



# OVERPROTECTED

## Can Supported Decision-Making Disrupt the Pipeline from Special Education into Guardianship?

By Beth L. Barnhard

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**T**he most restrictive response to decision-making challenges faced by people with disabilities is the appointment of a guardian as surrogate decision-maker.<sup>1</sup> In New Jersey, a guardianship is a court proceeding in which a judge declares someone to be an “incapacitated individual”<sup>2</sup> and appoints a third party to make decisions on behalf of them.

The appointed surrogate decision-maker is called the guardian. Although a guardian can be appointed for any individual deemed to be incapacitated, those most likely to find themselves the subjects of guardianships are people with intellectual disabilities (ID), individuals with developmental disabilities (DD), older adults with cognitive impairments, and those suffering from certain mental illnesses.

For the ID/DD population, there is a direct pipeline from their special education programs into plenary guardianships:<sup>3</sup> as part of an ID/DD student's Individualized Education Program (IEP) the school is required to give advance notice to the student and the family of the "transfer of rights" that will occur upon the student turning 18 years old, the age of majority, if guardianship is not obtained.<sup>4</sup> Accordingly, the school advises the family that it must communicate directly with the student for certain permissions, and certain aspects of the student's education moving forward. Whether intentional or unintentional, the disclosure and discussion of the transfer of rights creates a bias toward guardianship unless the school is aware of less restrictive alternatives and can apply the strengths of the individual student to those less restrictive alternatives.<sup>5</sup>

The pipeline to guardianship is disquieting considering what is at stake. The consequence of taking away constitutionally protected individual rights is viewed as "so severe" that courts must not permit its occurrence absent clear and convincing evidence of incapacity and a showing that no less restrictive alternative is available.<sup>6</sup> The guardianship system is supposed to be the avenue of last resort.<sup>7</sup> New Jersey has long acknowledged that a guardianship is a "drastic restraint on a person's liberty,"<sup>8</sup> and has encouraged limited guardianships<sup>9</sup> and other arrangements that promote personal autonomy for individuals with ID/DD.<sup>10</sup> Stripping a person with disabilities of their rights and substituting a third party as decision-maker is not intended to be perfunctory, yet the way the special education system is structured, guardianship has become almost a rite of passage of turning 18.

Guardianship has been described as the "civil death" of the person because even when functioning correctly, the guardianship, by its nature, requires the person to participate in society through a

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third-party intermediary, if at all.<sup>11</sup> On Sept. 25, 1987, a House Select Committee held hearings titled "Abuses in Guardianship of the Elderly and Infirm: A National Disgrace." In summarizing the Select Committee's findings, Chairman Claude Pepper famously stated:

The typical ward has fewer rights than the typical convicted felon.... 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 levied against an American citizen with the exception...of the death penalty.<sup>12</sup>

Unfortunately, the current system can make guardianship seem like a formality when the simple fact is that not every 18-year-old identified as ID/DD needs a guardian. The casualness of entering the guardianship for ease of education process belies the difficulty of extricating the individual from its confines. Once put in place, there is no easy "off ramp" for guardianship. Although the process for restoration of capacity is codified in New Jersey's statutes and court rules,<sup>13</sup>

the burden of proof required for restoration of capacity is not and, as a result, it is left to the individual counties to decide how a restoration action will proceed.<sup>14</sup> Further, going to court, for any reason, is an expensive and time-consuming proposition.

Long before *Last Week Tonight with John Oliver* (HBO, 2018) and *I Care a Lot* (Netflix, 2020) made the dangers of financial abuse and exploitation associated with guardianship of older adults part of the national consciousness, critics were ringing the alarm and states were making efforts to enact monitoring programs. However, guardianship did not truly become a household word until 2021 when #FreeBritney dominated national news coverage as details of the alleged abuse pop star Britney Spears suffered under her 13-year conservatorship shocked the world. Now, with an educated and angry public demanding justice, conversations are happening from Capitol Hill to kitchens across the U.S. and the spotlight is now on younger individuals<sup>15</sup> trapped in unnecessary guardianships, and on the availability of less restrictive alternatives. Stakeholders have seized the opportunity and are seeking to: 1) break the pipeline from special

education to guardianship, and 2) promote less restrictive alternatives to guardianships including an increased focus on estate planning (e.g., power of attorney, health care directive, trusts), representative payee arrangements, and Supported Decision-Making. Dominating the less restrictive alternative conversation is Supported Decision-Making.

