

March 2017

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Recommended Citation

Nicole M. Arsenault, *Start with a Presumption She Doesn't Want to Be Dead: Fatal Flaws in Guardianships of Individuals with Intellectual Disability*, 35(1) LAW & INEQ. 23 (2017).

Available at: <https://scholarship.law.umn.edu/lawineq/vol35/iss1/2>

Start with a Presumption She Doesn't Want to Be Dead: Fatal Flaws in Guardianships of Individuals with Intellectual Disability

Nicole M. Arsenault[†]

Introduction

Guardianships¹ are usually seen in cases involving two groups of people: children and the elderly. Individuals who come before the courts needing a guardian due to an intellectual disability² represent only a small subset of cases. Although the support needs of these adults are extremely diverse and are dictated by individual characteristics and circumstances not usually seen in the general population, in most jurisdictions, the

[†]. J.D., University of Memphis, Cecil C. Humphreys School of Law, 2011; B.A., University at Albany, State University of New York, 1995. This article is dedicated to Debbie, whose brave battle brought the later surrenders of so many others into sharp relief. The author also gratefully acknowledges the help of Aaron R. Parker, Esq., for helping her learn to write, Ralph C. Brashier, LL.M., for helping her learn to reason, and Marko Horn, Ph.D. for listening and critiquing those many hours while it all came together. This is the foundation that made this article possible, and the author is endlessly thankful.

1. The term “guardianship” refers to a legally-sanctioned arrangement where certain decisional rights are transferred from an individual found to be incapacitated (i.e., a ward) to another person or entity for the care and protection of the ward’s person. When rights regarding the ward’s estate are transferred, this is most often called a conservatorship. The terms are sometimes used interchangeably. *See, e.g.*, TENN. CODE ANN. § 34-1-101 (2015) (defining a “guardian” as a person appointed to provide “partial or full supervision, protection[,] and assistance” to a person or minor, and a “conservator” as a person appointed to make decisions on behalf of the ward and provide “partial or full supervision, protection[,] and assistance.”). This Article uses the term “guardianship.”

2. Intellectual disability is defined as a “disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social[,] and practical domains.” AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 33 (5th ed. 2013). With the passage of Rosa’s Law in 2010, the United States has advocated a more deferential reference to individuals affected in the manner described above as having an intellectual disability rather than mental retardation. Rosa’s Law, Pub. L. No. 111-256, 124 Stat. 2643 (2010). Research for this Article necessarily involved reference to materials published prior to 2010. Where practical, the author has substituted the term “intellectual disability” for “mental retardation” in deference to this forward progress in our collective respect for the rights and position in society of those persons impacted by this and similar diagnoses.

same laws and regulations govern the entire field. Without specific guidance and oversight of guardians who care for adults with intellectual disability, a variety of problems arise.

The competence of people with intellectual disability to make their own decisions is a tricky area. Depending upon the advocacy being brought to bear, supporters and occasionally the individuals themselves argue for more or less recognition of the choices they make. In June 2015, I was at a conference and the first two sessions I attended illustrated this point: the first argued for less decisional capacity for offenders with intellectual disability in capital cases and the second argued for greater self-determination and respect of individual decisions. Although the principles of person-centeredness that pervade the supporting culture direct us toward a greater respect of individual choice, there is no clear line between the arguments for more or less recognition of capacity. But how does this work in cases where a health care decision with potentially life-altering consequences is being made?

Beginning in 1996, I had the chance to work with a woman named Debbie.³ I met her while she was in remission from prolymphocytic leukemia, a rare and aggressive form of the disease. I worked with her when the cancer returned for a second and final time. Debbie was a funny lady. She had a strong sense of the ridiculous and liked to laugh at everyone around her. Her life was shaped, in part, by an intellectual disability. Although no court ever determined that Debbie lacked the capacity to make decisions for herself, in reality, she needed a lot of support. Debbie had a family and a network of social services to guide her through decisions she did not fully understand. Thus, while her rights were never formally transferred to someone else, Debbie had decision-making support similar to that of the many persons with intellectual disability who are under a guardianship.

Debbie understood general concepts, but was often less clear on their application to her. When Debbie first received the diagnosis, her sister Susan and other supporters tried to help her understand what she was facing. Although she had years of treatment, check-ups, bone biopsies, and countless hours spent in a doctor's office, it was not until the last weeks of her life that Debbie finally appeared to understand that she was dying. Before that point, her radiation and chemotherapy treatments were something to be endured and laughed about. There were also

3. Debbie's story is used in this Article with the express written permission of her family.

some misunderstandings along the way. Debbie had a cat of uncertain temperament, but unquestioned loyalty. When Debbie's family worked on planning her final services, her sister suggested having a cat etched on her grave marker. Debbie became very upset, thinking that the plan was to bury "Kitty." It may have been the lack of understanding of death and freedom from fear that kept Debbie alive for so long. She was something of a medical miracle, living over three years with a diagnosis that, in those days, was terminal within six months.

Debbie was the first person I met with an intellectual disability who battled cancer. I have met dozens more since then, but she is one of very few who has received the same aggressive level of treatment a non-disabled person would likely pursue. Intuitively, one might think that a person receiving decisional support would be more likely to be diagnosed early and supported to seek whatever treatment is likely to save or prolong his or her life. There is a line of research that indicates this is not true, at least as it pertains to adults with intellectual disability. As a group, these individuals are less likely than members of the general population to receive routine screenings, such as pap smears, mammograms, and colonoscopies, and are more likely to die of cancer.⁴

This Article explores the areas where guardianship laws fail individuals whose capacity is impaired by intellectual disability. Part I reviews the history of the concept of guardianship, its origins in the common law of England, adoption in the United States, and evolution to the laws on the books today. Part II summarizes the process by which guardians are appointed. Part III examines the practice of guardianship, decisional standards, and major case law relevant to the issue. Part IV looks at how persons with intellectual disability fit into guardianship law. Part V turns to the unique challenges faced by people who step into the shoes of individuals with intellectual disability to make decisions on their behalf and how this can lead to tragic results, even when underpinned by the best of intentions. Part VI offers suggestions for improving the legal and practical aspects of guardianship for these individuals.

4. See Nechama W. Greenwood et al., *More Than Just a Mammogram: Breast Cancer Screening Perspectives of Relatives of Women with Intellectual Disability*, 52 INTELL. AND DEV. DISABILITIES 444, 452 (2014); Susan M. Haverkamp et al., *Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina*, 119 PUB. HEALTH REP. 418, 421 (2004).

I. A Brief History of Guardianship

Like many legal doctrines, the concept of guardianship reached American jurisprudence via English common law. Guardianship springs from the doctrine of *parens patriae*, which refers to the right of the state to serve as protector for those who cannot care for themselves.⁵ This practice began when the English monarch assumed authority over the estates of orphaned infants and persons incompetent by reasons of “idiocy” or “lunacy.”⁶ One early court explained the rationale behind the protective role being taken up by the monarch rather than a family member: “It is not a profitable jurisdiction of the crown, but for the benefit of infants themselves, who must have some common parent.”⁷

In spite of the stated humanitarian motive, *parens patriae* facilitated some very profitable arrangements for the king from its earliest days. The crown enjoyed substantial largesse from those estates whose management it usurped under the role of “Father of the Country,” and abuses led to an eventual overhaul of the system in the seventeenth century.⁸ It took two further centuries of development for the doctrine to take on the beneficent patina it has today.⁹ The later-reported cases invoking *parens patriae* power involve guardianship of minors, in which responsibility reverted automatically to the crown when the natural guardian (i.e., the father) was unavailable or unfit.¹⁰

In 1890, the doctrine of *parens patriae* made it across the ocean when the Supreme Court of the United States expressly endorsed it in *Late Corp. of Church of Jesus Christ of Latter-Day Saints v. United States*.¹¹ The Court held that property seized from the former Church of Latter-Day Saints, which had been designated as a charity, would be redistributed for similar use by the state, rather than returned to the donors.¹² The basis of this part of the decision rested upon *parens patriae*.¹³ The Court distinguished the operation of *parens patriae* power in the United

5. *Parens Patriae*, BLACK’S LAW DICTIONARY 520 (3rd pocket ed. 2006).

6. See Lawrence B. Custer, *The Origins of the Doctrine of Parens Patriae*, 27 EMORY L. J. 195, 195–96 (1978).

7. *Id.* at 205.

8. *Id.* at 199–201.

9. *Id.* at 201–05.

10. *Id.* at 205–06.

11. 136 U.S. 1, 56 (1890).

12. *Id.* at 58–59.

