in all cases, to the director in charge of a facility AS DEFINED IN SECTION 47.01 OF
- 22 THE MENTAL HYGIENE LAW, if the person who is intellectually disabled or a person who is
- 23 developmentally disabled RESPONDENT resides in such facility; (d)
- 24 (c) one other person if designated in writing by the person who is intellectually disabled or
- 25 person who is developmentally disabled RESPONDENT; and (e)
- 26 (d) such other persons as the court may deem proper.
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- 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.
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- § 8. Article 17A of the surrogate's court procedure act is amended by adding a new section 1755 to read as follows:
- 37 38 39
- § 1755. COUNSEL; GUARDIAN AD LITEM
- 40 1. THE RESPONDENT SHALL BE ENTITLED TO BE REPRESENTED BY LEGAL 41 COUNSEL. THE COURT SHALL APPOINT AS COUNSEL THE MENTAL HYGIENE
- 42 LEGAL SERVICE. IF THE COURT DETERMINES THAT MENTAL HYGIENE LEGAL
- 43 SERVICE CANNOT ACCEPT AN APPOINTMENT BECAUSE OF A CONFLICT OF INTEREST, THE COURT SHALL APPOINT AN ATTORNEY WITH APPROPRIATE 44
- 45 EXPERTISE ELIGIBLE FOR APPOINTMENT PURSUANT TO SECTION THIRTY-
- 46 FIVE OF THE JUDICIARY LAW. IN THE EVENT THAT THE COURT DETERMINES

1 THAT THE RESPONDENT HAS RETAINED COUNSEL, THE COURT SHALL 2 SUBSTITUTE RETAINED COUNSEL FOR APPOINTED COUNSEL UPON THE 3 COURT'S DETERMINATION THAT RETAINED COUNSEL HAS BEEN CHOSEN 4 FREELY AND INDEPENDENTLY BY THE RESPONDENT. THE COURT APPOINTED 5 COUNSEL SHALL BE AT NO COST TO THE PETITIONER OR RESPONDENT. 6 COUNSEL FOR THE RESPONDENT SHALL BE PROVIDED WITH COPIES OF THE 7 PETITION AND THE SERVICE OF PROCESS AND NOTICE COMPLETED 8 PURSUANT TO SECTION SEVENTEEN FIFTY-FOUR. COUNSEL SHALL BE 9 AFFORDED ACCESS TO THE RESPONDENT'S CLINICAL RECORDS WITHOUT A 10 COURT ORDER TO THE EXTENT ACCESS IS OTHERWISE AUTHORIZED BY 11 STATE AND FEDERAL LAWS, AND MAY APPLY TO THE COURT FOR 12 PERMISSION TO INSPECT THE CLINICAL RECORDS PERTAINING TO THE 13 RESPONDENT IN ACCORDANCE WITH STATE AND FEDERAL LAWS. COUNSEL 14 SHALL ADVOCATE FOR THE RESPONDENT'S EXPRESSED WISHES, IF KNOWN. 15 IF THE RESPONDENT'S WISHES ARE NOT KNOWN AND CANNOT BE 16 ASCERTAINED AFTER INVESTIGATION, COUNSEL SHALL SAFEGUARD THE 17 RESPONDENT'S PROCEDURAL RIGHTS THROUGHOUT THE PROCEEDING 18 TOWARD ACHIEVING THE LEAST RESTRICTIVE DISPOSITION CONSISTENT WITH THE RESPONDENT'S NEEDS. 19

2. THE COURT IN ITS DISCRETION MAY APPOINT A GUARDIAN AD LITEM AS PROVIDED IN ARTICLE FOUR OF THIS ACT.

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§ 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
- 2 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.
- 4 3. If a hearing is conducted, the person who is intellectually disabled or a person who is
- 5 developmentally disabled shall be present unless it shall appear to the satisfaction of the court on
- 6 the certification of the certifying physician that the person who is intellectually disabled or
- 7 person who is developmentally disabled is medically incapable of being present to the extent
- 8 that attendance is likely to result in physical harm to such person who is intellectually disabled or
- 9 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
- 11 developmentally disabled THE RESPONDENT SHALL BE PRESENT AT THE HEARING
- 12 UNLESS SUCH PRESENCE IS EXCUSED BY THE COURT, TAKING INTO
- 13 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
- 15 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
- 17 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
- 20 intellectually disabled or person who is developmentally disabled and shall submit a written
- 21 report to the court. 5.
- 22 3.THE COURT, UPON THE PLEADINGS, OR AFTER A HEARING ON ANY CONTESTED
- 23 ISSUES OF FACT, SHALL MAKE FINDINGS REGARDING:
- 24 (a) WHETHER THE RESPONDENT HAS A DEVELOPMENTAL DISABILITY;
- 25 (b) THE EXTENT OF THE FUNCTIONAL LEVEL, THE FUNCTIONAL LIMITATIONS
- 26 AND THE LEVEL OF THE IMPAIRMENT IN THE RESPONDENT'S INTELLECTUAL
- 27 FUNCTIONING AND/OR ADAPTIVE BEHAVIORS;
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- 29 (c) THE RESPONDENT'S LACK OF UNDERSTANDING AND APPRECIATION OF THE
- 30 NATURE AND CONSEQUENCES OF THEIR FUNCTIONAL LIMITATIONS AND
 - IMPAIRMENT IN INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS;
- 31 32
- 33 (<u>d</u>) THE SUFFICIENCY AND RELIABILITY OF AVAILABLE RESOURCES AND
- 34 ALTERNATIVES TO GUARDIANSHIP;
- 35
- 36 (e) THE LIKELIHOOD THAT THE RESPONDENT WILL SUFFER HARM BECAUSE OF
- 37 THE RESPONDENT'S FUNCTIONAL LIMITATIONS AND IMPAIRMENT IN
- 38 INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS AND INABILITY
- 39 TO ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND
 - CONSEQUENCES OF SUCH FUNCTIONAL LIMITATIONS AND IMPAIRMENT;
- 40 41
- 42 (<u>f</u>) THE NECESSITY OF THE APPOINTMENT OF A GUARDIAN TO PREVENT SUCH
- 43 HARM;
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(g) THE SPECIFIC POWERS OF THE GUARDIAN WHICH CONSTITUTE THE LEAST RESTRICTIVE FORM OF INTERVENTION CONSISTENT WITH THE FINDINGS OF THIS SUBDIVISION.

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4. (a) IF IT IS DETERMINED THAT THE RESPONDENT DOES NOT HAVE A DEVELOPMENTAL DISABILITY, THE COURT SHALL DISMISS THE PETITION.

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(b) IF IT IS DETERMINED THAT THE RESPONDENT CAN PROVIDE FOR PERSONAL NEEDS AND/OR PROPERTY MANAGEMENT, THE COURT SHALL DISMISS THE PETITION.

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12 (c) IF IT IS FOUND THAT THE RESPONDENT IS A PERSON WITH A 13 DEVELOPMENTAL DISABILITY AND IT IS DETERMINED BY CLEAR AND 14 CONVINCING EVIDENCE THAT RESPONDENT IS LIKELY TO SUFFER HARM 15 BECAUSE OF THE RESPONDENT'S FUNCTIONAL LIMITATIONS AND IMPAIRMENT IN INTELLECTUAL FUNCTIONING AND/OR ADAPTIVE BEHAVIORS AND INABILITY 16 17 TO ADEQUATELY UNDERSTAND AND APPRECIATE THE NATURE AND 18 CONSEQUENCES OF SUCH FUNCTIONAL LIMITATIONS AND IMPAIRMENTS, EVEN 19 WITH THE SUPPORTS THEY MAY REQUIRE, THE COURT WITHOUT APPOINTING A 20 GUARDIAN, MAY AUTHORIZE, DIRECT, OR RATIFY ANY TRANSACTION OR SERIES 21 OF TRANSACTIONS NECESSARY TO ACHIEVE ANY SECURITY, SERVICE, OR CARE 22 ARRANGEMENT MEETING THE FORESEEABLE NEEDS OF THE RESPONDENT, OR 23 MAY AUTHORIZE, DIRECT, OR RATIFY ANY CONTRACT, TRUST, OR OTHER 24 TRANSACTION RELATING TO THE RESPONDENT'S PROPERTY AND FINANCIAL 25 AFFAIRS IF THE COURT DETERMINES THAT THE TRANSACTION IS NECESSARY AS 26 A MEANS OF PROVIDING FOR PERSONAL NEEDS AND/OR PROPERTY 27 MANAGEMENT FOR THE RESPONDENT. BEFORE APPROVING A PROTECTIVE 28 ARRANGEMENT OR OTHER TRANSACTION UNDER THIS SUBDIVISION, THE 29 COURT SHALL CONSIDER THE INTERESTS OF DEPENDENTS AND CREDITORS OF 30 THE RESPONDENT, AND IN VIEW OF THE RESPONDENT'S FUNCTIONAL LEVEL. WHETHER THE RESPONDENT NEEDS THE CONTINUING PROTECTION OF A 31 32 GUARDIAN. THE COURT MAY APPOINT A SPECIAL GUARDIAN TO ASSIST IN THE 33 ACCOMPLISHMENT OF ANY PROTECTIVE ARRANGEMENT OR OTHER 34 TRANSACTION AUTHORIZED UNDER THIS SUBDIVISION. THE SPECIAL GUARDIAN 35 SHALL HAVE THE AUTHORITY CONFERRED BY THE ORDER OF APPOINTMENT, 36 SHALL REPORT TO THE COURT ON ALL MATTERS DONE PURSUANT TO THE 37 ORDER OF APPOINTMENT, AND SHALL SERVE UNTIL DISCHARGED BY ORDER OF

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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 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.

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- 6 (e) IF IT IS FOUND THAT THE RESPONDENT IS A PERSON WITH A
 - DEVELOPMENTAL DISABILITY AND IT IS DETERMINED BY CLEAR AND
- 8 CONVINCING EVIDENCE THAT THE RESPONDENT IS LIKELY TO SUFFER HARM
- 9 BECAUSE THEY ARE TOTALLY UNABLE TO PROVIDE FOR THEIR PERSONAL
- 10 NEEDS AND/OR PROPERTY MANAGEMENT AND CANNOT ADEQUATELY
- 11 UNDERSTAND AND APPRECIATE THE NATURE AND CONSEQUENCES OF SUCH
- 12 INABILITY, EVEN WITH THE SUPPORTS THEY MAY REQUIRE, THE COURT SHALL
- 13 APPOINT A PLENARY GUARDIAN OF THE PERSON OR OF THE ESTATE OR BOTH
- 14 FOR THE RESPONDENT, SHALL ESTABLISH THE DURATION OF THE
- 15 GUARDIANSHIP, AND SHALL DISPOSE OF ANY REMAINING ISSUES IN THE
- 16 PROCEEDING.

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18 (<u>f</u>) THE ORDER APPOINTING A GUARDIAN SHALL IDENTIFY ALL PERSONS 19 ENTITLED TO NOTICE OF ALL FURTHER PROCEEDINGS.