### What is Supported Decision-Making?

Supported Decision-Making (SDM) is a person-centered and person-directed<sup>16</sup> alternative to guardianship that allows an individual with a disability to retain their civil rights and autonomy while still receiving necessary assistance. The Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (2017)<sup>17</sup> defines SDM as:

Assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions, which enables the individual to make the decisions, and in communicating a decision once made if consistent with the individual's wishes.

SDM is premised on the fact that *everyone* needs support or assistance with some of the choices they make; using friends, family members, and professionals as sounding boards as they analyze situations and determine how to react to the choices they face within those situations. Thus, SDM mirrors the real life of most adults. When confronted with choices and decisions, big or small, input and advice are sought from knowledgeable, trusted advisers so that well-informed choices can be made.<sup>18</sup> There is no single model of SDM.<sup>19</sup> Therefore, SDM relationships can be “of more or less formality and intensity”<sup>20</sup> ranging from informal arrangements between an individual and one trusted friend or family member to formalized “circles of support”<sup>21</sup> and “microboards.”<sup>22</sup> Regardless of

the structure, the SDM relationship allows the individual to receive the information needed to weigh options, make decisions based on their own preferences, and if necessary, communicate their decisions to third parties.<sup>23</sup>

To date, 11 states<sup>24</sup> and the District of Columbia have adopted statutes authorizing written SDM agreements and determining the circumstances under which supporters can access someone's confidential information. SDM has been endorsed by the American Bar Association,<sup>25</sup> the National Guardianship Association,<sup>26</sup> and the National Council on Disability.<sup>27</sup> There is evidence for judicial support for SDM dating back to 1999 when the Supreme Court of Pennsylvania interpreted Pennsylvania's guardianship statute<sup>28</sup> to mean that a person is not in need of guardianship services where the individual has a strong circle of support assisting with making decisions and meeting essential needs.<sup>29</sup> In a similar matter, New York terminated an existing guardianship finding that through a strong network of support in the community a young woman learned to make decisions and become a loving wife and mother.<sup>30</sup> New York continues to eschew guardianships in situations where people with disabilities can engage in SDM.<sup>31</sup> All of these decisions recognize more informal SDM arrangements.

Proponents of SDM note that its focus on self-determination and autonomy have psychological benefits for the individual, whereas guardianship is perceived as “anti-therapeutic.”<sup>32</sup> The guardianship process itself is viewed as damaging to self-worth as it subjects the person to the knowledge that family, friends, medical providers, and other witnesses, do not believe they are capable of taking care of themselves in many areas of life.<sup>33</sup> The lack of self-determination in guardianship has been described as “constructive isolation.”<sup>34</sup> For example, when a person is no longer allowed to make financial decisions, they

“become gradually disengaged from the management of those finances as well as the interactions with others involved in that management.”<sup>35</sup> The person who isn't going to the bank, isn't taking out money and spending it at shops and restaurants, and isn't interacting with sales people, waiters, other customers, friends, or family along the way.<sup>36</sup> Additionally, in a guardianship, the individual is told that they are not capable of doing certain things and because they are not capable, those things are taken away from them. That can be stigmatizing to the individual and affect self-worth. Conversely, SDM promotes social interaction and independence, which can help combat isolation and increase self-worth. Although scholars acknowledge that more studies need to be done on the outcomes of SDM for both the individual and the supporters,<sup>37</sup> existing studies have shown that people who exercised more self-determination were more likely to want to live independently, manage their own money, and be employed.<sup>38</sup>

Certainly, the same pitfalls that can occur in guardianship, such as abuse and exploitation, can occur in SDM relationships. Perhaps, of greater concern, would be that supporters would overstep their boundaries and unduly influence the individual during the decision-making process.

### What is New Jersey Doing to Break the Pipeline?

Disability Rights New Jersey is New Jersey's designated Protection and Advocacy system under federal law.<sup>39</sup> Disability Rights NJ has focused significant resources on breaking the special education to guardianship pipeline; Disability Rights NJ sees disruption of this pipeline as the most effective way to advocate for self-determination for individuals with disabilities, according to Legal Director, Michael R. Brower.<sup>40</sup> Brower noted that Disability Rights NJ has partnered with

the New Jersey Council on Developmental Disabilities,<sup>41</sup> the Boggs Center for Developmental Disabilities,<sup>42</sup> and the New Jersey State Parent Advocacy Network,<sup>43</sup> and is also working with a small cohort of youth ambassadors with disabilities to accelerate and amplify the conversation that not everyone with a disability needs a guardian for their 18<sup>th</sup> birthday. Brower advised that the goals of his team will largely be driven by the youth ambassadors and are still in the development stage, but Brower hopes to see intervention strategies including: 1) educating stakeholders about alternatives to guardianship; 2) identifying legal, political, and practical barriers to implementing SDM in New Jersey; and 3) partnering with interested surrogates, judges, and practitioners to reduce unnecessary guardianships. Brower also spoke passionately of the importance of removing abusive guardians and freeing individuals from unnecessary guardianships on an individual basis but noted that many individuals with disabilities lack funds to hire private attorneys. Brower also noted that organizations like Disability Rights NJ only have the staff and resources to help a few individual clients in restoration matters every year.