13. *Id.*

States from how it worked in England: in the United States, the legislature, rather than the monarch, takes on the protective role.¹⁴

To get an idea of how pervasive *parens patriae* power has become in our society (and how much we take it for granted), one need only to contemplate the areas where it is commonly applied. As the doctrine took a foothold in the United States, *parens patriae* empowered states to oversee child welfare, even going as far as restricting parental control over children¹⁵ where there was a compelling interest for doing so.¹⁶ The power of *parens patriae* extends to individuals afflicted with serious mental illness. With a demonstration of necessity and appropriate due process protections, states may administer antipsychotic medications to involuntarily committed patients suffering from mental illness, even when the patients refuse this treatment.¹⁷ The power is also used to support removal of decisional rights from the elderly in the management of their estates and persons.¹⁸ And it is used to support surrogate health care decisions for persons with intellectual disability, including end-of-life decisions.¹⁹

14. *Id.* at 58.

15. *See, e.g., Ginsburg v. New York*, 390 U.S. 629, 640 (1968) (upholding a New York law prohibiting the sale of pornographic materials to minors, the Court referenced society's interest in protecting the welfare of children as "transcendent") (quoting *People v. Kahan*, 206 N.E.2d 333 (N.Y. 1965)); *Prince v. Massachusetts*, 321 U.S. 158, 165 (1944) (stating that "[i]t is the interest of youth itself, and of the whole community, that children be both safeguarded from abuses and given opportunities for growth into free and independent well-developed men and citizens[.]" as a reason for upholding a Massachusetts law proscribing work for children under the age of twelve).

16. *See, e.g., Stanley v. Illinois*, 405 U.S. 645, 657–58 (1972) (holding that the state's interest was "*de minimis*" and therefore an insufficient basis for removing three children from the custody of their unwed father where no evidence showed father to be unfit).

17. *See, e.g., Project Release v. Prevost*, 722 F.2d 960, 981 (2d Cir. 1983) (upholding a New York law allowing for involuntary commitment and medication of patients with mental illness where a hearing was provided and mental health professionals conducted regular reviews).

18. *See* Peter M. Horstman, *Protective Services for the Elderly: The Limits of Parens Patriae*, 40 MO. L. REV. 215, 231–32 (1975).

19. *See Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977). In considering whether to allow removal of treatment from a terminally ill resident of the state school who had an intellectual disability, the Court opined:

We do not view the judicial resolution of this most difficult and awesome question—whether potentially life-prolonging treatment should be withheld from a person incapable of making his own decision—as constituting a "gratuitous encroachment" on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that

At points in its history, a very broad view of *parens patriae* power has been sanctioned by legal scholars and the courts.²⁰ In other instances, judges and justices have reached into previously-unfettered state practice and added a healthy dose of restraint. An example of the Supreme Court applying its restraint in *parens patriae* can be found in *In re Gault*, a near-total rejection of Arizona's method of ordering commitment of alleged juvenile delinquents to state facilities.²¹ In *Gault*, the Court reviewed the practice of trying juvenile offenders without affording them the benefit of counsel and other due process protections commonly afforded to adults.²² Justice Fortas, writing for the majority, likened the gravity of the consequences faced by the fifteen-year-old in *Gault* to a felony proceeding, referring to the threat of juvenile detention as "the awesome prospect of incarceration in a state institution until the juvenile reaches the age of 21."²³ The Court ultimately held that a juvenile commitment proceeding, which can result in loss of liberty for a minor, should include all or nearly all of those due process protections afforded to the accused in criminal proceedings.²⁴ Calling upon the language of an earlier opinion, the Court went on to explicitly reject the state's position that proceedings were conducted without due process formality to better serve the best interests of the minors: "[T]here is no place in our system of law for reaching a result of such tremendous consequences without ceremony—without hearing, without effective assistance of counsel, without a statement of reasons."²⁵

The lessons of *Gault* and similar decisions coming in its wake are not that *parens patriae* powers are less broad or invasive than in times past, although one could make the argument that the

forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.

Id. at 435.

20. See, e.g., *In re Quinlan*, 355 A.2d 647, 666 (N.J. 1976) ("The court's action . . . is not limited by any narrow bounds, but it is empowered to stretch forth its arm in whatever direction its aid and protection may be needed.").

21. *In re Gault*, 387 U.S. 1 (1967).

22. *Id.* at 5–7.

23. *Id.* at 36–37.

24. *Id.* at 30 (quoting *Kent v. United States*, 383 U.S. 541, 555 (1966)) ("We do not mean . . . to indicate that the hearing to be held must conform with all of the requirements of a criminal trial or even of the usual administrative hearing; but we do hold that the hearing must measure up to the essentials of due process and fair treatment.").

25. *Id.* (quoting *Kent v. United States*, 383 U.S. 541, 554 (1966)).

impact of the decisions leads to such a result. The real lesson in due process is that it is acceptable for states to interfere and subvert the rights of private citizens to protect the welfare of vulnerable individuals; just be sure the interference is necessary to protect a legitimate state interest and that all procedures are followed to the letter.

The practice of appointing guardians to make decisions on behalf of persons incapable of making some or all of their own decisions is one of the outgrowths of *parens patriae*.²⁶ Although many guardians, particularly family members, may be unaware of the nature of their appointment, guardians are “delegatee[s] of the state’s *parens patriae* power.”²⁷ Thus, in a purely legal sense, a mother and father appointed as guardians for medical decisions over their adult daughter with an intellectual disability, in consenting to or withholding consent for a medical procedure, speak not as parents, but as the state. Whether the parents in this hypothetical understand the distinction between the decision they made for their seventeen-year-old daughter and the one a court order authorized them to make for that same daughter, now twenty-one, is less than clear. While courts are charged with oversight of the guardianship arrangements they sanction, resources to police this responsibility are scarce or non-existent, and the reality is that most guardianships go unmonitored after the initial court hearing concludes.²⁸

Problems with guardianships came into sharp public focus in 1987, when the Associated Press published an article chronicling a study of guardianships in all fifty states and the District of Columbia.²⁹ The authors found that the guardianship system was “dangerously burdened and troubled[,]” stripping vulnerable older adults “to the rights of a 5-year-old” by creating guardianships that “sometimes result[] in financial or physical mistreatment”³⁰ Although the article focused on guardianships of the elderly, the findings had system-wide implications, and the response was immediate. New guardianship

26. Sally Hurme & Erica Wood, *Third National Guardianship Summit Introduction*, 2012 UTAH L. REV. 1157, 1158 (2012).

27. *Cruzan v. Harmon*, 760 S.W.2d 408, 425 (Mo. 1988).

28. See Hurme & Wood, *supra* note 26, at 1160–62.

29. Fred Bayles & Scott McCartney, *Guardians of the Elderly: An Ailing System Part I: Declared ‘Legally Dead’ by a Troubled System*, ASSOCIATED PRESS (Sept. 19, 1987), <http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally-Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f>.

30. *Id.*

legislation was introduced at the federal and state levels with a goal of reforming the system to prevent those abuses the article brought to light.³¹

In 1988, the American Bar Association's Commission on the Mentally Disabled and Commission on Legal Problems of the Elderly, working with national guardianship advocacy associations, brought together a group of experts to examine the state of guardianship systems and make recommendations for reform.³² The Symposium produced thirty-one draft recommendations, which were later ratified by the American Bar Association.³³ The recommendations focused on procedural due process, legal representation for the proposed ward, determination of incapacity, judicial practices, accountability of guardians, and guardianship agencies.³⁴

Over the ensuing years, many changes to guardianship laws were made throughout the country.³⁵ In 1997, the National Conference of Commissioners on Uniform State Laws revised the Uniform Guardianship and Protective Proceedings Act (UGPPA) and incorporated the previously free-standing Act into the Uniform Probate Code (UPC) as Article 5.³⁶ This was an effort to standardize guardianship law and to separate laws regarding incapacitated adults from those regarding minors. As of the 1997 amendment, Section 2 of the UGPPA addresses guardianship of minors and Sections 3 and 4 address guardianships and conservatorships of adults.³⁷ Unfortunately, states have largely

31. John Parry, *Selected Recommendations from the National Guardianship Symposium at Wingspread*, 12 MENTAL & PHYSICAL DISABILITY L. REP. 398, 398 (1988) (stating that the AP report "led to the publication of more than 300 stories in various newspapers" and the enactment of guardianship legislation at the federal and state levels "aimed at addressing many reporting abuses and deficiencies").

32. *Id.*

33. Comm'n on Mentally Disabled & Comm'n on Legal Problems of the Elderly, *Guardianship, An Agenda for Reform: Recommendations of the National Guardianship Symposium and Policy of the American Bar Association*, 13 MENTAL & PHYSICAL DISABILITY L. REP. 271, 275 (1989) [hereinafter *An Agenda for Reform*].

34. *Id.* at 277-305.

35. See Hurme & Wood, *supra* note 26, at 1160 ("The late 1980s and the 1990s saw sweeping changes in state laws involving improved due process, a more functional determination of capacity not based on labels or age, use of less restrictive alternatives, limited orders, and greater guardian accountability. The 'backwater' topic of guardianship was finally gaining visibility in statehouses across the nation.").

36. UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT, 8A U.L.A. 471 (1997).

37. *Id.* at 509-71.

given the UGPPA the cold shoulder; by the end of 2016, it had only been adopted in five states and the District of Columbia.³⁸

In 2001, a second National Guardianship Symposium convened.³⁹ This effort produced sixty-eight recommendations focusing on developing standards for interstate transfers of guardianships, practice guidelines, education, research, funding, agency guardianships, monitoring, and accountability.⁴⁰ Although these reform efforts made significant inroads towards improving processes and protecting the rights of wards throughout the country, troubling issues lingered.⁴¹ Some courts blatantly disregarded new regulations and best practice guidelines, and stories of individuals subject to serious abuses through guardianship began to emerge again in the mid-2000s.⁴² These stories prompted changes in several state laws and initiatives on the Federal level as well.⁴³ The National Conference of Commissioners on Uniform State Laws took another stab at reform with development of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), which was added to the UPC as Article 5A.⁴⁴ By the end of 2016, the UAGPPJA has been enacted by forty-five states and the District of Columbia, making this Act far more successful than the UGPPA.⁴⁵

In 2011, a third National Guardianship Symposium convened.⁴⁶ This time, the focus shifted to developing recommendations to incorporate person-centered practices into guardianship proceedings.⁴⁷ Indeed, this person-centered focus

38. The Uniform Law Commission maintains a website that tracks enactment of the various uniform acts. See *Legislative Enactment Status: Guardianship and Protective Proceedings Act (1997)*, UNIF. L. COMM'N, [http://www.uniformlaws.org/Act.aspx?title=Guardianship%20and%20Protective%20Proceedings%20Act%20\(1997\)](http://www.uniformlaws.org/Act.aspx?title=Guardianship%20and%20Protective%20Proceedings%20Act%20(1997)) (last visited Jan. 12, 2017).

39. A. Frank Johns & Charles P. Sabatino, *Wingspan—The Second National Guardianship Conference, Introduction*, 31 STETSON L. REV. 573, 573–74 (2002).

40. *Wingspan—The Second National Guardianship Conference, Recommendations*, 31 STETSON L. REV. 595, 595–609 (2002).

41. See Hurme & Wood, *supra* note 26, at 1159–60.

42. See *id.* at 1160–61.

43. See *id.* at 1161–62.

44. UNIF. ADULT GUARDIANSHIP & PROTECTIVE PROCEEDINGS JURISDICTION ACT, 8A U.L.A. 10 (2007).

45. See *Legislative Enactment Status: Adult Guardianship and Protective Proceedings Jurisdiction Act*, UNIF. L. COMM'N, <http://www.uniformlaws.org/LegislativeMap.aspx?title=Adult%20Guardianship%20and%20Protective%20Proceedings%20Jurisdiction%20Act> (last visited Jan. 12, 2017).

46. See *Third National Guardianship Summit: Standards of Excellence and Recommendations*, 2012 UTAH L. REV. 1991, 1991 (2012) [hereinafter *Third National Guardianship*].

47. Leslie P. Francis, *Third National Guardianship Summit: Standards of*

pervades the findings and recommendations developed by the Symposium.⁴⁸ It is unclear yet what the impact of these latest ambitious reform efforts will be, but it is evident that guardianship practice has come a long way since King Edward I of England decided to take over the estates of his incapacitated subjects.⁴⁹

II. The Mechanics of State Guardianship Systems: What the Courts Do

There is no national procedure for appointment of a guardian; the practice belongs to the individual states to define. Although each state has a vehicle for evaluating capacity and transferring decisional rights, there are as many models as there are jurisdictions. This becomes evident when one compares guardianship statutes from state to state. Although there are many differences in language and structure, there are some elements common to every state. From start to finish, guardianship proceedings have several tasks or steps that must be completed, with variations in the order of the second and third steps.

Step 1: Petition

Guardianship laws throughout the country have liberal standing requirements for initial filing of the petition.⁵⁰ The statutes of most states allow any interested person to file a petition for guardianship of an adult, which makes it easy to initiate the process. The required contents of petitions have become more uniform over the years. Although some states have additional requirements, in general, a petition must contain: the name and demographic information of the person alleged to be

Excellence, 2012 UTAH L. REV. 1155, 1156 (2012) (“A core theme of the Summit is that shaping guardianship practices to center on the person him- or herself—so-called person-centeredness—is the touchstone of excellence in guardianship.”).

48. *Third National Guardianship*, *supra* note 46, 1199–1205.

49. See Custer, *supra* note 6, at 195–96.

50. See, e.g., CONN. GEN. STAT. ANN. § 45a-646 (West 2014) (“[a]ny person”); GA. CODE ANN. § 29-4-10 (2007) (“[a]ny interested person or persons, including the proposed ward”); NEV. REV. STAT. ANN. § 159.044 (LexisNexis 2014) (“a proposed ward, a governmental agency, a nonprofit corporation or any interested person”); W. VA. CODE ANN. § 44A-2-2 (LexisNexis 2014) (“the individual alleged to be a protected person, by a person who is responsible for the individual’s care or custody, by the facility providing care to the individual, by the person that the individual has nominated as guardian or conservator, by a person acting as a de facto guardian or de facto conservator or by any other interested person, including, but not limited to, the department of health and human resources”).

incapacitated; the nature of his or her disability; the name and contact information of the proposed guardian and that person's qualifications; the names and contact information of any family members; the specific rights to be transferred if the guardianship is granted; the rationale for transferring those rights; and an inventory of the property owned by the person alleged to be incapacitated.⁵¹

Step 2: Notice

After the petition is filed, each state has a requirement that the petitioner and others receive notice of the petition and that a hearing has been scheduled.⁵² Timing of notice varies and different states measure timing in different ways. Some states count the days before the hearing, and require notice to be served by as few as five⁵³ to as many as twenty⁵⁴ days before the hearing. The UGPPA requires a fourteen-day notice.⁵⁵ Some states measure the timing of notice from the filing of the petition,⁵⁶ while other states do not require a specific number of days, but instead rely on the courts to provide "reasonable" notice.⁵⁷ Still other states do not expressly specify a timing of notice.⁵⁸ Some statutes require that notice be read to the respondent.⁵⁹ In addition to the

51. *E.g.*, IND. CODE ANN. § 29-3-5-1 (LexisNexis 2011); N.M. STAT. ANN. § 45-5-303 (West 2013).

52. *E.g.*, ARIZ. REV. STAT. ANN. § 14-5309 (2012); FLA. STAT. ANN. § 744.331 (West 2014); 755 ILL. COMP. STAT. ANN. 5/11a-10 (West 2013).

53. MISS. CODE ANN. § 93-13-111 (2013).

54. *E.g.*, 20 PA. STAT. AND CONS. STAT. ANN. § 5511 (West 2005); S.C. CODE ANN. § 62-1-401 (2009).

55. UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 113(a), 8A U.L.A. 10 (1997).

56. *E.g.*, LA. CODE CIV. PROC. ANN. art. 4543 (2013) (requiring that notice be mailed within three days of the filing); WASH. REV. CODE ANN. § 11.88.030 (West 2006) (requiring that notice be served "not more than five court days after the petition has been filed").

57. *E.g.*, DEL. CODE ANN. tit. 12, § 3901(c) (2007) ("The Court shall by rule provide for reasonable notice to the person with an alleged disability and to such others, if any, as the Court may deem desirable; provided that, in all cases where a guardian of the person or guardian of the property of an adult with a disability is sought, the person with an alleged disability shall be entitled to representation by counsel . . ."); MO. REV. STAT. § 475.075 (2009) ("The notice shall be signed by the judge or clerk of the court and . . . served in person on the respondent a reasonable time before the date set for the hearing.").

58. *E.g.*, IOWA CODE ANN. § 633.554 (West 2014).