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§ 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.
- 25 (a) Any person who is intellectually disabled or person who is developmentally disabled,
- 26 eighteen years of age or older WITH A DEVELOPMENTAL DISABILITY FOR WHOM A
- 27 GUARDIAN HAS BEEN APPOINTED BY THIS COURT, or any person on behalf of any
- 28 person who is intellectually disabled or person who is developmental 1 disabled WITH A
- 29 DEVELOPMENTAL DISABILITY for whom a guardian has been appointed BY THIS
- COURT, may apply to the court having jurisdiction over the guardianship order requesting
- 31 REMOVAL OR DISCHARGE OF THE GUARDIAN OR modification of THE
- 32 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
- 34 personal interests. A REQUEST FOR REMOVAL, DISCHARGE OR MODIFICATION
- 35 UNDER THIS SECTION, IF MADE BY THE INDIVIDUAL FOR WHOM A GUARDIAN
- 36 HAS BEEN APPOINTED, MAY BE COMMUNICATED TO THE COURT BY ANY
- 37 MEANS, INCLUDING, BUT NOT LIMITED TO, ORAL COMMUNICATION OR LETTER.
- 38 (b) The court may SHALL, upon receipt of any such request to REMOVE OR DISCHARGE
- 39 THE GUARDIAN, OR modify the guardianship order, appoint MENTAL HYGIENE LEGAL
- 40 SERVICE AS COUNSEL FOR THE PERSON WITH A DEVELOPMENTAL DISABILITY
- 41 UNLESS IT APPEARS TO THE COURT THAT THE PERSON WITH A
- 42 DEVELOPMENTAL DISABILITY HAS RETAINED COUNSEL, AND IF THE REQUEST
- 43 HAS BEEN MADE BY MEANS OTHER THAN A MOTION, REQUIRE COUNSEL TO
- 44 PREPARE A WRITTEN MOTION FOR REMOVAL, DISCHARGE OR MODIFICATION TO
- 45 BE SUBMITTED TO THE COURT. a guardian ad litem. The court shall so modify the

- 1 guardianship order if in its judgment the interests of the guardian are adverse to those of the
- 2 person who is intellectually disabled or person who is developmentally disabled or if the interests
- 3 of justice will be best served including, but not limited to, facts showing the necessity for
- 4 protecting the personal and/or financial interests of the person who is intellectually disabled or
- 5 person who is developmentally disabled
- 6 (c) THE COURT WHICH APPOINTED THE GUARDIAN SHALL REMOVE THE
- 7 GUARDIAN WHEN THE GUARDIAN FAILS TO COMPLY WITH AN ORDER, IS GUILTY
- 8 OF MISCONDUCT, OR FOR ANY OTHER CAUSE WHICH TO THE COURT SHALL
- 9 APPEAR JUST.
- 10 (d) THE COURT WHICH APPOINTED THE GUARDIAN SHALL DISCHARGE THE
- GUARDIAN OR MODIFY THE POWERS OF THE GUARDIAN WHERE APPROPRIATE,
- 12 IF IT APPEARS TO THE SATISFACTION OF THE COURT THAT:
- 13 (1) PERSON HAS BECOME ABLE TO EXERCISE SOME OR ALL OF THE POWERS
- 14 NECESSARY TO PROVIDE FOR PERSONAL NEEDS OR PROPERTY MANAGEMENT
- 15 WHICH THE GUARDIAN IS AUTHORIZED TO EXERCISE;
- 16 (2) THE PERSON HAS BECOME UNABLE TO EXERCISE POWERS NECESSARY TO
- 17 PROVIDE FOR PERSONAL NEEDS OR PROPERTY MANAGEMENT WHICH THE
- 18 GUARDIAN IS NOT AUTHORIZED TO EXERCISE;
- 19 (3) THE PERSON HAS DIED; OR
- 20 (4) FOR SOME OTHER REASON, THE APPOINTMENT OF THE GUARDIAN IS NO
- 21 LONGER NECESSARY FOR THE PERSON WITH A DEVELOPMENTAL DISABILITY,
- OR THE POWERS OF THE GUARDIAN SHOULD BE MODIFIED BASED UPON
- 23 CHANGES IN THE CIRCUMSTANCES OF THE PERSON.
- 24 (e) THE COURT SHALL CONDUCT A HEARING ON THE APPLICATION UPON NOTICE
- TO THE PERSONS ENTITLED TO NOTICE UNDER SUBDIVISION (f) OF SECTION 1756.
- 26 THE COURT MAY FOR GOOD CAUSE SHOWN DISPENSE WITH THE HEARING
- 27 PROVIDED THAT AN ORDER OF MODIFICATION INCREASING THE POWERS OF THE
- 28 GUARDIAN SHALL SET FORTH THE FACTUAL BASIS FOR DISPENSING WITH THE
- 29 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
- 31 PROPERTY MANAGEMENT AND DEMANDS A JURY TRIAL OF SUCH ISSUE, THE
- 32 COURT SHALL ORDER A TRIAL BY JURY THEREOF.
- 33 (f). TO THE EXTENT THAT RELIEF SOUGHT UNDER THIS SECTION WOULD
- 34 TERMINATE THE GUARDIANSHIP OR RESTORE CERTAIN POWERS TO THE PERSON
- 35 WITH A DEVELOPMENTAL DISABILITY THE BURDEN OF PROOF SHALL BE ON THE
- 36 PERSON OBJECTING TO SUCH RELIEF. TO THE EXTENT THAT RELIEF SOUGHT
- 37 UNDER THIS SECTION WOULD FURTHER LIMIT THE POWERS OF THE PERSON
- 38 WITH A DEVELOPMENTAL DISABILITY, THE BURDEN OF PROOF SHALL BE ON
- 39 THE PERSON SEEKING SUCH RELIEF.
- 40 (g). IF THE GUARDIAN IS DISCHARGED BECAUSE THE PERSON WITH A
- 41 DEVELOPMENTAL DISABILITY BECOMES FULLY ABLE TO CARE FOR THEIR
- 42 PROPERTY. THE COURT SHALL ORDER THAT THE PROPERTY REMAINING IN THE
- 43 HANDS OF THE GUARDIAN BE RESTORED TO SUCH PERSON. IF THE PERSON WITH
- 44 A DEVELOPMENTAL DISABILITY HAS DIED, THE GUARDIAN SHALL PROVIDE FOR
- 45 SUCH PERSON'S BURIAL OR OTHER DISPOSITION THE COST OF WHICH SHALL BE
- 46 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.

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§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:

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§ 17571758. Standby guardian of a mentally retarded or developmentally disabled person WITH A DEVELOPMENTAL DISABILITY

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- 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
- 12 WITH A DEVELOPMENTAL DISABILITY FOR WHOM A GUARDIAN HAS BEEN
- 13 APPOINTED may be appointed by the court. The court may also, upon application, appoint an
- 14 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 15
- made in accordance with the provisions of this article. 16
- 17 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 18
- her office immediately upon death, renunciation or adjudication of incompetency-INCAPACITY 19
- 20 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 21
- 22 assumption of his or her duties of such office. Before confirming the appointment of the standby
- 23 guardian or alternate guardian, the court may conduct a hearing pursuant to section seventeen
- 24 hundred fifty-four SIX of this article upon petition by anyone on behalf of the mentally retarded
- 25 or developmentally disabled person WITH A DEVELOPMENTAL DISABILITY or the
- 26 mentally retarded or developmentally disabled person WITH A DEVELOPMENTAL
 - DISABILITY if such person is eighteen years of age or older, or upon its discretion.

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§ 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:

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1758 1759. Court jurisdiction, VENUE, AND JUDICIAL REVIEW OF GUARDIANSHIP **APPOINTMENTS**

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- 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
- 39 SUBDIVISION. 40
- 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 41
- developmentally disabled person WITH A DEVELOPMENTAL DISABILITY for whom such 42
- guardian shall have been appointed, to take of its own motion or to entertain and adjudicate such 43 44 steps and proceedings relating to such guardian, standby, or alternate guardianship as may be
- 45 deemed necessary or proper for the welfare of such mentally retarded or developmentally
- disabled person. ANY PROCEEDING TO REMOVE OR DISCHARGE A GUARDIAN, OR 46

- 1 TO MODIFY A PRIOR ORDER SHALL BE BROUGHT IN THE SURROGATE'S COURT
- 2 WHICH APPOINTED THE GUARDIAN OR GRANTED THE PRIOR ORDER, UNLESS AT
- 3 THE TIME OF THE APPLICATION, THE RESPONDENT RESIDES ELSEWHERE IN
- 4 WHICH CASE THE PROCEEDING SHALL BE BROUGHT IN THE COUNTY WHERE THE
- 5 RESPONDENT IS LOCATED, SUBJECT TO AN APPLICATION BY AN INTERESTED
- 6 PARTY FOR A CHANGE IN VENUE TO THE COURT WHICH APPOINTED THE
- 7 GUARDIAN OR GRANTED THE PRIOR ORDER BECAUSE OF THE INCONVENIENCE
- 8 OF THE PARTIES OR WITNESSES OR THE CONDITION OF THE PERSON.
- 9 <u>3.</u> THE COURT SHALL REVIEW THE GUARDIANSHIP EVERY THREE YEARS AFTER
- 10 THE APPOINTMENT OF THE GUARDIAN. THE REVIEW SHALL CONSIST OF THE
- 11 APPOINTMENT OF MENTAL HYGIENE LEGAL SERVICE AS COUNSEL WHO SHALL
- 12 REPORT TO THE COURT AS TO WHETHER THE GUARDIANSHIP SHOULD BE
- 13 MODIFIED OR THE GUARDIAN DISCHARGED. THE COURT ALSO MAY, ON ITS
- 14 OWN MOTION OR UPON REQUEST BY ANY INTERESTED PERSON, TAKE
- 15 APPROPRIATE ACTION, INCLUDING, BUT NOT LIMITED TO, ORDERING A REVIEW
- 16 OF THE GUARDIANSHIP, INCLUDING AT A NOTICED HEARING, AT ANY TIME.

§ 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
- 22 DECISIONS MADE BY A GUARDIAN APPOINTED PURSUANT TO THIS ARTICLE
- 23 SHALL BE MADE IN ACCORDANCE WITH THE FOLLOWING STANDARDS:
- 1. A GUARDIAN SHALL EXERCISE AUTHORITY ONLY AS NEEDED BECAUSE OF
- 25 THE LIMITATIONS OF THE PERSON WITH A DEVELOPMENTAL DISABILITY, AND,
- 26 TO THE EXTENT POSSIBLE, SHALL ENCOURAGE THE PERSON WITH A
- 27 DEVELOPMENTAL DISABILITY TO PARTICIPATE IN DECISIONS AND TO ACT ON
- 28 HIS OR HER OWN BEHALF.
- 29 2. A GUARDIAN SHALL ENCOURAGE THE PERSON WITH A DEVELOPMENTAL
- 30 DISABILITY TO DEVELOP OR REGAIN TO THE MAXIMUM EXTENT POSSIBLE THE
- 31 CAPACITY TO MEET HIS OR HER NEEDS.
- 32 3. A GUARDIAN SHALL CONSIDER THE EXPRESSED DESIRES AND PERSONAL
- 33 VALUES OF THE PERSON WITH A DEVELOPMENTAL DISABILITY TO THE EXTENT
- 34 KNOWN WHEN MAKING DECISIONS AND SHALL CONSULT WITH THE PERSON
- 35 WITH A DEVELOPMENTAL DISABILITY WHENEVER MEANINGFUL
- 36 COMMUNICATION IS POSSIBLE.
- 4. IF THE PERSON'S WISHES ARE UNKNOWN AND REMAIN UNKNOWN AFTER
- 38 REASONABLE EFFORTS TO DISCERN THEM, THE DECISION SHALL BE MADE ON
- 39 THE BASIS OF THE BEST INTERESTS OF THE PERSON WITH A DEVELOPMENTAL
- 40 DISABILITY AS DETERMINED BY THE GUARDIAN. IN DETERMINING THE BEST
- 41 INTERESTS OF THE PERSON WITH A DEVELOPMENTAL DISABILITY, THE
- 42 GUARDIAN SHALL WEIGH THE REASON FOR, AND NATURE OF, THE PROPOSED
- 43 ACTION, THE BENEFIT OR NECESSITY OF THE ACTION, THE POSSIBLE RISKS AND
- 44 OTHER CONSEQUENCES OF THE PROPOSED ACTION, AND ANY AVAILABLE
- 45 ALTERNATIVES AND THEIR RISKS, CONSEQUENCES, AND BENEFITS. THE
- 46 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.