New Jersey does not presently have a SDM statute on the books. However, the lack of infrastructure does not mean that there is a lack of recognition in New Jersey courts that SDM is an appropriate, less restrictive alternative to guardianship. To the contrary, the new model Report of Court Appointed Counsel for the Alleged Incapacitated Person expressly requires counsel to report if they have considered SDM as a less restrictive alternative to guardianship.<sup>44</sup> The concern with moving forward with SDM without statutory support would be the enforceability of any SDM agreement, the willingness of third parties to accept SDM agreements, termination of agreements, and the ability of supporters to obtain and review confidential information. All

of these issues are addressed, in varying ways, in the statutes that have been enacted in other states.<sup>45</sup> This lack of infrastructure does not preclude the success of informal SDM agreements, nor does it preclude other less restrictive alternatives such as trusts, powers of attorney, health care directives, HIPAA authorizations, representative payee arrangements, and conservatorships, which the model Report of Court Appointed Counsel for the Alleged Incapacitated Person also requires court appointed counsel to consider.

While it is true that there will always be people with disabilities who, regardless of the supports in place for them, require a guardian, there can be no question that the pipeline is causing unnecessary guardianships to occur. It is incumbent upon attorneys practicing in this space to have a foundational knowledge in SDM. SDM and other less restrictive alternatives need to become a bigger part of the conversation; counseling clients about decision-making options is the only way they can make informed decisions about their case. The developing national conversation has come to New Jersey. It is time to prepare for the future. ■

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## Endnotes

1. Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN. ST. L. REV. 1111, 1115 (2013).
2. N.J.S.A. 3B:1-2 defines “Incapacitated individual” as an individual who is impaired by reason of mental illness or intellectual disability to the extent that the individual lacks sufficient capacity to govern himself and manage his affairs. The term can also designate an individual who is impaired by reason of physical illness or disability, chronic use of

drugs, chronic alcoholism, or other cause (except minority) to the extent that the individual lacks sufficient capacity to govern himself and manage the individual’s affairs.

3. Plenary guardianship is a guardianship of the person and the estate, in which the court makes a finding that the individual is incapacitated as defined in N.J.S.A. 3B:1-2, and thus is without capacity to make legal, medical, financial, educational, residential, and vocational decisions. The court will then appoint a general guardian to make decisions for the incapacitated in all areas. N.J.S.A. 3B:12-24.1a.
4. N.J.A.C. 6A:14-3.7(e)14.
5. National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (2019) at 31: available at [ncd.gov/sites/default/files/NCD\\_Turning-Rights-into-Reality\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf).
6. *In re Keeter*, Docket No.: A-0553-10T4, 2011 N.J. Super. Unpub. LEXIS 1200 (App. Div. 2011) at \*3, citing *In re M.R.*, 135 N.J. 155; *In re Conroy*, 98 N.J. 321 (1985).
7. Kohn, *et al.* at 1117.
8. *In re M.R.*, 135 N.J. 155, 171 citing *Lommason v. Washington Trust Co.*, 140 N.J.Eq. 207, 209 (E&A 974).
9. If the court finds that an individual is incapacitated pursuant to N.J.S.A. 3B:1-2, but only lacks capacity to do some, but all tasks to care for themselves, the court may appoint a limited guardian of the person, a limited guardian estate, or a limited guardian of the person and estate. In so doing, the court must make specific findings of fact as to which of the decision making areas (legal, medical, financial, educational, residential, vocational) the individual retains decision making capacity in. The Judgment of