59. *E.g.*, FLA. STAT. ANN. § 744.331 (West 2016) ("Notice of the filing of a petition to determine incapacity and a petition for the appointment of a guardian if any and copies of the petitions must be served on and read to the alleged incapacitated person."); R.I. GEN. LAWS § 33-15-17.1 (2011) ("The court officer shall present the written notice and shall also read the notice to the respondent.").

respondent, most states require that other persons receive notice of the proceedings. Several persons or entities may be entitled to notice, including spouses, adult children, parents, next of kin, heirs-at-law, any person named in the petition, provider of residential care (including institutional providers such as nursing homes), counsel, guardians *ad litem*, and interested persons designated by the court.⁶⁰

Step 3: Counsel

One of the most significant impacts of recent guardianship reform is the availability of counsel to the person alleged to be incapacitated in a guardianship proceeding. Several jurisdictions require the appointment of counsel as a matter of right.⁶¹ Appointment is permissive in some states, although the courts are usually bound to appoint counsel if requested or necessary.⁶² While each state has statutory guidance on the appointment of counsel for the respondent, guardians *ad litem* receive less attention. Those statutes that speak to appointment of a guardian *ad litem*, as with the appointment of counsel, take one of two approaches: either to require appointment,⁶³ or leave it to the

60. *E.g.*, ALA. CODE § 26-2A-103 (LexisNexis 2009) (including a spouse, adult children, parents, a current guardian or conservator, nearest living adult relative, or any other person as directed by the court); FLA. STAT. ANN. § 744.3371 (West 2016) (including the attorney of the alleged incapacitated person, any guardian then serving, next of kin, such other interested persons as the court may direct); GA. CODE ANN. § 29-4-12 (2007) (including the proposed ward's legal counsel and guardian *ad litem* (if any), the petitioner and the petitioner's legal counsel (if any), all adult individuals, and other persons who are named in the petition); N.H. REV. STAT. ANN. § 464-A:5 (LexisNexis 2007) (including the attorney of the proposed ward, relatives whose names and addresses appear on the petition, the proposed guardian, the petitioner, or the medical director of a state or private institution, if the proposed ward was ever a patient of said institution); R.I. GEN. LAWS § 33-15-17.1 (2011) (including respondent's spouse, heirs at law, the administrator of any care and treatment facility where the respondent resides or receives primary services, any individual or entity known or reasonably known to the petitioner to be regularly providing protective services to the respondent).

61. *E.g.*, N.H. REV. STAT. ANN. § 464-A:6 (LexisNexis 2007) (describing the right to counsel as "absolute and unconditional").

62. *E.g.*, MASS. GEN. LAWS ch. 190B § 5-106 (LexisNexis 2011) (stating that counsel shall be appointed "if the ward, incapacitated person or person to be protected or someone on his [or her] behalf requests appointment of counsel; or if the court determines at any time in the proceeding that the interests of the ward, incapacitated person or person to be protected are or may be inadequately represented"); MICH. COMP. LAWS § 700.5305 (2014) (stating that counsel shall be appointed "[i]f the individual alleged to be incapacitated requests legal counsel or the guardian *ad litem* determines it is in the individual's best interest to have legal counsel").

63. *E.g.*, MICH. COMP. LAWS ANN. § 700.5305 (West 2012) (setting out the duties of the guardian *ad litem*, whose appointment is required).

judge's discretion.⁶⁴ Where a guardian *ad litem* is appointed, some states provide statutory guidance for which inquiries should be made on behalf of the court, who to consult, and the types of expertise the guardian *ad litem* should possess or seek out in another.⁶⁵

Step 4: Hearing

The hearing is the final procedural step in appointment of a guardian. One of the most frightening findings reported in the Associated Press article was that forty-nine percent of wards did not attend their guardianship hearing.⁶⁶ Today, almost all guardianship laws explicitly recognize the right of a person alleged to be incapacitated to be present at his or her hearing.⁶⁷ Some states have a more stringent requirement, mandating that, in the absence of defined circumstances, the person attend the hearing or that the hearing be brought to the person.⁶⁸ Many statutes allow for respondent's presence to be waived with a showing of good cause.⁶⁹ For a guardian to be appointed, the majority of states

64. *E.g.*, MASS. GEN. LAWS ch. 190B § 5-106 (LexisNexis 2011) ("The court may appoint as guardian *ad litem*, an individual or any public or charitable agency to investigate the condition of the ward, incapacitated person or person to be protected and make appropriate recommendations to the court.").

65. *E.g.*, 755 ILL. COMP. STAT. ANN. 5/11a-10 (West 2007) ("The guardian *ad litem* may consult with a person who by training or experience is qualified to work with persons with a developmental disability, persons with mental illness, or physically disabled persons, or persons disabled because of mental deterioration, depending on the type of disability that is alleged.").

66. Bayles & McCartney, *supra* note 29.

67. *E.g.*, ARK. CODE ANN. § 28-65-213 (2012); CONN. GEN. STAT. ANN. § 45a-650 (West 2014); TENN. CODE ANN. § 34-3-106 (2015).

68. *E.g.*, N.Y. MENTAL HYG. LAW § 81.11 (McKinney 2006) ("The hearing must be conducted in the presence of the person alleged to be incapacitated, either at the courthouse or where the person alleged to be incapacitated resides, so as to permit the court to obtain its own impression of the person's capacity. If the person alleged to be incapacitated physically cannot come or be brought to the courthouse, the hearing must be conducted where the person alleged to be incapacitated resides unless . . . all the information before the court clearly establishes that (i) the person alleged to be incapacitated is completely unable to participate in the hearing or (ii) no meaningful participation will result from the person's presence at the hearing."); NEV. REV. STAT. ANN. § 159.0535 (LexisNexis 2014) ("A proposed ward who is found in this State must attend the hearing for the appointment of a guardian unless: (a) A certificate signed by a physician or psychiatrist . . . specifically states the condition of the proposed ward, the reasons why the proposed ward is unable to appear in court and whether the proposed ward's attendance at the hearing would be detrimental to the physical or mental health of the proposed ward; or (b) A certificate signed by any other person the court finds qualified to execute a certificate . . .").

69. *E.g.*, FLA. STAT. ANN. § 744.331 (West 2016) (stating that presence is required "unless waived by the alleged incapacitated person or the person's

require a finding of incapacity by clear and convincing evidence,⁷⁰ although New Hampshire expects incapacity to be proven beyond a reasonable doubt,⁷¹ and Wyoming requires only a preponderance of evidence.⁷² Once the burden of proof is met, and it is established to the satisfaction of the court that a person lacks capacity to make some or all decisions, the judge must determine which rights to transfer to the guardian. The court may order a full (plenary) guardianship, transferring all or nearly all of the rights of the incapacitated person to the guardian, or take a more conservative approach, granting a limited guardianship covering only those areas where decisional incapacity is specifically proven.⁷³

Step 5: Monitoring

One scholarly article about guardianship referred to the procedure of adjudicating an incapacitated person and appointing a guardian as the “front end” of the process, and the ensuing accountability of the guardian and court monitoring as the “back end.”⁷⁴ Ten years later, the same authors wrote that, in spite of sweeping changes to the law nationally, the back end has not seen the same level of reform as the front end, and although monitoring is both required and necessary, resources are largely unavailable to facilitate assurance of guardian accountability.⁷⁵ Some level of post-adjudication monitoring of guardianships is required under

attorney or unless good cause can be shown for his or her absence”); IND. CODE ANN. § 29-3-5-1(d) (LexisNexis 2011) (stating that the person alleged to be incapacitated must be present unless he or she has “voluntarily waived notice of the hearing,” there is evidence the person “voluntarily consented to the appointment of a guardian,” it is not “in the person’s best interest to be present because of a threat to the health or safety” of the person, or it is “impossible or impractical for the alleged incapacitated person to be present”); KAN. STAT. ANN. § 59-3063 (2005) (stating that attendance is required “unless the court makes a finding prior to the trial that the presence of the proposed ward . . . will be injurious to the person’s health or welfare, or that the proposed ward’s . . . impairment is such that the person could not meaningfully participate in the proceedings, or that the proposed ward . . . has filed with the court a written waiver of such person’s right to appear in person”).

70. See, e.g., ALASKA STAT. § 13-26-113 (2014); HAW. REV. STAT. ANN. § 560:5-311 (West 2008); N.M. STAT. ANN. § 45-5-303 (West 2014); S.D. CODIFIED LAWS § 29A-5-312 (2004).

71. N.H. REV. STAT. ANN. § 464A:8 (LexisNexis 2007).

72. WYO. STAT. ANN. § 3-2-104 (2015).

73. Mary J. Quinn & Howard S. Krooks, *The Relationship Between the Guardian and the Court*, 2012 UTAH L. REV. 1611, 1620–33 (2012).

74. Sally Balch Hurme & Erica Wood, *Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role*, 31 STETSON L. REV. 867, 867 (2002).

75. See Hurme & Wood, *supra* note 26, at 1160–61.

the laws of every state.⁷⁶ There is little consistency, however, in how this is accomplished.⁷⁷ In fact, a 2006 study co-sponsored by the American Bar Association (ABA) and the American Association of Retired Persons (AARP) found that court oversight of guardianships varies widely between jurisdictions.⁷⁸ Lack of funding for monitoring was cited as a problem,⁷⁹ as was the failure to verify the contents of guardians' filed reports and the failure to conduct visits to the wards.⁸⁰ Around the same time, the ABA teamed up with the American Psychological Association to publish a guidebook for judges who adjudicate guardianships.⁸¹ The guidebook outlined several practices for monitoring guardianships to guide courts in ensuring this vital function is met, including use of volunteer and other non-court resources.⁸²

III. The Practice of Guardianship: What the Guardians Do

"To be sure, most guardians are honest and well-intentioned."⁸³ As unwieldy as the reformation of the guardianship system in this country has proven to be, this is a silver lining. The introduction to the Third National Guardianship Symposium's collected reports describes a continuum: "Anecdotal evidence suggests guardianship practice can range from quietly heroic, to satisfactory, to unknowingly deficient, to malfeasant," but the authors note that the proportions attributable to each category are not known.⁸⁴ The court order granting authority to a guardian is simple: make these decisions

76. See, e.g., MASS. GEN. LAWS ANN. ch. 190B § 5-309 (2014) (requiring the guardian to file a report sixty days after appointment and annually thereafter, and the court to establish a system for monitoring guardianships); MO. ANN. STAT. § 475.082 (West 2009) (requiring the court to evaluate the status of every person under a guardianship annually, also requiring the guardian to file an annual report).