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1 2

§ 15. Section 1759 of the surrogate's court procedure act is REPEALED.

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§ 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:

9 10 11

- 17601761. 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
- 14 York and having the corporate power to act as guardian of THE PERSON OF A PERSON
- 15 WITH A DEVELOPMENTAL DISABILITY, GUARDIAN OF THE PROPERTY OF mentally
- 16 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.

19 20

§ 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:

212223

§ 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.

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§ 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
- 37 DATE OF THIS ACT. ANY ORDERS, DETERMINATIONS OR DECISIONS OF THE
- 38 APPOINTING OR SUBSEQUENT COURT SHALL CONTINUE IN FORCE AND EFFECT
- 39 UNTIL DULY MODIFIED OR ABROGATED BY A JUDGE PURSUANT TO ARTICLE 17A
- 40 AS AMENDED BY THIS ACT. ANY GUARDIAN APPOINTED PRIOR TO THE
- 41 EFFECTIVE DATE OF THIS ACT SHALL BE GOVERNED BY THE REPORTING
- 42 REQUIREMENTS OF SECTION 1762, AS OF APRIL 1, 2020.
- 43 (b) PRIOR PROCEEDINGS. IN ALL PROCEEDINGS COMMENCED UNDER ARTICLE
- 44 17A PRIOR TO APRIL 1, 2020 BUT UNDER WHICH NO DETERMINATION FOR THE
- 45 APPOINTMENT OF A GUARDIAN HAS BEEN MADE, THE COURT SHALL MAKE THE
- 46 FINDINGS REQUIRED BY SECTION 1756 OF THE SURROGATE'S COURT

1	PROCEDURE ACT 1/A AS AMENDED BY THIS ACT. UNLESS THE COURT DEEMS IT
2	IMPRACTICABLE, SUCH PROCEEDINGS SHALL OTHERWISE BE GOVERNED BY ALL
3	OTHER PROVISIONS OF ARTICLE 17A AS AMENDED BY THIS ACT.
4	
5	§ 10. THIS ACT SHALL TAKE EFFECT ON THE FIRST OF APRIL NEXT SUCCEEDING
6	THE DATE ON WHICH IT SHALL HAVE BECOME A LAW.
7	

Appendix B

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

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	e02 Flanagan	s09 Keminsky	#25 Montgomery	s23 Savino
852 Akshar	e55 Punke	s07 Raplan	s20 Myria	#32 Sepulveda
#46 Amedors	#59 Gallivan	s26 Ravenagh	a58 O'Mara	#41 Serino
#50 Antonacci	e05 Gaughran	s63 Kennedy	s62 Ortt	all Serveno
s36 Bailey	#12 Gianaria	s28 Erusger	s21 Perker	#51 Soward
e30 Denjamin	s22 Gounardes	s24 lansa	s19 Perseud	all Shoufie
s34 Blaggi	a47 Griffo	s01 LaValla	sl3 Remos	s16 Stavisky
s04 Boyle	s40 Harokham	445 Little	s61 Rentunbofer	all Stewart-
#44 Brealin	#54 Helming	#11 14u	a48 Ritchia	Cousing
sts brooks	s27 Noylman	s03 Martines	e33 Rivers	#49 Tedisco
s3# Carlucci	#31 Jackson	e53 May	a56 Robach	s06 Thomas
s14 Comrie	s60 Jacobs	e37 Mayer	als Salazar	#57 Young
al7 Pelder	#43 Jordan	#42 Metager	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:

m049 Abbate	a072 De La Bose	a029 Nyndman	al44 Morris	a030 Sayegh
a092 Abinanti	a034 DenDekker	al04 Jacobson	4069 O'Donnell	al40 Schimings
a984 Arroyo	a003 DeStefano	a097 Jaffee	a051 Ortis	4059 Schmitt
alor Ashby	a070 Dickens	a011 Jean-Fierre	a091 Otie	a076 Secwright
a035 Aubry	a054 Dilan	al35 Johns	al32 Palmesano	4052 Simm
el20 Barcley	a081 Dinowitz	all5 Jumes	a002 Palumbo	4016 Simotes
a030 Barreell	al47 DiPietro	a077 Joyner	e088 Paulin	a005 Smith
al06 Barrett	a016 D'Orso	a040 Eim	al41 Peoples-	allS Smullen
aff0 Barron	a048 Richenstein	al31 Eolb	Stoken	a022 Solages
s092 Benedatto	a004 Englebright	al05 Lalor	a058 Perry	all4 Stac
m042 Bichotte	a074 Epstein	e013 Lavine	a023 Pheifer	allO Stock
s079 Blake	al09 Faby	all4 Lewrence	Ameto	e010 Stern
all7 Blankenbush	a061 Pall	a050 Lentol	a086 Pichardo	al27 Stirpe
a098 Brabenec	a000 Permandes	el25 Lifton	a089 Pratlow	m102 Tague
a024 Braunstein	al26 Finch	a009 LiPetri	a073 Quart	a071 Taylor
	a008 Fitspatrick		e019 Re	a001 Thiele
e093 Buchweld	al24 Friend	al29 Magnarulli	e012 Raie	a031 Titus
al42 Burks	a046 Frantus	m066 Mallintakis	acce Bames	m033 Vanel
all9 Buttenschon	a095 Galef	8130 Manktelow	a010 Reymor	allé Walczyk
			a062 Reilly	a055 Walker
all3 Byrnes	a007 darbarino	a014 McDonough	a087 Reyes	m143 Wallace
al03 Cabill	al48 Giglio	al46 Mullahon	e043 Richardson	all2 Walsh
a044 Carroll	a066 Glick	a017 Hikulin	a078 Mivera	a041 Weinstein
			a068 Rodrigues	
e032 Cook	a075 Gottfried	a038 Miller, M.G.	all Riman	a059 Williams
#085 Crespo	a021 Griffin	a020 Miller, M.L.	s027 Rosenthal, D.	all3 Woerner
al22 Crouch	el00 Gunther	e015 Nontesano	a067 Rosenthal, L.	a056 Wright
			e025 Bosic	a096 Sebrowski
		a057 Mosley	al49 Byan	
a045 Cymbrowitz	a028 Esvesi	e865 Miou	el21 Selka	
a053 Devila	al28 Hunter	a037 Molan	elll Santabarbara	

- 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 hill and 4 copies of memorandum in support (single house); or 4 signed copies of hill and 8 copies of memorandum in support (uni-bill).

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

- 1 Section 1. Section 1750 of the surrogate's court procedure act is
- 2 REPEALED and a new section 1750 is added to read as follows:
- 3 <u>§ 1750. Definitions</u>
- When used in this article:
- 5 1. "Developmental disability" shall mean a developmental disability
- 6 within the meaning of subdivision twenty-two of section 1.03 of the
- 7 mental hygiene law.
- 8 2. "Traumatic brain injury" shall mean an injury, as defined in
- 9 section twenty-seven hundred forty-one of the public health law, which
- 10 originated before the age of twenty-two.
- 11 3. "Respondent" shall mean an individual listed in the petition as
- 12 alleged to have a developmental disability or traumatic brain injury,
- 13 which disability originates before such person attains age twenty-two.
- 14 § 2. Section 1750-a of the surrogate's court procedure act, as amended
- 15 by chapter 198 of the laws of 2016, is amended to read as follows:
- 16 § 1750-a. Guardianship of persons [who are developmentally disabled]
- with a developmental disability or traumatic brain injury
- 18 1. When it shall appear to the satisfaction of the court [that a
- 19 person is a person who is developmentally disabled, the court is author-
- 20 ized to appoint a guardian of the person or of the property or of both
- 21 if such appointment of a guardian or guardians is in the best interest
- 22 of the person who is developmentally disabled. Such appointments shall
- 23 be made pursuant to the provisions of this article, provided however
- 24 that the provisions of section seventeen hundred fifty of this article
- 25 shall not apply to the appointment of a guardian or guardians of a
- 26 person who is developmentally disabled. For the purposes of this arti-
- 27 cle, a person who is developmentally disabled is a person who has been
- 28 certified by one licensed physician and one licensed psychologist, or by

- l two licensed physicians at least one of whom is familiar with or has
- 2 professional knowledge in the care and treatment of persons with devel-
- 3 opmental disabilities, having qualifications to make such certification,
- 4 as having an impaired ability to understand and appreciate the nature
- 5 and consequences of decisions which result in such person being incapa-
- 6 ble of managing himself or herself and/or his or her affairs by reason
- 7 of developmental disability and that such condition is permanent in
- 8 nature or likely to continue indefinitely, and whose disability:
- 9 (a) is attributable to cerebral palsy, epilepsy, neurological impair-
- 10 ment, autism or traumatic head injury;
- 11 (b) is attributable to any other condition of a person found to be
- 12 closely related to intellectual disability because such condition
- 13 results in similar impairment of general intellectual functioning or
- 14 adaptive behavior to that of persons with intellectual disabilities; or
- 15 (c) is attributable to dyslexia resulting from a disability described
- 16 in subdivision one or two of this section or from intellectual disabili-
- 17 ty; and
- 18 (d) originates before such person attains age twenty-two, provided,
- 19 however, that no such age of origination shall apply for the purposes of
- 20 this article to a person with traumatic head injury.
- 21 2. Notwithstanding any provision of law to the contrary, for the
- 22 purposes of subdivision two of section seventeen hundred fifty and
- 23 section seventeen hundred fifty-b of this article, "a person who is
- 24 intellectually disabled and his or her guardian" shall also mean a
- 25 person and his or her guardian appointed pursuant to this section;
- 26 provided that such person has been certified by the physicians and/or
- 27 psychologists, specified in subdivision one of this section, as (i)
- 28 having an intellectual disability, or (ii) having a developmental disa-