- Incapacity will specify accordingly. N.J.S.A. 3B:12-24.1b.
10. M.R., 135 N.J. at 170-171.
  11. Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianships to Supported Decision-Making*, 19 Hum. Rts. Brief 8, 9 (2012).
  12. H.R. Rep. No. 100-641, at 1 (1987).
  13. See, N.J.S.A. 3B:12-28; R. 4:86-7(b)
  14. The burden of proof issue is under review and is expected to be addressed.
  15. David Goldfarb, *#FreeBritney Made Guardianship a National Issue, But Will Congress Act?* NAELA News, Oct/Nov/Dec 2021, 30.
  16. "...meaning the values, priorities, and wishes of the individual drive the decision-making process. " Supporting Decision Making Across the Age Spectrum, A Report by The American Bar Association Commission on Law and Aging, March 2020.
  17. §§301(a)(1)(A), 310(a)(1), not adopted in New Jersey.
  18. Quality Trust for individuals with Disabilities, *Supported Decision-Making: An Agenda for Action (2014)*, <http://jennyhatchjusticeproject.org/node/264>
  19. Leslie Salzman, *Guardianship for Persons with Mental Illness – A Legal & Appropriate Alternative?* 4 ST. LOUIS U. J HEALTH L. & POL'Y 279, 306 (2011).
  20. Dinerstein, *supra*, note viii, at page 4.
  21. Circles of Support are groups comprised of family and friends, who meet regularly with the individual with a disability to "help that person formulate and realize his or her hopes and desires." Kohn, *et. al. supra*. note i at 1123.
  22. Microboards are similar to circles of support but are typically comprised of organizations that formed to support, and possibly provide services to the individual. Kohn, *et. al. supra*. note i at 1123.
  23. Salzman, *supra*, note xiv at 306.
  24. Alaska, Colorado, Delaware, Indiana, Louisiana, Nevada, North Dakota, Rhode Island, Texas, Washington, and Wisconsin.
  25. American Bar Association ("ABA") House of Delegates Resolution (2017) available at [americanbar.org/content/dam/aba/administrative/law\\_aging/2017\\_SD\\_M\\_%20Resolution\\_Final.pdf](http://americanbar.org/content/dam/aba/administrative/law_aging/2017_SD_M_%20Resolution_Final.pdf); see also *Guardianship and Supported Decision-Making ABA*, available at [americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/](http://americanbar.org/groups/law_aging/resources/guardianship_law_practice/)
  26. National Guardianship Association, *Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making* (2017), available at: [guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf](http://guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf)
  27. National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (2019), *supra*, at 79-83.
  28. 20 Pa.C.S. § 5512.1.
  29. *In re Peery*, 727 A. 2d 539 (Pa. 1999).
  30. *In re Dameris L.*, 956 N.Y.S.2d 848 (N.Y.Sur. Ct. 2012).
  31. See, e.g., *Matter of D.D.*, 50 N.Y.Misc. 3d 666 (N.Y. Surr. Ct. Kings County, Oct. 28, 2015); *Matter of Hytham M.G.*, 52 N.Y.Misc. 3d 1211(A) (N.Y. Surr. Ct. Kings County, July 27, 2016); *Matter of Eli T.* 89 N.Y.S.3d 844, 849 (N.Y. Surr. Ct. Kings County, 2018).
  32. Jennifer Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J.L. & Psychiatry 350 (2010).
  33. *Id.* at 354.
  34. 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 (2010).
  35. *Id.*
  36. *Id.*
  37. Kohn, *supra*.
  38. Michael Wehmeyer & Susan Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination*, 38 Educ. & Training Developmental Disabilities 131 (2003); Michael Wehmeyer & Michelle Schwartz, *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth*
  39. Disabilityrightsny.org.
  40. Michael R. Brower, Esq., Legal Director, Disability Rights NJ interview with Beth L. Barnhard, Esq., CELA, August 19, 2022, follow up correspondence, August 23, 2022 to August 26, 2022. Beth L. Barnhard, Esq., CELA, is a member of the Board of Trustees of Disability Rights NJ.
  41. [njcdd.org/about-the-njcdd/](http://njcdd.org/about-the-njcdd/).
  42. [boggscenter.rwjms.rutgers.edu/](http://boggscenter.rwjms.rutgers.edu/).
  43. [spanadvocacy.org/about/](http://spanadvocacy.org/about/).
  44. See, Report of Court Appointed Counsel for the Alleged Incapacitated Person, Paragraph 25, Recommendations Concerning Suitability of Less Restrictive Alternatives/Areas of Decision-making That the Alleged Incapacitated Person May be Capable of Exercising, available at [njcourts.gov](http://njcourts.gov).
  45. See, American Bar Association on Law and Aging, Access to Information Under Supported Decision-Making Statutes (Laws Current as of July 2022), available at: [americanbar.org/aging](http://americanbar.org/aging).