77. See U.S. GOV'T ACCOUNTABILITY OFF., GAO-04-655, GUARDIANSHIPS: COLLABORATION NEEDED TO PROTECT INCAPACITATED ELDERLY PEOPLE 9–12 (2004), <http://www.gao.gov/new.items/d04655.pdf> (describing broad categories and methods of monitoring activities noted throughout the country).

78. Naomi Karp & Erica Wood, *Guardianship Monitoring: A National Survey of Court Practices* 31–35 (AARP PUB. POL'Y INST. et al., eds., 2006).

79. *Id.* at 24.

80. *Id.* at 22.

81. See ABA COMM'N ON L. & AGING & AM. PSYCHOL. ASS'N, JUDICIAL DETERMINATION OF CAPACITY OF OLDER ADULTS IN GUARDIANSHIP PROCEEDINGS: A HANDBOOK FOR JUDGES (2006), <https://www.apa.org/pi/aging/resources/guides/judges-diminished.pdf>.

82. *Id.* at 56–58.

83. See Bayles & McCartney, *supra* note 29.

84. See Hurme & Wood, *supra* note 26, at 1162.

on behalf of this person under these circumstances. The reality of guardianship in practice, however, is much more complex. Experts and advocates for guardianship reform have frequently observed the many hats an effective guardian must wear:

[A] good guardian [must] be knowledgeable about housing and long-term care options, community resources, protection and preservation of the estate, accounting, medical and psychological treatment, public benefits and communication with elderly and disabled individuals. A guardian should develop advocacy skills; assume “case management” functions; monitor the ward’s living situation; make decisions that are, to the greatest extent possible, in accord with the ward’s values; avoid any conflict of interest; and regularly report to the court.⁸⁵

In recognition of the gravity of the role of the guardian and the lack of post-adjudication support, all three National Guardianship Symposia included training and education for guardians as a component of their recommendations.⁸⁶ Yet, only a handful of states require training for non-professional guardians.⁸⁷

Perhaps the most important thing a guardian needs to understand is the standard upon which to base a decision. The two prevailing standards are substituted judgment and best

85. Hurme & Wood, *supra* note 74, at 872 (quoting *An Agenda for Reform*, *supra* note 33, at 296).

86. See *An Agenda for Reform*, *supra* note 33, at 296; *Wingspan*, *supra* note 40, at 602, 605; *Third National Guardianship*, *supra* note 48, at 1200.

87. See, e.g., ADMIN. ORDER NO. 2012-62 (Ariz. 2012) (“Any person who is neither a licensed fiduciary . . . nor a financial institution shall complete the training The training shall be completed before letters to serve as guardian, conservator, or personal representative are issued unless the appointment was made”); FLA. STAT. ANN. § 744.3145 (West 2016) (setting out curriculum requirements and requiring “[e]ach person appointed by the court to be a guardian must complete the required number of hours of instruction and education within 4 months after his or her appointment as guardian. The instruction and education must be completed through a course approved by the chief judge of the circuit court and taught by a court-approved organization”); N.Y. MENTAL HYG. LAW § 81.39 (McKinney 2006) (“Each person appointed by the court to be a guardian must complete a training program approved by the chief administrator which covers: 1. the legal duties and responsibilities of the guardian; 2. the rights of the incapacitated person; 3. the available resources to aid the incapacitated person; 4. an orientation to medical terminology, particularly that related to the diagnostic and assessment procedures used to characterize the extent and reversibility of any impairment; 5. the preparation of annual reports, including financial accounting for the property and financial resources of the incapacitated person.”); WASH. REV. CODE § 11.88.020(3) (West 2006) (“If a guardian or limited guardian is not a certified professional guardian or financial institution authorized under this section, the guardian or limited guardian shall complete any standardized training video or web cast for lay guardians made available by the administrative office of the courts and the superior court where the petition is filed unless granted a waiver by the court”).

interest. In order to exercise substituted judgment, the decision-maker must “attempt to establish, with as much accuracy as possible, what healthcare decision an incompetent patient would make if he or she were competent to do so.”⁸⁸ The best interest standard, by contrast, is an “attempt[] to weigh the burdens and benefits of treatment to the patient *in his present condition*, when no clear preferences of the patient can be determined.”⁸⁹ While substituted judgment asks what the person under a guardianship would decide, the best interest standard asks, instead, what a reasonable person would decide under the circumstances.⁹⁰ The UGPPA holds guardians to both standards: “A guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian. A guardian at all times shall act in the ward’s best interest and exercise reasonable care, diligence, and prudence.”⁹¹ This “dual mandate”⁹² requires guardians to consider what the person under a guardianship would decide for him or herself and what would protect the person’s best interest.⁹³ The addition of substituted judgment to the UGPPA is a positive development, in that it gives high priority to the self-determination interest of the ward.⁹⁴ The problem with applying both standards arises when there is discord between them, i.e. what the person under a guardianship would decide is not in his or her best interest. Despite the opportunity for tension, the UGPPA at least provides a standard.

As of 2011, only about one-third of American states had decision-making standards for guardians incorporated into their statutes.⁹⁵ Of those jurisdictions where a standard is articulated, some are states that have adopted UGPPA.⁹⁶ In the remaining states, some articulate a hierarchy, requiring that the guardian attempt to apply substituted judgment before resorting to a best

88. *Substituted-Judgment Doctrine*, BLACK’S LAW DICTIONARY (3d pocket ed. 2006).

89. PRESIDENT’S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 231 (2005), <http://hdl.handle.net/10822/559378> (emphasis in original).

90. *Id.* at 231, 233.

91. UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314(a), 8A U.L.A. 559 (1997).

92. Lawrence A. Frolik & Linda S. Whitton, *The UPC Substituted Judgment/Best Interest Standard for Guardian Decisions: A Proposal for Reform*, 45 U. MICH. J.L. REFORM 739, 741 (2012).

93. *Id.*

94. *Id.*

95. *Id.*

96. *Id.* at 744.

interest decision.⁹⁷ Other states name both standards, but do not provide any guidance on which to use in preference to the other.⁹⁸

Interpretation of the correct standard of decision-making is often left to the judicial branch. The cases that inform our collective legal knowledge on this subject often involve tragic circumstances. In many cases, the person at the center of the controversy dies before the appeal process is complete, even where expedited appeals are allowed.⁹⁹ In those situations where the person survives the case, they are often languishing in a persistent vegetative state without any hope of recovery.¹⁰⁰ That we now have this line of cases is due, at least in part, to advances in medical science. In the landmark *Quinlan* case, one of the physicians who examined Ms. Quinlan testified, "[T]hese things have occurred all along but the technology has now reached a point where you can in fact start to replace anything outside of the brain to maintain something that is irreversibly damaged."¹⁰¹ Prior to modern advances in medical science, "the physician perceived his duty as that of making every conceivable effort to prolong life."¹⁰² With the emergence of the ability to stave off death in the face of even the gravest diagnosis, a new type of question arises: When is the cost of prolonging life too high? "The debate here is . . . not between life and death; it is between quality of life and death . . ."¹⁰³

In 1976, in *Quinlan*, the New Jersey Supreme Court opened the door for surrogates to make end-of-life decisions by allowing Karen Quinlan's father to render a decision to terminate life-sustaining treatment on her behalf.¹⁰⁴ Such a decision rests on a foundation of the constitutionally-protected right to privacy, which, among other things, allows an adult to decide whether to

97. *Id.* at 744–45.

98. *Id.* at 746–47.

99. See, e.g., *In re Storar*, 420 N.E.2d 64, 66 n.1 (N.Y. 1981) (stating that "Storar died after the case had been argued" in court); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 422 (Mass. 1977) (stating that Saikewicz died due to bronchial pneumonia, a complication of leukemia).

100. See *In re Fiori*, 673 A.2d 905, 908–09 (Pa. 1996) (describing the attempt of a mother/guardian to obtain court approval to remove a feeding tube from her adult son who had been in a persistent vegetative state for approximately 16 years); *In re Quinlan*, 355 A.2d 647, 653–56 (N.J. 1976) (describing a father's court petition to remove life support from his daughter in a persistent vegetative state).

101. *Quinlan*, 355 A.2d at 652 n.2.

102. *Saikewicz*, 370 N.E.2d at 423.