- 1 bility, as defined in section 1.03 of the mental hygiene law, which (A)
- 2 includes intellectual disability, or (B) results in a similar impairment
- 3 of general intellectual functioning or adaptive behavior so that such
- 4 person is incapable of managing himself or herself, and/or his or her
- 5 affairs by reason of such developmental disability] based on clear and
- 6 convincing evidence that the respondent is a person with a developmental
- 7 disability or traumatic brain injury, the court may appoint pursuant to
- B the provisions of this article a guardian of the person or of the prop-
- 9 erty or both provided that quardianship shall be imposed only if neces-
- 10 sary and in the least restrictive manner specifically considering the
- 11 respondent's functional abilities.
- 2. Every decree issued pursuant to this article shall include a find-
- 13 ing as to whether the respondent has the capacity to make health care
- 14 decisions, as defined by subdivision three of section twenty-nine
- 15 hundred eighty of the public health law. A determination that the
- 16 respondent has the capacity to make health care decisions shall not
- 17 preclude the appointment of a quardian to make other decisions on behalf
- 18 of the respondent.
- 19 § 3. Section 1750-b of the surrogate's court procedure act, as amended
- 20 by chapter 198 of the laws of 2016, is amended to read as follows:
- 21 § 1750-b. Health care decisions for persons [who are intellectually
- 22 disabled] with a developmental disability or traumatic brain
- 23 <u>injury</u>
- 24 1. Scope of authority. Unless specifically prohibited by the court
- 25 after consideration of the determination, if any, regarding a person
- 26 [who is intellectually disabled's capacity] with a developmental disa-
- 27 bility or traumatic brain injury to make health care decisions, which is
- 28 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 10 nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable 11 medical judgment, the patient will die within a relatively short time 12 period. Cardiopulmonary resuscitation is presumed to be life-sustaining 14 treatment without the necessity of a medical judgment by an attending physician. The provisions of this article are not intended to permit or 16 promote suicide, assisted suicide or euthanasia; accordingly, nothing in this section shall be construed to permit a guardian to consent to any 17 act or omission to which the person [who is intellectually disabled] 18 with a developmental disability or traumatic brain injury could not 19 consent if such person had capacity. 20 21 (a) For the purposes of making a decision to withhold or withdraw 22 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, 24 "guardian" shall also mean a family member of a person who (i) has 25 [intellectual disability] a traumatic brain injury, or (ii) has a devel-26 opmental 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 10 of the former Willowbrook state school on March seventeenth, nineteen 11 hundred seventy-two and those individuals who were in community care 12 status on that date and subsequently returned to Willowbrook or a 13 related facility, who are fully represented by the consumer advisory board and who have no guardians appointed pursuant to this article or 15 have no qualified family members to make such a decision, then a "guard-16 ian" shall also mean the Willowbrook consumer advisory board. A decision 17 of such family member or the Willowbrook consumer advisory board to 18 withhold or withdraw life-sustaining treatment shall be subject to all 19 of the protections, procedures and safeguards which apply to the decision of a guardian to withhold or withdraw life-sustaining treatment 21 pursuant to this section. 22 In the case of a person for whom no guardian has been appointed pursu-

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

- 1 declarations and procedures, including expedited procedures, to comply
- 2 with this section shall be established by regulations promulgated by the
- 3 commission on quality of care and advocacy for persons with disabili-
- 4 ties.
- 5 (b) Regulations establishing the prioritized list of qualified family
- 6 members required by paragraph (a) of this subdivision shall be developed
- 7 by the commissioner of the office for people with developmental disabil-
- 8 ities in conjunction with parents, advocates and family members of
- 9 persons who are intellectually disabled. Regulations to implement the
- 10 authority of the Willowbrook consumer advisory board pursuant to para-
- 11 graph (a) of this subdivision may be promulgated by the commissioner of
- 12 the office for people with developmental disabilities with advice from
- 13 the Willowbrook consumer advisory board.
- 14 [(c) Notwithstanding any provision of law to the contrary, the formal
- 15 determinations required pursuant to section seventeen hundred fifty of
- 16 this article shall only apply to guardians appointed pursuant to section
- 17 seventeen hundred fifty or seventeen hundred fifty-a of this article.]
- 18 2. Decision-making standard. (a) The guardian shall base all advocacy
- 19 and health care decision-making solely and exclusively on the best
- 20 interests of the person [who is intellectually disabled] with a develop-
- 21 mental disability or traumatic brain injury and, when reasonably known
- 22 or ascertainable with reasonable diligence, on [the person who is intel-
- 23 lectually disabled's] such person's wishes, including moral and reli-
- 24 gious beliefs.
- 25 (b) An assessment of [the person who is intellectually disabled's]
- 26 <u>such person's</u> best interests shall include consideration of:
- 27 (i) the dignity and uniqueness of every person;

- 1 (ii) the preservation, improvement or restoration of [the person who
- 2 is intellectually disabled's] such person's health;
- 3 (iii) the relief of [the person who is intellectually disabled's] such
- 4 person's suffering by means of palliative care and pain management;
- 5 (iv) the unique nature of artificially provided nutrition or
- 6 hydration, and the effect it may have on [the] such person [who is
- 7 intellectually disabled]; and
- 8 (v) the entire medical condition of the person.
- 9 (c) No health care decision shall be influenced in any way by:
- 10 (i) a presumption that persons [who are intellectually disabled] with
- ll a developmental disability or traumatic brain injury are not entitled to
- 12 the full and equal rights, equal protection, respect, medical care and
- 13 dignity afforded to persons without [an intellectual disability or] a
- 14 developmental disability or traumatic brain injury; or
- 15 (ii) financial considerations of the guardian, as such considerations
- 16 affect the guardian, a health care provider or any other party.
- 17 3. Right to receive information. Subject to the provisions of sections
- 18 33.13 and 33.16 of the mental hygiene law, the guardian shall have the
- 19 right to receive all medical information and medical and clinical
- 20 records necessary to make informed decisions regarding the [person who
- 21 is intellectually disabled's] health care of the person with a develop-
- 22 mental disability or traumatic brain injury.
- Life-sustaining treatment. The guardian shall have the affirmative
- 24 obligation to advocate for the full and efficacious provision of health
- 25 care, including life-sustaining treatment. In the event that a guardian
- 26 makes a decision to withdraw or withhold life-sustaining treatment from
- 27 a person [who is intellectually disabled] with a developmental disabili-
- 28 ty or traumatic brain injury:

1 The attending physician, as defined in subdivision two of section 2 twenty-nine hundred eighty of the public health law, must confirm to a 3 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 6 thereof shall be included in [the person who is intellectually disabled's] such person's medical record, and shall contain such attending 7 8 physician's opinion regarding the cause and nature of [the person who is intellectually disabled's | such person's incapacity as well as its 10 extent and probable duration. The attending physician who makes the 11 confirmation shall consult with another physician, or a licensed 12 psychologist, to further confirm [the person who is intellectually disa-13 bled's] such person's lack of capacity. The attending physician who makes the confirmation, or the physician or licensed psychologist with 14 15 whom the attending physician consults, must (i) be employed by a devel-16 opmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with develop-17 18 mental disabilities to provide treatment and care to people with developmental disabilities, or (ii) have been employed for a minimum of two 19 20 years to render care and service in a facility or program operated, 21 licensed or authorized by the office for people with developmental disa-22 bilities, or (iii) have been approved by the commissioner of the office for people with developmental disabilities in accordance with regu-23 24 lations promulgated by such commissioner. Such regulations shall require 25 that a physician or licensed psychologist possess specialized training or three years experience in treating intellectual disability. A record 26 of such consultation shall be included in the [person who is intellectu-

- 1 ally disabled's] medical record of the person with a developmental disa-
- 2 bility or traumatic brain injury.
- 3 (b) The attending physician, as defined in subdivision two of section
- 4 twenty-nine hundred eighty of the public health law, with the concur-
- 5 rence of another physician with whom such attending physician shall
- 6 consult, must determine to a reasonable degree of medical certainty and
- 7 note on the [person who is intellectually disabled's] chart of the
- 8 person with a developmental disability or traumatic brain injury that:
- 9 (i) [the] such person [who is intellectually disabled] has a medical
- 10 condition as follows:
- 11 A. a terminal condition, as defined in subdivision twenty-three of
- 12 section twenty-nine hundred sixty-one of the public health law; or
- 13 B. permanent unconsciousness; or
- 14 C. a medical condition other than such person's [intellectual] devel-
- 15 opmental disability or traumatic brain injury which requires life-sus-
- 16 taining treatment, is irreversible and which will continue indefinitely;
- 17 and
- 18 (ii) the life-sustaining treatment would impose an extraordinary
- 19 burden on such person, in light of:
- 20 A. such person's medical condition, other than such person's [intel-
- 21 lectual] developmental disability or traumatic brain injury; and
- B. the expected outcome of the life-sustaining treatment, notwith-
- 23 standing such person's [intellectual] developmental disability or trau-
- 24 matic brain injury; and
- 25 (iii) in the case of a decision to withdraw or withhold artificially
- 26 provided nutrition or hydration:
- 27 A. there is no reasonable hope of maintaining life; or

- B. the artificially provided nutrition or hydration poses an extraor-
- 2 dinary burden.
- 3 (c) The guardian shall express a decision to withhold or withdraw
- 4 life-sustaining treatment either:
- 5 (i) in writing, dated and signed in the presence of one witness eigh-
- 6 teem years of age or older who shall sign the decision, and presented to
- 7 the attending physician, as defined in subdivision two of section twen-
- 8 ty-nine hundred eighty of the public health law; or
- 9 (ii) orally, to two persons eighteen years of age or older, at least
- 10 one of whom is the person who is [intellectually disabled's] the attend-
- ll ing physician to the person with a developmental disability or traumatic
- 12 brain injury, as defined in subdivision two of section twenty-nine
- 13 hundred eighty of the public health law.
- 14 (d) The attending physician, as defined in subdivision two of section
- 15 twenty-nine hundred eighty of the public health law, who is provided
- 16 with the decision of a guardian shall include the decision in the
- 17 [person who is intellectually disabled's] medical chart of the person
- 18 with a developmental disability or traumatic brain injury, and shall
- 19 either:
- 20 (i) promptly issue an order to withhold or withdraw life-sustaining
- 21 treatment from [the] such person [who is intellectually disabled], and
- 22 inform the staff responsible for such person's care, if any, of the
- 23 order; or
- 24 (ii) promptly object to such decision, in accordance with subdivision
- 25 five of this section.
- 26 (e) At least forty-eight hours prior to the implementation of a deci-
- 27 sion to withdraw life-sustaining treatment, or at the earliest possible

- 1 time prior to the implementation of a decision to withhold life-sustain-
- 2 ing treatment, the attending physician shall notify:
- 3 (i) the person [who is intellectually disabled] with a developmental
- 4 disability or traumatic brain injury, except if the attending physician
- 5 determines, in writing and in consultation with another physician or a
- 6 licensed psychologist, that, to a reasonable degree of medical certain-
- 7 ty, the person would suffer immediate and severe injury from such
- 8 notification. The attending physician who makes the confirmation, or the
- 9 physician or licensed psychologist with whom the attending physician
- 10 consults, shall:
- 11 A. be employed by a developmental disabilities services office named
- 12 in section 13.17 of the mental hygiene law or employed by the office for
- 13 people with developmental disabilities to provide treatment and care to
- 14 people with developmental disabilities, or
- 15 B. have been employed for a minimum of two years to render care and
- 16 service in a facility operated, licensed or authorized by the office for
- 17 people with developmental disabilities, or
- 18 C. have been approved by the commissioner of the office for people
- 19 with developmental disabilities in accordance with regulations promul-
- 20 gated by such commissioner. Such regulations shall require that a physi-
- 21 cian or licensed psychologist possess specialized training or three
- 22 years experience in treating intellectual disability. A record of such
- 23 consultation shall be included in the [person who is intellectually
- 24 disabled's] medical record of the person with a developmental disability
- 25 or traumatic brain injury;
- 26 (ii) if the person is in or was transferred from a residential facili-
- 27 ty operated, licensed or authorized by the office for people with devel-
- 28 opmental disabilities, the chief executive officer of the agency or

- l organization operating such facility and the mental hygiene legal
- 2 service; and
- 3 (iii) if the person is not in and was not transferred from such a
- 4 facility or program, the commissioner of the office for people with
- 5 developmental disabilities, or his or her designee.
- 6 5. Objection to health care decision. (a) Suspension. A health care
- 7 decision made pursuant to subdivision four of this section shall be
- 8 suspended, pending judicial review, except if the suspension would in
- 9 reasonable medical judgment be likely to result in the death of the
- 10 person [who is intellectually disabled] with a developmental disability
- 11 or traumatic brain injury, in the event of an objection to that decision
- 12 at any time by:
- 13 (i) the person [who is intellectually disabled] with a developmental
- 14 disability or traumatic brain injury on whose behalf such decision was
- 15 made; or
- 16 (ii) a parent or adult sibling who either resides with or has main-
- 17 tained substantial and continuous contact with the person [who is intel-
- 18 lectually disabled) with a developmental disability or traumatic brain
- 19 injury; or
- 20 (iii) the attending physician, as defined in subdivision two of
- 21 section twenty-nine hundred eighty of the public health law; or
- 22 (iv) any other health care practitioner providing services to the
- 23 person [who is intellectually disabled] with a developmental disability
- 24 or traumatic brain injury, who is licensed pursuant to article one
- 25 hundred thirty-one, one hundred thirty-one-B, one hundred thirty-two,
- 26 one hundred thirty-three, one hundred thirty-six, one hundred thirty-
- 27 nine, one hundred forty-one, one hundred forty-three, one hundred
- 28 forty-four, one hundred fifty-three, one hundred fifty-four, one hundred

- 1 fifty-six, one hundred fifty-nine or one hundred sixty-four of the
- 2 education law; or
- 3 (v) the chief executive officer identified in subparagraph (ii) of
- 4 paragraph (e) of subdivision four of this section; or
- 5 (vi) if the person is in or was transferred from a residential facili-
- 6 ty or program operated, approved or licensed by the office for people
- 7 with developmental disabilities, the mental hygiene legal service; or
- 8 (vii) if the person is not in and was not transferred from such a
- 9 facility or program, the commissioner of the office for people with
- 10 developmental disabilities, or his or her designee.
- 11 (b) Form of objection. Such objection shall occur orally or in writ-
- 12 ing.
- 13 (c) Notification. In the event of the suspension of a health care
- 14 decision pursuant to this subdivision, the objecting party shall prompt-
- 15 ly notify the guardian and the other parties identified in paragraph (a)
- 16 of this subdivision, and the attending physician shall record such
- 17 suspension in the [person who is intellectually disabled's] medical
- 18 chart of the person with a developmental disability or traumatic brain
- 19 injury.
- 20 (d) Dispute mediation. In the event of an objection pursuant to this
- 21 subdivision, at the request of the objecting party or person or entity
- 22 authorized to act as a guardian under this section, except a surrogate
- 23 decision making committee established pursuant to article eighty of the
- 24 mental hygiene law, such objection shall be referred to a dispute medi-
- 25 ation system, established pursuant to section two thousand nine hundred
- 26 seventy-two of the public health law or similar entity for mediating
- 27 disputes in a hospice, such as a patient's advocate's office, hospital
- 28 chaplain's office or ethics committee, as described in writing and

- 1 adopted by the governing authority of such hospice, for non-binding
- 2 mediation. In the event that such dispute cannot be resolved within
- 3 seventy-two hours or no such mediation entity exists or is reasonably
- 4 available for mediation of a dispute, the objection shall proceed to
- 5 judicial review pursuant to this subdivision. The party requesting medi-
- 6 ation shall provide notification to those parties entitled to notice
- 7 pursuant to paragraph (a) of this subdivision.
- 8 6. Special proceeding authorized. The guardian, the attending physi-
- 9 cian, as defined in subdivision two of section twenty-nine hundred
- 10 eighty of the public health law, the chief executive officer identified
- ll in subparagraph (ii) of paragraph (e) of subdivision four of this
- 12 section, the mental hygiene legal service (if the person is in or was
- 13 transferred from a residential facility or program operated, approved or
- 14 licensed by the office for people with developmental disabilities) or
- 15 the commissioner of the office for people with developmental disabili-
- 16 ties or his or her designee (if the person is not in and was not trans-
- 17 ferred from such a facility or program) may commence a special proceed-
- 18 ing in a court of competent jurisdiction with respect to any dispute
- 19 arising under this section, including objecting to the withdrawal or
- 20 withholding of life-sustaining treatment because such withdrawal or
- 21 withholding is not in accord with the criteria set forth in this
- 22 section.
- 7. Provider's obligations. (a) A health care provider shall comply
- 24 with the health care decisions made by a guardian in good faith pursuant
- 25 to this section, to the same extent as if such decisions had been made
- 26 by the person [who is intellectually disabled] with a developmental
- 27 disability or traumatic brain injury, if such person had capacity.

- 1 (b) Notwithstanding paragraph (a) of this subdivision, nothing in this
- 2 section shall be construed to require a private hospital to honor a
- 3 guardian's health care decision that the hospital would not honor if the
- 4 decision had been made by the person [who is intellectually disabled]
- 5 with a developmental disability or traumatic brain injury, if such
- 6 person had capacity, because the decision is contrary to a formally
- 7 adopted written policy of the hospital expressly based on religious
- 8 beliefs or sincerely held moral convictions central to the hospital's
- 9 operating principles, and the hospital would be permitted by law to
- 10 refuse to honor the decision if made by such person, provided:
- 11 (i) the hospital has informed the guardian of such policy prior to or
- 12 upon admission, if reasonably possible; and
- 13 (ii) the person [who is intellectually disabled] with a developmental
- 14 <u>disability or traumatic brain injury</u> is transferred promptly to another
- 15 hospital that is reasonably accessible under the circumstances and is
- 16 willing to honor the guardian's decision. If the guardian is unable or
- 17 unwilling to arrange such a transfer, the hospital's refusal to honor
- 18 the decision of the guardian shall constitute an objection pursuant to
- 19 subdivision five of this section.
- 20 (c) Notwithstanding paragraph (a) of this subdivision, nothing in this
- 21 section shall be construed to require an individual health care provider
- 22 to honor a guardian's health care decision that the individual would not
- 23 honor if the decision had been made by the person [who is intellectually
- 24 disabled] with a developmental disability or traumatic brain injury, if
- 25 such person had capacity, because the decision is contrary to the indi-
- 26 vidual's religious beliefs or sincerely held moral convictions, provided
- 27 the individual health care provider promptly informs the guardian and
- 28 the facility, if any, of his or her refusal to honor the guardian's

- l decision. In such event, the facility shall promptly transfer responsi-
- 2 bility for the person [who is intellectually disabled] with a develop-
- 3 mental disability or traumatic brain injury to another individual health
- 4 care provider willing to honor the guardian's decision. The individual
- 5 health care provider shall cooperate in facilitating such transfer of
- 6 the patient.
- 7 (d) Notwithstanding the provisions of any other paragraph of this
- 8 subdivision, if a guardian directs the provision of life-sustaining
- 9 treatment, the denial of which in reasonable medical judgment would be
- 10 likely to result in the death of the person [who is intellectually disa-
- 11 bled] with a developmental disability or traumatic brain injury, a
- 12 hospital or individual health care provider that does not wish to
- 13 provide such treatment shall nonetheless comply with the guardian's
- 14 decision pending either transfer of the person [who is intellectually
- 15 disabled] with a developmental disability or traumatic brain injury to a
- 16 willing hospital or individual health care provider, or judicial review.
- 17 (e) Nothing in this section shall affect or diminish the authority of
- 18 a surrogate decision-making panel to render decisions regarding major
- 19 medical treatment pursuant to article eighty of the mental hygiene law.
- 20 8. Immunity. (a) Provider immunity. No health care provider or employ-
- 21 ee thereof shall be subjected to criminal or civil liability, or be
- 22 deemed to have engaged in unprofessional conduct, for honoring reason-
- 23 ably and in good faith a health care decision by a guardian, or for
- 24 other actions taken reasonably and in good faith pursuant to this
- 25 section.
- 26 (b) Guardian immunity. No guardian shall be subjected to criminal or
- 27 civil liability for making a health care decision reasonably and in good
- 28 faith pursuant to this section.

- S 4. Section 1751 of the surrogate's court procedure act, as amended
- 2 by chapter 198 of the laws of 2016, is amended to read as follows:
- 3 § 1751. Petition for appointment; by whom [made] and where made
- 4 1. A petition for the appointment of a guardian of the person or prop-
- 5 erty, or both, [of a person who is intellectually disabled or a person
- 6 who is developmentally disabled] may be made by a parent of a person
- 7 asserted to have a developmental disability or traumatic brain injury,
- 8 any [interested] person eighteen years of age or older on behalf of the
- 9 [person who is intellectually disabled or a person who is develop-
- 10 mentally disabled respondent, including a corporation authorized to
- ll serve as a guardian as provided for by this article, or by the person
- 12 who is [intellectually disabled or a person who is developmentally disa-
- 13 bled] asserted to have a developmental disability or traumatic brain
- 14 injury when such person is eighteen years of age or older.
- 2. A proceeding under this article shall be brought in the surrogate's
- 16 court within the county in which the respondent resides. If the respond-
- 17 ent is a resident in a residential facility, the residence of the
- 18 respondent shall be deemed to be in the county where that facility is
- 19 located.
- 20 § 5. Section 1752 of the surrogate's court procedure act, as amended
- 21 by chapter 198 of the laws of 2016, is amended to read as follows:
- 22 \$ 1752. Petition for appointment; contents
- 23 The petition for the appointment of a guardian shall be filed with the
- 24 court on forms to be prescribed by the [state] chief administrator of
- 25 the courts. Such petition for a guardian of a [person who is intellectu-
- 26 ally disabled or a person who is developmentally disabled] respondent
- 27 shall include, but not be limited to, the following information:

- 1 1. the full name, date of birth and residence of the [person who is
- 2 intellectually disabled or a person who is developmentally disabled
- 3 respondent;
- 4 2. the name, age, address and relationship or interest of the peti-
- 5 tioner to the [person who is intellectually disabled or a person who is
- 6 developmentally disabled] respondent;
- 7 3. the names of the [father, the mother] parents, children, adult
- 8 siblings [if eighteen years of age or older], the spouse [and primary
- 9 care physician if other than a physician having submitted a certif-
- 10 ication with the petition, if any, of the person who is intellectually
- ll disabled or a person who is developmentally disabled], if any, of the
- 12 respondent, and whether or not they are living, and if living, their
- 13 addresses and the names and addresses of the nearest [distributees]
- 14 family members of full age who are domiciliaries, if both parents are
- 15 [dead] <u>deceased;</u>
- 16 4. the name and address of the person with whom the [person who is
- 17 intellectually disabled or a person who is developmentally disabled]
- 18 respondent resides if other than the parents or spouse. If the respond-
- 19 ent resides in a facility, the name and address of the facility;
- 5. the name, age, address, education and other qualifications, and
- 21 consent of the proposed guardian, standby and alternate guardian[, if].
- 22 If petitioner is someone other than the parent, spouse, adult child [if
- 23 eighteen years of age or older] or adult sibling [if eighteen years of
- 24 age or older], and if such parent, spouse [or], adult child or adult
- 25 sibling be living, why any of them should not be appointed guardian;
- 26 6. the estimated value of real and personal property and the annual
- 27 income therefrom and any other income including governmental entitle-