103. *Cruzan v. Harmon*, 760 S.W.2d 408, 412 (Mo. 1988).

104. *Quinlan*, 355 A.2d at 671–72 (remanding the case to the trial court to "appoint Joseph Quinlan as guardian of the person of Karen Quinlan with full power to make decisions with regard to the identity of her treating physicians").

refuse or terminate life-sustaining treatment.¹⁰⁵ The right to privacy remains vested, even in a person no longer able to communicate their preferences, but where a surrogate decision-maker speaks for the patient in a manner that will result in death, the state's interests must also be taken into account.¹⁰⁶ To wit, according to the *Quinlan* court, those interests are "the preservation and sanctity of human life and defense of the right of the physician to administer medical treatment according to his [or her] best judgment."¹⁰⁷ The court came down firmly on the side of substituted judgment as the guiding standard.

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death We have no hesitancy in deciding, in the instant . . . case, that no external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life. We perceive no thread of logic distinguishing between such a choice on Karen's part and a similar choice which, under the evidence in this case, could be made by a competent patient terminally ill, riddled by cancer and suffering great pain¹⁰⁸

Fourteen years later, the United States Supreme Court picked up the *Quinlan* thread to give guidance on the standard to use when considering evidence of a previously-expressed wish to forego life-sustaining treatment.¹⁰⁹ The case concerned the controversy over an end-of-life decision for Nancy Cruzan, who had been in a persistent vegetative state since shortly after sustaining injuries in an automobile accident seven years earlier.¹¹⁰ Nancy was receiving her food and hydration via a feeding tube, and, after it became clear that she would not recover, her parents sought to have the tube removed and allow her to die.¹¹¹ The hospital required a court order to remove the feeding tube.¹¹² The basis for the Cruzans' assertion that Nancy would not wish to be kept alive

105. *Id.* at 662–64.

106. *Id.* at 663.

107. *Id.* at 663.

108. *Id.*

109. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

110. *Id.* at 266.

111. *Id.* at 266–67.

112. *Id.* at 268.

in her present condition with no hope of recovery was a statement she had made to a roommate some time before her incapacitating accident.¹¹³ At the state court level, this evidence was rejected as “unreliable for the purpose of determining [Nancy’s] intent,”¹¹⁴ and insufficient to counterbalance Missouri’s “strong policy favoring life.”¹¹⁵ The Missouri Supreme Court looked unfavorably upon the use of substituted judgment in Nancy’s case:

As applied in right-to-terminate-treatment decisions, the doctrine of substituted judgment is applied in abrogation of the state’s *parens patriae* power, not in furtherance of it. In cases like this one, the doctrine authorizes a guardian to cause the death of a ward unilaterally, without interference by the state, and contrary to the state’s vital interests in preserving life and in assuring the safekeeping of those who cannot care for themselves.¹¹⁶

In deference to the *Quinlan* decision, Missouri determined that a guardian could undertake an end-of-life decision based on substituted judgment, but that there must be clear and convincing evidence of the incapacitated person’s prior-expressed wishes.¹¹⁷ The United States Supreme Court ultimately upheld the lower court’s decision to affirm the requirement of clear and convincing evidence of an individual’s prior-expressed wishes before allowing a surrogate to exercise the right-to-die on his or her behalf.¹¹⁸

IV. Guardianship of Persons with Intellectual Disability: What the Law Says

As the underlying reason for incapacity, intellectual disability is distinct from the disabling condition of an elder adult or the minority of a child. By statute or regulation, each state provides a cut-off age by which a person’s intellectual disability must be manifest, with the states falling into one of two groups:

113. *Id.*

114. *Cruzan v. Harmon*, 760 S.W.2d 408, 424 (Mo. 1988).

115. *Id.* at 426.

116. *Id.*

117. *Id.* at 415.

118. The Supreme Court wrote:

In sum, we conclude that a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state. We note that many courts which have adopted some sort of substituted judgment procedure in situations like this, whether they limit consideration of evidence to the prior expressed wishes of the incompetent individual, or whether they allow more general proof of what the individual’s decision would have been, require a clear and convincing standard of proof for such evidence.

Cruzan, 497 U.S. at 284.

those calling for identification before the age of eighteen,¹¹⁹ and those that allow an additional four years, setting the cut-off age at twenty-two.¹²⁰ Intellectual disability is one of several types of developmental disabilities, meaning that the onset of the condition occurs during childhood.¹²¹ These individuals are, therefore, distinct from elderly adults after the onset of a disabling condition (who once had capacity) and from non-disabled children (who presumably one day will). Guardianship laws do not always recognize a difference.

A few states have laws that specify separate procedures for persons in need of decisional support by reason of an intellectual disability.¹²² The focus of some laws is to simplify the process for families and caregivers to arrange for guardians to assist these vulnerable adults.¹²³ Procedure is taken away, not added. Other states go to great lengths to include additional protections.¹²⁴ Still

119. *E.g.*, FLA. STAT. ANN. § 393.063(9) (West 2011); MISS. CODE ANN. § 41-21-61(f) (2013); OR. REV. STAT. ANN. § 427.005(4) (West 2011); VT. STAT. ANN. TIT. 14, § 3061(1)(a) (2010).

120. *E.g.*, GA. CODE ANN. § 37-1-1(8) (2012); IDAHO ADMIN. CODE r. 16.03.21.010 (2014); NEB. REV. STAT. § 83-1205 (2014); N.Y. MENTAL HYG. LAW § 1.03(22) (McKinney 2011).

121. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 33, 38–39 (5th ed. 2013).

122. *E.g.*, CONN. GEN. STAT. §§ 45a-669–684 (2014); IDAHO CODE § 66-404 (2015).

123. *See, e.g.*, ALA. CODE § 26-2A-102(e) (LexisNexis 2009) (“The custodial parent or parents or an adult custodial sibling of an adult child who is incapacitated *by reason of an intellectual disability*, may file, in lieu of a petition, a written request to be appointed guardian of his or her adult child or his or her adult sibling in order to continue performing custodial and other parental responsibilities or family responsibilities, or both responsibilities, for the child after the child has passed his or her minority. The court may waive any or all procedural requirements of the Uniform Guardianship Act, including notice and service, and appointments, and interviews. The adult child alleged to be incapacitated shall have had an examination by a physician or other qualified person and furnish a written report of the findings to the court. In lieu of a hearing, the probate court shall hold an informal hearing with the custodial parent or custodial parents or custodial adult sibling requesting the guardianship, the adult child for whom the guardianship is sought, and a guardian *ad litem* for the adult child chosen by the judge of probate.”) (emphasis added); FLA. STAT. ANN. § 393.12(1)–(2) (West 2011) (advising, on one hand, that a person with a developmental disability is not considered incapacitated solely by reason of the individual’s acceptance and receipt of services, but, on the other hand, providing that a court can appoint a “guardian advocate,” vested with the same authority as a traditional guardian, without first making a finding of incapacity).

124. *See, e.g.*, CAL. PROB. CODE § 1801(d) (West 2016) (“A limited conservator of the person or of the estate, or both, may be appointed for a developmentally disabled adult. A limited conservatorship may be utilized only as necessary to promote and protect the well-being of the individual, shall be designed to encourage the development of maximum self-reliance and independence of the individual, and shall be ordered only to the extent necessitated by the individual’s proven mental and adaptive limitations. The conservatee of the limited conservator shall not be

others have laws on the books that seem to conflate the intellectual disability with incapacity.¹²⁵ Often, the laws addressing guardianship for persons with intellectual disability are found in a separate section of the code from the state's traditional guardianship statutes.¹²⁶

Even when a guardian is needed to help with some decisions, people who live with intellectual disability do not necessarily lack capacity to make all decisions. For example, *In re M.R.* was a New Jersey Supreme Court case involving a young woman with both Down syndrome and an intellectual disability in the mild to moderate range.¹²⁷ The controversy arose when M.R. expressed a preference to live with her father, rather than her mother, with whom she resided at the time of the case and who was her appointed guardian.¹²⁸ M.R.'s mother refused to allow the move

presumed to be incompetent and shall retain all legal and civil rights except those which by court order have been designated as legal disabilities and have been specifically granted to the limited conservator. *The intent of the Legislature . . . that developmentally disabled citizens of this state receive services resulting in more independent, productive, and normal lives is the underlying mandate of this division in its application to adults alleged to be developmentally disabled.*") (emphasis added); CAL. PROB. CODE § 2351.5 (West 2016) (expanding California protections for adults with intellectual disability, providing that the limited conservator is precluded from exercising decision-making authority over seven areas, unless authority is requested in the petition and granted in the order: residential placement, execution of releases of information; consent to marriage or entry into a domestic partnership, consent to enter into a contract, consent for provision or withholding of medical treatment; consent to sexual and social relationships, and education decisions); MICH. COMP. LAWS ANN. § 330.1620 (West 1999) ("A court order establishing partial guardianship shall contain findings of fact, shall define the powers and duties of the partial guardian so as to permit the individual with a developmental disability to care for himself or herself and his or her property commensurate with his or her ability to do so, and shall specify all legal disabilities to which the individual is subject.");

125. See, e.g., N.Y. SURR. CT. PROC. ACT § 1750 (McKinney 2011) (authorizing the court to appoint a guardian where it is demonstrated that the person is "mentally retarded," is "incapable [of] manag[ing] him or herself," and that appointment of a guardianship is in the person's best interest).