- l ments to which the [person who is intellectually disabled or person who
- 2 is developmentally disabled] respondent is entitled; [and]
- 3 7. any circumstances which the court should consider in determining
- 4 whether [it is in the best interests of the person who is intellectually
- 5 disabled or person who is developmentally disabled to] the respondent
- 6 should not be present at the hearing [if conducted];
- 7 8. a statement that the respondent has a developmental disability or
- 8 traumatic brain injury, including the basis for same, and the nature and
- 9 extent of the respondent's functional abilities; and
- 9. a statement of the alternatives to guardianship considered, includ-
- 11 ing but not limited to the execution of a health care proxy, power of
- 12 attorney, representative payee, care coordination and/or other social
- 13 support services, or other supported or shared decision-making, and
- 14 reasons for the declination of such alternatives.
- 15 § 6. Section 1753 of the surrogate's court procedure act, as amended
- 16 by chapter 198 of the laws of 2016, is amended to read as follows:
- 17 § 1753. Persons to be served
- 18 1. Upon presentation of the petition, process shall issue to:
- 19 (a) the spouse, the parent or parents, and adult children and adult
- 20 siblings, if the petitioner is other than a parent[, adult siblings, if
- 21 the petitioner is other than a parent, and if the person who is intel-
- 22 lectually disabled or person who is developmentally disabled is married,
- 23 to the spouse, if their residences are known);
- 24 (b) the person [having] providing care [and custody of] to the [person
- 25 who is intellectually disabled or person who is developmentally disa-
- 26 bled] respondent, or with whom such person resides if other than the
- 27 parents or spouse; and

- 1 (c) the [person who is intellectually disabled or person who is devel-
- 2 opmentally disabled if fourteen years of age or older for whom an appli-
- 3 cation has been made in such person's behalf] respondent.
- 4 2. Upon presentation of the petition, notice of such petition shall be
- 5 served by certified mail to:
- 6 (a) the adult siblings if the petitioner is a parent, and adult chil-
- 7 dren if the petitioner is a parent;
- 8 (b) [the mental hygiene legal service in the judicial department where
- 9 the facility, as defined in subdivision (a) of section 47.01 of the
- 10 mental hygiene law, is located if the person who is intellectually disa-
- 11 bled or person who is developmentally disabled resides in such a facili-
- 12 ty;
- 13 (c)] in all cases, to the director in charge of a facility licensed or
- 14 operated by an agency of the state of New York, if the [person who is
- 15 intellectually disabled or person who is developmentally disabled]
- 16 respondent resides in such facility;
- 17 [(d) one other person] (c) any other person or persons if designated
- 18 in writing by the [person who is intellectually disabled or person who
- 19 is developmentally disabled] respondent; and
- 20 [(e)] (d) such other persons as the court may deem proper.
- 21 3. [No process or notice shall be necessary to a parent, adult child,
- 22 adult sibling, or spouse of the person who is intellectually disabled or
- 23 person who is developmentally disabled who has been declared by a court
- 24 as being incompetent. In addition, no process or notice shall be neces-
- 25 sary to a spouse who is divorced from the person who is intellectually
- 26 disabled or person who is developmentally disabled, and to a parent,
- 27 adult child, adult sibling when it shall appear to the satisfaction of
- 28 the court that such person or persons have abandoned the person who is

- 1 intellectually disabled or person who is developmentally disabled] The
- 2 court shall upon the issuance of a citation assign counsel for the
- 3 respondent and shall provide said counsel with a copy of the petition
- 4 and any supporting papers filed therein. Process or notice may be
- 5 dispensed with in the court's discretion.
- § 7. Section 1754 of the surrogate's court procedure act, as amended
- 7 by chapter 198 of the laws of 2016, is amended to read as follows:
- B § 1754. Hearing and trial
- 9 1. Upon a petition for the appointment of a guardian of a [person who
- 10 is intellectually disabled or person who is developmentally disabled
- ll eighteen years of age or older] respondent, the court shall conduct a
- 12 hearing at which [such person] the respondent shall have the right to
- 13 jury trial. The right to a jury trial shall be deemed waived by failure
- 14 to make a demand therefor. [The court may in its discretion dispense
- 15 with a hearing for the appointment of a guardian, and may in its
- 16 discretion appoint a guardian ad litem, or the mental hygiene legal
- 17 service if such person is a resident of a mental hygiene facility as
- 18 defined in subdivision (a) of section 47.01 of the mental hygiene law,
- 19 to recommend whether the appointment of a guardian as proposed in the
- 20 application is in the best interest of the person who is intellectually
- 21 disabled or person who is developmentally disabled, provided however,
- 22 that such application has been made by:
- 23 (a) both parents or the survivor; or
- 24 (b) one parent and the consent of the other parent; or
- 25 (c) any interested party and the consent of each parent.
- 26 2. When it shall appear to the satisfaction of the court that a parent
- 27 or parents not joining in or consenting to the application have aban-
- 28 doned the person who is intellectually disabled or person who is devel-

- 1 opmentally disabled or are not otherwise required to receive notice, the
- 2 court may dispense with such parent's consent in determining the need to
- 3 conduct a hearing for a person under the age of eighteen. However, if
- 4 the consent of both parents or the surviving parent is dispensed with by
- 5 the court, a hearing shall be held on the application.
- 6 3. If a hearing is conducted, the person who is intellectually disa-
- 7 bled or person who is developmentally disabled]
- 8 2. (a) The court shall appoint mental hygiene legal services as coun-
- 9 sel for the respondent unless it appoints other counsel. The court may
- 10 also appoint a guardian ad litem for the respondent. Such assignments of
- 11 counsel or quardian ad litem shall be implemented as provided in section
- 12 four hundred seven of this act.
- 13 (b) If the respondent objects to having counsel, the respondent may
- 14 proceed self-represented only with leave of the court. The court may
- 15 appoint counsel or guardian ad litem at its discretion, over the
- 16 respondent's objection.
- 3. Counsel for the respondent or the guardian ad litem may:
- 18 (a) apply to the court for an order to inspect the clinical records
- 19 pertaining to the respondent in accordance with state and federal laws;
- 20 (b) be allowed access to the respondent's clinical records without a
- 21 court order as otherwise limited by law; and
- (c) request that the court issue such orders to permit access.
- 23 4. At the scheduled hearing, the respondent shall be present unless it
- 24 shall appear to the satisfaction of the court [on the certification of
- 25 the certifying physician that the person who is intellectually disabled
- 26 or person who is developmentally disabled is medically incapable of
- 27 being present to the extent that attendance is likely to result in phys-
- 28 ical harm to such person who is intellectually disabled or person who is

- 1 developmentally disabled, or under such other circumstances which the
- 2 court finds would not be in the best interest of the person who is
- 3 intellectually disabled or person who is developmentally disabled.
- 4. If either a hearing is dispensed with pursuant to subdivisions one
- 5 and two of this section or the person who is intellectually disabled or
- 6 person who is developmentally disabled is not present at the hearing
- 7 pursuant to subdivision three of this section, the court may appoint a
- 8 guardian ad litem if no mental hygiene legal service attorney is author-
- 9 ized to act on behalf of the person who is intellectually disabled or
- 10 person who is developmentally disabled. The guardian ad litem or mental
- ll hygiene legal service attorney, if appointed, shall personally interview
- 12 the person who is intellectually disabled or person who is develop-
- 13 mentally disabled and shall submit a written report to the court] that
- 14 the respondent's presence would result in harm to such person.
- 15 5. If, upon conclusion of [such hearing or jury trial or if none be
- 16 held upon the application] the proceeding, the court is satisfied [that
- 17 the best interests of the person who is intellectually disabled or
- 18 person who is developmentally disabled will be promoted by the appoint-
- 19 ment of a guardian of the person or property, or both, it shall make a
- 20 decree naming such person or persons to serve as such guardians] based
- 21 on clear and convincing evidence that the respondent is incapable of
- 22 managing her or his affairs, it shall make a decree appointing a guardi-
- 23 an provided that quardianship shall be imposed only if necessary and in
- 24 the least restrictive manner specifically considering the respondent's
- 25 <u>functional</u> abilities.
- 26 6. Where the court has determined that the respondent has certain
- 27 decision-making capacity, the court shall appropriately limit the scope
- 28 or duration of the quardianship it decrees.

- 1 S 8. The surrogate's court procedure act is amended by adding a new
- 2 section 1754-a to read as follows:
- 3 § 1754-a. Decision-making standard
- 4 Decisions made by a guardian appointed hereunder shall be made in
- 5 accordance with the following standards:
- 6 1. A guardian shall exercise authority only as necessary and shall
- 7 encourage the person with a developmental disability or traumatic brain
- 8 injury to participate in making decisions and to act on his or her own
- 9 behalf.
- 2. A guardian shall consider the expressed desires and personal values
- 11 of the person with a developmental disability or traumatic brain injury
- 12 to the extent known when making decisions and shall consult such person.
- 3. If the person's wishes are unknown and remain unknown after reason-
- 14 able efforts are made to discern them, the decision shall be made on the
- 15 basis of the best interests of such person as determined by the guardi-
- 16 an. In determining the best interests of such person, the quardian shall
- 17 weigh the reason for and nature of the proposed action; the benefit or
- 18 necessity of the action; the possible risks and other consequences of
- 19 the proposed action; and any available alternatives and their risks,
- 20 consequences and benefits. The quardian shall take into account any
- 21 other information, including the views of family and friends that the
- 22 quardian believes said person would have considered if able to act for
- 23 herself or himself.
- S 9. Section 1755 of the surrogate's court procedure act is REPEALED
- 25 and a new section 1755 is added to read as follows:
- 26 § 1755. Duration, modification and revocation
- 27 1. Such guardianship shall remain in effect until modified or revoked
- 28 by the court.

- 2. Any person for whom a guardian has been appointed pursuant to this
- 2 article, or anyone, including the guardian, on behalf of such person may
- 3 petition to the court to discharge the guardian and appoint a successor,
- 4 to designate the quardian of the property as a limited quardian of the
- 5 property, to appoint a spouse as stand-by quardian, or to otherwise
- 6 modify or revoke the guardianship order. Upon such a petition, the court
- 7 shall conduct a hearing and such review pursuant to section seventeen
- 8 hundred fifty-four of this article. The court may modify or revoke an
- 9 order if it deems that the circumstances or needs of the person with a
- 10 developmental disability or traumatic brain injury have changed and the
- 11 provisions of the order are no longer appropriate or necessary.
- 3. Any proceeding to modify or revoke a prior guardianship order may
- 13 be brought in the surrogate's court which granted the prior order,
- 14 unless at the time of the application to modify or revoke the order the
- 15 person with a developmental disability or traumatic brain injury resides
- 16 elsewhere, in which case the proceeding may be brought in the county
- 17 where the person with a developmental disability or traumatic brain
- 18 injury resides.
- 19 \$ 10. Section 1756 of the surrogate's court procedure act, as amended
- 20 by chapter 198 of the laws of 2016, is amended to read as follows:
- 21 § 1756. Limited guardian of the property
- 22 When it shall appear to the satisfaction of the court that [such
- 23 person who is intellectually disabled or person who is developmentally
- 24 disabled for whom an application for guardianship is made is eighteen
- 25 years of age or older and] the respondent is wholly or substantially
- 26 self-supporting by means of [his or her] wages or earnings from employ-
- 27 ment, the court is authorized and empowered to appoint a limited guardi-
- 28 an of the property of [such person who is intellectually disabled or

- l person who is developmentally disabled] the respondent who shall
- 2 receive, manage, disburse and account for only such property of said
- 3 person [who is intellectually disabled or person who is developmentally
- 4 disabled] as shall be received from other than the wages or earnings of
- 5 said person.
- 6 [The] Said person [who is intellectually disabled or person who is
- 7 developmentally disabled] for whom a limited guardian of the property
- 8 has been appointed shall have the right to receive and expend any and
- 9 all wages or other earnings of [his or her] employment and shall have
- 10 the power to contract or legally bind himself or herself for such sum of
- 11 money not exceeding one month's wages or earnings from such employment
- 12 or three hundred dollars, whichever is greater, or as otherwise author-
- 13 ized by the court.
- 14 § 11. Section 1757 of the surrogate's court procedure act, as amended
- 15 by chapter 198 of the laws of 2016, is amended to read as follows:
- 16 § 1757. Standby guardian of a person [who is intellectually disabled or
- 17 person who is developmentally disabled] with a developmental
- disability or traumatic brain injury
- 19 1. Upon application, a standby guardian of the person or property or
- 20 both of a person [who is intellectually disabled or person who is devel-
- 21 opmentally disabled) with a developmental disability or traumatic brain
- 22 injury may be appointed by the court. The court may also, upon applica-
- 23 tion, appoint an alternate and/or successive alternates to such standby
- 24 guardian, to act if such standby guardian shall die, or become incapaci-
- 25 tated, or shall renounce. Such appointments by the court shall be made
- 26 in accordance with the provisions of this article.
- 27 2. Such standby guardian, or alternate in the event of such standby
- 28 guardian's death, incapacity or renunciation, shall without further

1 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 quardian's duties of such office. Before confirming the appointment of the standby guardian or alternate guardithe 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 11 injury or the person [who is intellectually disabled or person who is 12 developmentally disabled if such person is eighteen years of age or 13 older] with a developmental disability or traumatic brain injury, or 14

16 3. Failure of a standby or alternate standby guardian to assume the duties of guardian, seek court confirmation or to renounce the guardian-17 ship within sixty days of written notice by certified mail or personal 18 delivery given by or on behalf of the person [who is intellectually 19 disabled or person who is developmentally disabled] with a developmental 20 disability or traumatic brain injury of a prior guardian's inability to 21 22 serve and the standby or alternate standby guardian's duty to serve, seek court confirmation or renounce such role shall allow the court to: 23

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upon its discretion.

- 24 (a) deem the failure an implied renunciation of guardianship, and
- 25 (b) authorize, notwithstanding the time period provided for in subdi-
- 26 vision two of this section to seek court confirmation, any remaining
- 27 standby or alternate standby guardian to serve in such capacity provided
- 28 (i) an application for confirmation and appropriate notices pursuant to

- l subdivision one of section seventeen hundred fifty-three of this article
- 2 are filed, or (ii) an application for modification of the guardianship
- 3 order pursuant to section seventeen hundred fifty-five of this article
- 4 is filed.
- 5 § 12. Subdivision 2 of section 1758 of the surrogate's court procedure
- 6 act, as amended by chapter 198 of the laws of 2016, is amended to read
- 7 as follows:
- 2. After the appointment of a guardian, standby guardian or alternate
- 9 guardians, the court shall have and retain general jurisdiction over the
- 10 person (who is intellectually disabled or person who is developmentally
- ll disabled] with a developmental disability or traumatic brain injury for
- 12 whom such guardian shall have been appointed, to take of its own motion
- 13 or to entertain and adjudicate such steps and proceedings relating to
- 14 such guardian, standby, or alternate guardianship as may be deemed
- 15 necessary or proper for the welfare of such person [who is intellectual-
- 16 ly disabled or person who is developmentally disabled].
- 17 § 13. Section 1759 of the surrogate's court procedure act is REPEALED.
- 18 § 14. Section 1760 of the surrogate's court procedure act, as amended
- 19 by chapter 198 of the laws of 2016, is amended to read as follows:
- 20 § 1760. Corporate guardianship
- 21 No corporation may be appointed guardian of the person under the
- 22 provisions of this article, except that a non-profit corporation organ-
- 23 ized and existing under the laws of the state of New York and having the
- 24 corporate power to so act [as guardian of a person who is intellectually
- 25 disabled or person who is developmentally disabled may be appointed as
- 26 the guardian of the person only of such person who is intellectually
- 27 disabled or person who is developmentally disabled] may be appointed.

- 1 § 15. Section 1761 of the surrogate's court procedure act, as amended
- 2 by chapter 198 of the laws of 2016, is amended to read as follows:
- 3 \$ 1761. Application of other provisions
- 4 To the extent that the context thereof shall admit, the provisions of
- 5 article seventeen of this act shall apply to all proceedings under this
- 6 article [with the same force and effect as if an "infant", as therein
- 7 referred to, were a "person who is intellectually disabled" or "person
- 8 who is developmentally disabled" as herein defined, and a "guardian" as
- 9 therein referred to were a "guardian of the person who is intellectually
- 10 disabled" or a "guardian of a person who is developmentally disabled" as
- 11 herein provided for].
- 12 § 16. This act shall take effect on the first of January next succeed-
- 13 ing the date on which it shall have become a law.

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.

Appendix C

Memorandum

RE: OCA's Proposed Amendments to Surrogate's Court Procedure Act Article 17A

DATE: July 15, 2022

A comparison of current Article 17A and amendments offered by the Surrogate's Court Advisory Committee of the Office of Court Administration (OCA) is set out below.¹

Applicability

SCPA 17A -- individuals with intellectual disabilities,² developmental disabilities that occur prior to the age of 22, and traumatic brain injury occurring at any age. Sections 1750(1); 1750-a(1)(d)

OCA # 30 -- individuals with developmental disabilities as defined in MHL 1.03(22)³, and traumatic brain injury that occur prior to the age of 22. Coverage of traumatic brain injury occurring after age 22 is eliminated. Amended Section 1752, p. 21, lines 10-14

Alternatives to guardianship identified in statute

SCPA 17A – Silent

OCA # 30 – any guardianship petition must allege the inadequacy of alternatives. Amended Section 1752, p. 21, lines 10-14 (describing a non-exclusive list of alternatives)

Medical certificates

SCPA 17A – <u>required.</u> Sections 1750(1)-(2); 1750-a(2)

OCA # 30— eliminates the requirement of certificates; however, *there must be clear and convincing evidence that the respondent has a developmental disability*. Amended Section 1750-A, page 5, lines 5-7

Amended section 1750-A provides that the guardianship shall be imposed only if necessary and in the least restrictive manner, with an emphasis on the least restrictive form of guardianship, and the need for a guardian. Page 5, lines 7-11. Section 1750 is repealed.

Petition – allegations of functional abilities/limitations

SCPA 17A – none required. Section 1752

OCA #30 – required. Amended Section 1752 (8), p.21, lines 7-9

¹ Amendments that reflect changes in language are not discussed.

² 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 at least one of whom is familiar with or has professional knowledge in the care and treatment of persons with an intellectual disability, having qualifications to make such certification, as being incapable to manage him or herself and/or his or her affairs by reason of intellectual disability and that such condition is permanent in nature or likely to continue indefinitely. SCPA §1750(1).

³ "Developmental disability" means a disability of a person which:(a)(1) is attributable to intellectual disability, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, Prader-Willi syndrome or autism;(2) 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 intellectually disabled persons or requires treatment and services similar to those required for such person; or (3) is attributable to dyslexia resulting from a disability described in subparagraph one or two of this paragraph; (b) originates before such person attains age twenty-two; (c) has continued or can be expected to continue indefinitely; and (d) constitutes a substantial handicap to such person's ability to function normally in society." SCPA §1750-a(1).

Appointment of Guardian ad litem

SCPA 17A – discretionary appointment if court dispenses with hearing or respondent is not present. Section 1754(4)

OCA # 30 -- Appointment of a guardian ad litem is in the court's discretion, and the appointment may be in addition to the appointment of counsel. Amended Section 1754, page 24, lines 9-10

Appointment of counsel

SCPA 17A – SILENT; however, under SCPA Section 407, a "judge may assign counsel to represent any adult in a proceeding under this act if he determines that such assignment of counsel is mandated by the constitution of this state or of the United States, and includes such determination in the order assigning counsel."

OCA # 30 - Appointment of counsel is required; the court shall appoint Mental Hygiene Legal Service, unless it appoints other counsel. Amended Section 1753, page 23, lines 2-3; Section 1754, page 24, lines 8-9

Hearing

SCPA 17A -- The court may dispense with a hearing if guardian is sought 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. Section 1754(1)

OCA # 30 -- A hearing is required in all cases. Amended Section 1754(1), page 23, lines 9-14

Respondent's attendance at hearing

SCPA 17A -- if a hearing is conducted, the respondent shall be present unless it shall appear to the satisfaction of the court on the certification of the certifying physician that person is medically incapable of being present to the extent that attendance is likely to result in physical harm, or under such other circumstances which the court finds would not be in the respondent's best interest. Section 1754(3)

OCA # 30 – no change. Amended Section 1754(4), page 24, lines 23-28, p. 25, lines 1-3

Appointment of Guardian

SCPA 17A – "When it shall appear to the satisfaction of the court that a person is a person who is 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 guardians is in the best interest of the person who is intellectually disabled." Section 1750. "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. . . . For the purposes of this article, a person who is developmentally disabled is a person who has been certified 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 "Section 1750-a.

OCA # 30 – "If the court is satisfied, based on clear and convincing evidence that the respondent is incapable of managing his or her affairs, it shall make a decree appointing a guardian provided that guardianship shall be imposed only if necessary and is the least restrictive manner specifically considering the respondent's functional abilities." Amended Section 1754(5), page 25, lines 21-25

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. Amended Section 1754(6), page 25, lines 26-28

Guardian's Decision-making standard

SCPA 17A -- Silent

OCA # 30 -- The guardian shall encourage the individual to participate in decision-making and to act on their own behalf. The guardian's authority is to be exercised only as needed and their decisions are to be guided by the expressed desires and values of the person; if these are unknown and remain unknown after reasonable efforts to discern them, the decisions must be made in the best interests of the person. New Section 1754-a, page 26, lines 3-23

Duration

SCPA 17A – "Such guardianship shall not terminate at the age of majority or marriage of such person who is intellectually disabled or person who is developmentally disabled but shall continue during the life of such person, or until terminated by the court." Section 1759.

OCA # 30 – Guardianship shall remain in effect until modified or revoked by the court. New Section 1755(1), page 26, lines 27-28. Section 1759 is repealed.

Modification/Termination

SCPA 17A – "The court shall 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. Section 1755.