126. E.g., ARIZ. REV. STAT. ANN. § 36-551.01(H) (2010) ("Persons with developmental disabilities have the right to presumption of legal competency in guardianship proceedings," which is found in Title 36, Public Health and Safety, whereas traditional guardianship statutes are located in Title 14, Trusts, Estates, and Protective Proceedings); MICH. COMP. LAWS ANN. §§ 330.1600–1644 (West 1999) (locating the Guardianship for the Developmentally Disabled statute sections in Chapter 330, Mental Health Code, whereas traditional guardianship statutes are located in Chapter 700, Estates and Protected Individuals Code); N.Y. SURR. CT. PROC. ACT §§ 1750–1761 (McKinney 2011) (locating the Guardians of Mentally Retarded and Developmentally Disabled Persons statute sections in the Surrogate Court Procedures Act, whereas traditional guardianship statutes are located in the Mental Hygiene Law).

127. 638 A.2d 1274, 1276 (N.J. 1994).

128. *Id.*

on the grounds that M.R. lacked capacity to make the decision to relocate to her father's house.¹²⁹ M.R.'s father advocated his daughter's position.¹³⁰ The court reversed the mother's appointment as guardian and remanded to the lower court to make specific findings as to M.R.'s capacity to express a reliable preference about where to live.¹³¹ In justifying its decision, the court drew an important and often-overlooked distinction between the type of decision M.R. was attempting to make and other, more permanent decisions:

We are reminded also that the mere fact that a person is generally incompetent does not mean that person is incompetent for all purposes A person who is generally incompetent can still make choices about specific matters. Depending on the facts of the case, someone who is unable to manage his or her own affairs may still be capable of deciding where and with whom to live A second distinction . . . concerns the seriousness of the incompetent's decision. The decision where to live, if proved incorrect, can be corrected more easily than can the decision to be sterilized. We recognize the argument that as a decision increases in importance, so should the right of the affected person to make that decision Our goal is to permit developmentally-disabled people to make as many decisions as possible, while protecting them from the harmful effects of bad decisions that they do not fully understand.¹³²

The lesson from *In re M.R.* seems to be that the level of specific competence needed to make a decision increases with the gravity and irreversibility of that decision.¹³³ It is, therefore, not unexpected that the area where the judicial branch most frequently steps in is health care decisions. Although there is not a lot of reported case law involving health care decisions for persons with intellectual disability, two examples illustrate the unique difficulties faced by courts in evaluating how surrogate decisions should be made for these individuals.

In the first case, a Massachusetts man named Joseph Saikewicz lived all but the first twenty of his sixty-seven years at Belchertown State School, an institution for the care of individuals with intellectual disability.¹³⁴ His life was impacted by an intellectual impairment that was classified in the profound

129. *Id.* at 1276.

130. *Id.*

131. *Id.* at 1282.

132. *Id.* at 1281.

133. *Id.*

134. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 420 (Mass. 1977).

range.¹³⁵ In 1976, Joseph was diagnosed with incurable leukemia; even with treatment, he had only months to live.¹³⁶ Joseph could not communicate his own wishes, and, as he had no involved family willing to serve as his legal decision-maker, the administrator of the school sought the guidance from the court.¹³⁷ A guardian *ad litem* was appointed, and made the recommendation not to treat Joseph, on the grounds that Joseph would not be able to understand the treatment, which, if administered, would lead to fear, pain, and little extension of life.¹³⁸ The probate court judge issued an order agreeing with the recommendation of the guardian *ad litem*, but asked the higher court to review the decision.¹³⁹ The Superior Court issued an order affirming the probate decision, and Joseph died about eight weeks after the order without receiving chemotherapy, but in relative comfort.¹⁴⁰ Several months later, the court issued a written opinion explaining its decision, thereby providing the first guidance we have about medical decisions for people with intellectual disability.

As a threshold matter, the *Saikewicz* court noted that persons who lack capacity have the same substantive right to decline medical treatment as everyone else.¹⁴¹ The court found that the most appropriate way to approach a surrogate decision is to attempt, as nearly as possible, to determine the ward's actual interests and preferences, and be guided by those.¹⁴² In short, the court advocated a substituted judgment standard, but stopped short of developing guidelines for guardians making healthcare decisions.¹⁴³

Four years later, the New York Court of Appeals reached the opposite conclusion in *In re Storar*.¹⁴⁴ This opinion was the consolidation of two cases. The first concerned Joseph Fox, a member of a Catholic religious order, who, at the age of eighty-

135. *Id.*

136. *Id.* at 420-21.

137. *Id.* at 419.

138. *Id.*

139. *Id.* at n.2.

140. *Id.* at 419-22.

141. *Id.* at 423.

142. *Id.* at 431.

143. *Id.* at 432 n.18 ("We decline the invitation of several of the amicus and party briefs to formulate a comprehensive set of guidelines applicable generally to emergency medical situations involving incompetent persons. Such a wide-ranging effort is better left to the legislative branch after appropriate study.")

144. *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981).

three, suffered cardiac arrest during an operation.¹⁴⁵ In order to be kept alive, Brother Fox was kept on a respirator, but the lack of oxygen to his brain left him in a persistent vegetative state.¹⁴⁶ The director of his order petitioned the court to honor Brother Fox's prior-expressed wish not to be kept alive by such measures.¹⁴⁷

By contrast, fifty-two-year-old John Storar had lived almost all of his life in an institution due to his intellectual disability and accompanying deficits, described to be in the profound range.¹⁴⁸ Around the same time as Brother Fox's surgery, John was diagnosed with bladder cancer.¹⁴⁹ His mother was appointed his guardian and approved radiation treatment for the cancer, which subsequently went into remission.¹⁵⁰ The cancer returned the following year and was then determined to be terminal.¹⁵¹ As a result of the cancer, John developed internal bleeding and required transfusions.¹⁵² His mother initially consented but withdrew her consent because John was apprehensive about the transfusions and resisted them.¹⁵³ It was uncontroverted among the experts that John's bladder cancer would result in his death within a few months, and that not receiving the transfusions would hasten his death.¹⁵⁴

The court took the opportunity to juxtapose these cases and draw a distinction between surrogate end-of-life decision-making on behalf of a person who once had capacity to make his own decisions and a person who never had such capacity.¹⁵⁵ There was no difficulty in disposing of Brother Fox's case; there was sufficient evidence of his previous comments—repeated two months prior to his final hospitalization—to support a finding that he would not want to remain alive under the circumstances.¹⁵⁶ The court passed over the constitutional privacy right that the *Quinlan* court

145. *Id.* at 67.

146. *Id.*

147. *Id.* at 67–68.

148. *Id.* at 68.

149. *Id.*

150. *Id.*

151. *Id.* at 68–69.

152. *Id.*

153. *Id.* at 69–70.

154. *Id.* at 69.

155. *Id.* at 73 (“[T]his case bears only superficial similarities to [Br. Fox’s situation] and the determination must proceed from different principles.”).

156. *Id.* at 72.

rested upon, saying rather that Brother Fox had a common law right to refuse treatment.¹⁵⁷

In the second case, the court noted that John never had capacity to make his own decisions: "Thus it is unrealistic to attempt to determine whether he would want to continue potentially life prolonging treatment if he were competent."¹⁵⁸ For this court, the important distinction was that the blood transfusions could successfully treat the loss of blood indefinitely, and without excessive pain.¹⁵⁹ The court looked at the blood loss in isolation from the cancer. With the transfusions, John was essentially as he was before; without them, he became weak, listless, and faced an earlier death.¹⁶⁰ Citing law regarding health care decisions for children, the court found that the benefits of the blood transfusions to John outweighed the burdens, and the treatment was thus in his best interest.¹⁶¹

There is some consensus that, while self-determination and preservation of autonomy point to use of a substituted judgment standard for many decisions, for health care decisions, the better standard is best interest.¹⁶² One author notes:

Although people with [intellectual disability] are capable of gaining (or losing) skills over time, the level of an individual's underlying intellectual impairment does not change appreciably. As a result, it will seldom be possible to refer to an individual's preferences as expressed during a previous period of greater decisional capacity.¹⁶³

The definition of the term "substituted judgment doctrine" includes this qualifier: "Generally, the doctrine is used for a person who was once competent, but no longer is."¹⁶⁴ It would seem, then, that substituted judgment should rarely be used as

157. *Id.* at 70.