Upon an application to have the guardian discharged and a successor appointed, or to have the guardian of the property designated as a limited guardian of the property, or to have the guardianship order modified, dissolved or otherwise amended. Upon such a petition for review, the court shall conduct a hearing in accordance with section 1754. Section 1759. If the application is made in connection with the marriage of the individual, the court may conduct a hearing. *Id.*

OCA # 30 – Upon an application to modify or terminate the guardianship, the court shall conduct a hearing in accordance with section 1754, and modify or revoke the guardianship if it deems that the circumstances or needs of the individual have changed and the terms of the order are no longer appropriate or necessary. New Section 1755, page 27, lines 1-11.

Both current SCPA 17A, and OCA #30 are silent as to the burden of proof on a motion to reduce the guardian's authority or terminate the guardianship. See N.Y Men. Hyg. Law § 81.36 (d)(" (d) To the extent that relief sought under this section would terminate the guardianship or restore certain powers to the incapacitated person, 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 incapacitated person, the burden shall be on the person seeking such relief.")

OCA #30 does not address review/accountability of a guardian of the person.

Appendix D

STATE OF NEW YORK

7107--B

Cal. No. 540

2021-2022 Regular Sessions

IN SENATE

June 1, 2021

Introduced by Sens. MANNION, GAUGHRAN -- (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 -- recommitted to the Committee on Disabilities in accordance with Senate Rule 6, sec. 8 -- reported favorably from said committee, ordered to first and second report, ordered to a third reading, amended and ordered reprinted, retaining its place in the order of third reading -- passed by Senate and delivered to the Assembly, recalled, vote reconsidered, restored to third reading, amended and ordered reprinted, retaining its place in the order of third reading

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:

SUPPORTED DECISION-MAKING

1 Section 1. The mental hygiene law is amended by adding a new article 2 82 to read as follows:

ARTICLE 82

5 <u>Section 82.01 Legislative findings and purpose.</u>

6 82.02 Definitions.

82.03 Presumption of capacity.

8 82.04 Scope.

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9 82.05 Duties, responsibilities, and authority of supporters.

10 82.06 Formation and term of agreement.

82.07 Revocation and amendment of agreement.

12 82.08 Eligibility and resignation of supporters.

13 82.09 Facilitation of agreement.

14 82.10 Form of agreement.

15 <u>82.11 Legal effect of decisions made with support and third-par-</u> 16 <u>tv obligations.</u>

EXPLANATION--Matter in italics (underscored) is new; matter in brackets
[-] is old law to be omitted.

LBD09657-09-2

82.12 Limitations on liability.

82.13 Supporter notice.

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82.14 Reporting abuse, coercion, undue influence, or financial exploitation.

82.15 Rules and regulations.

§ 82.01 Legislative findings and purpose.

(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 <u>different kinds of supports.</u>

(b) The legislature further finds that the, now well recognized, practice of supported decision-making is a way in which many 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. 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 when appropriate for 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.
- 35 (d) The legislature also strongly urges relevant state agencies and 36 civil society to research and develop appropriate and effective means of 37 support for older persons with cognitive decline, persons with traumatic brain injuries, and persons with psychosocial disabilities, so that full 38 39 legislative recognition can also be accorded to the decisions made with supported decision-making agreements by persons with such conditions, 40 based on a consensus about what kinds of support are most effective and 41 how they can best be delivered.

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43 § 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:

- 47 (a) "abuse" encompasses physical abuse, sexual abuse, and emotional 48 abuse, as defined in section four hundred seventy-three of the social 49 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

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1 patient's medical record, or other legally-recognized statements of
2 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.
- 9 (g) "neglect" has the meaning defined in paragraph (d) of subdivision
 10 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. Supported decision-making agreements can either be an informal arrangement between the decision-maker and his or her supporter or supporters, or one that is in accordance with section 82.11 of this article, which has been reviewed and signed by a facilitator.
 - (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.
- 32 (1) "undue influence" means moral or mental coercion that leads some-33 one to carry out the wishes of another instead of their own because they 34 are unable to refuse or resist.
 - (m) "facilitator" means an individual or entity authorized by the office for people with developmental disabilities that works with and educates the decision-maker and his or her supporter or supporters about supported decision-making and supported decision-making agreements authorized under this article.
 - § 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.
- 47 (b) Capacity shall include capacity with decision-making support 48 and/or accommodations.
- 49 (c) A diagnosis of a developmental or other disability or condition 50 shall not constitute evidence of incapacity.
- 51 (d) The manner in which an adult communicates with others shall not constitute evidence of incapacity.
- (e) Neither the execution of a supported decision-making agreement by an individual, nor the interest in or wish to execute a supported decision-making agreement by an individual, nor the failure of an individual to execute a supported decision-making agreement may be used or consid-

ered as evidence that the individual lacks capacity, or to deny the decision-maker benefits to which they are otherwise entitled, including 2 adult protective services.

(f) A decision-maker may make and execute a supported decision-making agreement, if the decision-maker understands that they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily.

§ 82.04 Scope.

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- (a) If a decision-maker voluntarily enters into a supported decisionmaking 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 if the decision-maker is present and requests their participation, 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 not intended to limit the informal use of supported decision-making, or to preclude judicial consideration of such informal arrangements as less restrictive alternatives to quardianship.
- 45 (g) Execution of a supported decision-making agreement may not be a 46 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, including adult protective services, absent entering into a supported decision-making agreement under the provisions of this article.

- (j) A supported decision-making agreement made between a decision-maker and his or her supporter or supporters after consultation and education, which is signed by a facilitator shall have the legal force and effect authorized under section 82.11 of this article.
- 9 § 82.05 Duties, responsibilities, and authority of supporters.
 - (a) A supporter must:

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- 11 <u>1. respect the decision-maker's right to make a decision, even when</u>
 12 <u>the supporter disagrees with the decision or believes it is not in the</u>
 13 <u>decision-maker's best interests;</u>
 - 2. act honestly, diligently, and in good faith;
- 3. act within the scope set forth in the executed supported decisionmaking agreement;
 - 4. avoid conflicts of interest;
- 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; and
- 6. participate in facilitation and/or education programs developed under regulations promulgated by the office for people with developmental disabilities in order to enter a formal supported decision-making agreement.
 - (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;
 - 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 33.13 of this chapter; and
 - 6. communicating a decision-maker's decision to a third-party without the participation and presence of the decision-maker.
 - (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

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Accountability Act of 1996 (45 CFR §§ 164.502, 164.508), clinical records and information under subdivision (c) of section 33.13 of this chapter, or patient information under subdivisions two and three of section eighteen of the public health law.

- (f) A supporter shall ensure the information obtained under subdivision (e) of 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.
- 9 (a) An adult may enter into a supported decision-making agreement at 10 any time if the adult enters into the agreement voluntarily.
- 11 (b) A decision-maker may sign a supported decision-making agreement in 12 any manner, including electronic signatures permitted under article 13 three of the state technology law.
- 14 (c) A supported decision-making agreement formed under the provisions
 15 of this article shall remain in effect unless and until revoked by the
 16 decision-maker.
- 17 <u>§ 82.07 Revocation and amendment of agreement.</u>
- 18 (a) The decision-maker may revoke all or part of a supported deci19 sion-making agreement by notifying the supporters orally or in writing,
 20 or by any other act evincing a specific intent to revoke the agreement.
 21 The failure of the decision-maker to notify supporters shall not invali22 date the revocation of all or part of the supported decision-making
 23 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.
- 30 (a) A supporter shall be any adult chosen by the decision-maker; if 31 the supporter chosen by the decision-maker is an employee of a provider from whom the decision-maker receives services, the employee and the 32 33 provider shall follow the requirements set out in regulations promulgat-34 ed by the office for people with developmental disabilities, or other appropriate regulatory body which address those circumstances, with 35 attention paid to relative labor law and employment obligations and 36 37 possible conflicts of interest or the appearance of a conflict of inter-38 est.
- (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, or 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.
- 51 (d) If the supported decision-making agreement includes more than one
 52 supporter or is amended to replace the supporter who is ineligible under
 53 subdivision (b) of this section or resigns under subdivision (c) of this
 54 section, the supported decision-making agreement shall survive for the
 55 remaining supporters, unless it is otherwise revoked under section 82.07
 56 of this article.

- 1 (e) If the supported decision-making agreement does not include more
 2 than one supporter, and is not amended to replace the supporter who
 3 becomes ineligible under subdivision (b) of this section or resigns
 4 under subdivision (c) of this section, the supported decision-making
 5 agreement shall be considered terminated.
- § 82.09 Facilitation of agreement. 7 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 8 9 decision is made by a decision-maker pursuant to a supported decision-10 making agreement created in accordance with this article where such decision-maker and his or her supporter or supporters have worked with a 11 12 facilitator, such supporter or supporters have followed a recognized supported decision-making facilitation or education process as defined 13 and prescribed by regulations promulgated by the office for people with 14 15 developmental disabilities and such facilitator has signed such agree-16 ment.
- 17 <u>§ 82.10 Form of agreement.</u>
- 18 <u>(a) A supported decision-making agreement may be in any form consist-</u>
 19 <u>ent with the requirements set forth in this article.</u>
 - (b) A supported decision-making agreement must:
- 21 <u>1. be in writing;</u>
- 22 **2.** be dated;

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- 23 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;
- 26 <u>5. list the kinds of support that each supporter may give for each</u> 27 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
- 45 <u>4. detail any other limitations on the scope of a supporter's role</u> 46 <u>that the decision-maker deems important.</u>
- 47 (d) In order to be subject to the provisions of section 82.11 and
 48 subdivisions (b) through (d) of section 82.12 of this article, a
 49 supported decision-making agreement must also:
 - 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
- 54 <u>3. include an attached attestation by the decision-maker that a</u>
 55 <u>particular decision has been made in accordance with the support</u>
 56 <u>described in the supported decision-making agreement.</u>

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§ 82.11 Legal effect of decisions made with support and third party obligations.

- (a) This section shall apply only to decisions made pursuant to supported decision-making agreements created 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. Additionally, such decisions shall be signed by a facilitator.
- (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 decisionmaking 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 pursuant to supported decision-making agreements created in accordance with this article which are signed by a facilitator 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 a decision-maker pursuant to a duly executed supported decision-making agreement created 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 created 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 created in 55 56 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 the decision-maker had revoked such authorization.

- (e) This section may not be construed to provide immunity from actions alleging that a health care provider, or other third party, has done any of the following:
- 10 <u>1. caused personal injury as a result of a negligent, reckless, or</u> 11 <u>intentional act;</u>
 - 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.
- 16 (f) The existence or availability of a supported decision-making 17 agreement does not relieve a health care provider, or other third party, of any legal obligation to provide services to individuals with disabil-18 ities, including the obligation to provide reasonable accommodations or 19 20 auxiliary aids and services, including, but not limited to, interpreta-21 tion services and communication supports to individuals with disabili-22 ties under the federal Americans with Disabilities Act (42 U.S.C. § 23 12101).
- 24 § 82.13 Supporter notice.

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- (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.
- 41 <u>§ 82.14 Reporting abuse, coercion, undue influence, or financial exploi-</u> 42 <u>tation.</u>
 - (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.
- 52 § 82.15 Rules and regulations.
- 53 (a) The commissioner of the office for people with developmental disa-54 bilities shall promulgate within one year of the passage of this act the 55 rules and regulations necessary to implement this article for adults who 56 receive or are eligible to receive services that are operated, certi-

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1 <u>fied, funded or approved by the office for people with developmental</u> 2 <u>disabilities.</u>

- (b) Additional 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 effectuating the provisions of section 44 of the legislative law and section 70-b of the public officers law.