158. *Id.* at 72.

159. *Id.* at 73.

160. *Id.*

161. *Id.*

162. A. Frank Johns, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 UTAH L. REV. 1541, 1556 (2012) ("One practical application of best interest comes when decisions are being made for end of life or for significant acute medical choices, including ending life."); AM. ASS'N ON MENTAL RETARDATION, A GUIDE TO CONSENT 52 (Robert D. Dinerstein et al. eds., 1999) (regarding medical decisions when the person is unable to give consent, "[t]he guardian stands in the place of the person and must act in the best interest of the person") [*hereinafter* A GUIDE TO CONSENT].

163. James W. Ellis, *Decisions by and for People with Mental Retardation: Balancing Considerations of Autonomy and Protection*, 37 VILL. L. REV. 1779, 1790 (1992).

164. *Substituted Judgment Doctrine*, BLACK'S LAW DICTIONARY, 686 (3d pocket ed. 2006).

the only standard for making health care decisions for an adult with intellectual disability.

V. Guardianship of Persons with Intellectual Disability: Practical Problems

There are some troubling facts surrounding health care outcomes for people whose lives are impacted by an intellectual disability. A growing number of studies substantiate claims that health disparities exist across several measures for people with intellectual disability as compared with the general population.¹⁶⁵ Absent a physician's recommendation to the contrary, people with intellectual disability should receive screening tests (e.g., cardiovascular screening, cancer screening) at least as often as members of the general population.¹⁶⁶ Although these individuals have about the same rates of cancer as the general population,¹⁶⁷ they receive routine cancer screenings far less frequently, or not at all, and are more likely to die of cancer.¹⁶⁸ A 1999 study found that breast cancer deaths among individuals with cerebral palsy, a condition often co-occurring with intellectual disability,¹⁶⁹ were three times higher than in the general population.¹⁷⁰ The authors of the study hypothesized that this was at least in part due to failure of timely diagnosis and treatment in this group.¹⁷¹

165. See Haverkamp et al., *supra* note 4, at 420–25.

166. Joanne E. Wilkenson et al., *Screening Tests for Adults with Intellectual Disabilities*, 20 J. AM. BOARD FAM. MED. 399, 399 (2007) (asserting that evidence-based screening recommendations are lacking among adults with intellectual disabilities, and there is a need to examine screening recommendations using guidelines of the US Preventative Service Task Force).

167. Kristina Patja et al., *Cancer Incidence Among People with Intellectual Disability*, 45 J. INTELL. DISABILITY RES. 300, 305 (2001) (finding “[i]n the present study, the incidence of cancer among people with [intellectual disability] was comparable with the general population, despite their low prevalence of smoking and apparently decreased involvement in diagnostic screening activities”).

168. See Haverkamp et al., *supra* note 4, at 424–25; Greenwood et al., *supra* note 4, at 444.

169. See, e.g., Amy Thornhill Pakula et al., *Cerebral Palsy: Classification and Epidemiology*, 20 PHYSICAL MED. & REHABILITATION CLINICS N. AM. 425, 442 (2009) (“More than half of individuals with CP have some type of intellectual or neuropsychological impairment . . .”); J.L. Hutton & P.O.D. Pharoah, *Effects of Cognitive, Motor, and Sensory Disabilities on Survival in Cerebral Palsy*, 86 ARCHIVES DISEASE IN CHILDHOOD 84, 86 (2002) (finding 1,335 of 1,942 children, living and dead, approximately sixty-nine percent with cerebral palsy in the study sample also had a cognitive disability).

170. David Strauss et al., *Causes of Excess Mortality in Cerebral Palsy*, 41 DEV. MED. & CHILD NEUROLOGY 580, 584 (1999) (stating that, for individuals with cerebral palsy, “death from breast cancer is three times more likely than in a group of comparable age and sex distribution in the general population”).

171. *Id.* (stating that “[i]n a population with development disability and frequent

How does this implicate guardians? In the real world, guardians of persons with intellectual disability are a subset of decisional support available to adults with diminished capacity.¹⁷² Because an individual under a guardianship is, in effect, “reduced to the status of a child in the eyes of the law[,]”¹⁷³ most advocates agree that guardianship should be the last port of call.¹⁷⁴ Guardians, thus, are part of a larger group of supporters who assist adults with intellectual disabilities in making decisions, in ways that are recognized formally at law (e.g., powers of attorney, representative payees) and in ways that are not (e.g., family support of a legally-competent adult who needs help with some decisions). There is a growing body of research that tends to indicate that some of these supported decisions are different from the decisions the average person would make for him or herself, particularly in the area of healthcare. Consider the following examples.

In one study, sixteen mothers and sisters of women with intellectual disability submitted to interviews exploring their perspectives on mammography for their loved one.¹⁷⁵ Although family members reported that they valued quality health care for their daughter or sister, they hesitated to schedule mammograms, citing worries that a cancer screening and diagnosis would lead to unnecessary suffering.¹⁷⁶ Those interviewed also reported worries about the inability of their loved one to understand the rationale for cancer treatment, and one sister reported, “We’re not as aggressive as we would be if it was me, or my husband.”¹⁷⁷ Several participants, however, also reported stories where they were surprised by their loved one’s resilience.¹⁷⁸ In particular, one mother, who dreaded taking her daughter for her first mammogram, reported, “[W]e got up to the plate, and this very nice young woman came out, and [my daughter] said ‘okay you can wait here.’ And she went with the woman and she did a great job. She did a really, really good job.”¹⁷⁹ A second study, conducted in

difficulty in communication, delay in diagnosis of cancer may be common”).

172. Horstman, *supra* note 18, at 217.

173. *Id.* at 231.

174. A GUIDE TO CONSENT, *supra* note 162, at 10–11 (“Because guardianship is such an invasive procedure and has such long-lasting consequences for the person with disabilities, it is best to seek alternatives if at all possible.”).

175. Greenwood et al., *supra* note 4, at 446.

176. *Id.*

177. *Id.* at 448.

178. *Id.* at 449.

179. *Id.*

2010, asked nurses who provide services to persons with intellectual and developmental disabilities about the barriers to cancer screenings for these patients.¹⁸⁰ Twenty-six percent of study participants reported that they had experienced instances where a screening was ordered, but the family refused.¹⁸¹

It is not just the attitudes of family members providing support that can lead to poor decisions. Even in these times, people with intellectual disabilities face “discriminatory social attitudes,” and this experience sometimes extends to the doctor’s office.¹⁸² Among the answers provided by the nurses in the study described above were several that point to a need for greater education in the health care community about patients with intellectual disabilities.¹⁸³ As a result, sometimes the reason for lower numbers of screening and treatment is that a physician or nurse advised the family against the procedure, and a decision consistent with that medical advice was made.¹⁸⁴ The need for additional education among health care providers has been repeatedly recognized.¹⁸⁵ As long as there are health care providers who make different recommendations for persons with intellectual disability than for their other patients, those providing

180. Carl V. Tyler et al., *Nursing Perspectives on Cancer Screenings in Adults with Intellectual and Other Disabilities*, 48 INTELL. & DEV. DISABILITIES 271, 272 (2010).

181. *Id.* at 273 tbl.1.

182. Allison A. Brown & Carol J. Gill, *New Voices in Women’s Health: Perceptions of Women with Intellectual and Developmental Disabilities*, 47 INTELL. & DEV. DISABILITIES 337, 343 (2009).

183. Tyler notes several answers that reflect the acceptance of health care conditions/outcomes for persons with intellectual disability distinct from the general population:

The individual’s behaviors/lack of cooperation does not permit screenings to be completed without additional intervention (i.e., sedation, etc.); Cancer screening tests are attempted, but they are not successfully completed; They have preventive health care visits, but cancer screenings are NOT ordered; The individual is fearful; Cancer screening tests are ordered, but the individual refuses them; The individual/family does not understand the benefit of cancer screening.

Tyler et al., *supra* note 180, at 273.

184. See, e.g., Jamie G. Swaine et al., *Family Caregivers’ Perspectives on Barriers and Facilitators of Cervical and Breast Cancer Screenings for Women with Intellectual Disability*, 51 INTELL. & DEV. DISABILITIES 62, 68 (2013); Haverkamp, *supra* note 4, at 424.

185. See, e.g., Brown & Gill, *supra* note 182, at 345 (“Improving the quality of health care for women with intellectual and developmental disabilities requires . . . health providers address their own need for adequate skills and training in both disability and women’s health.”); Tyler et al., *supra* note 180, at 274 (noting that the nurses who participated in the survey identified a need for education in the health care community as one of the greatest barriers to provision of cancer screenings to the women with intellectual disability).

decisional support stand in a position of pivotal importance as health care advocates.

The attitude of the person in need of decisional support can also be a problem. Many adults with intellectual disability do not consider themselves disabled and regard any indicia of disability as stigmatizing.¹⁸⁶ These individuals will often go to great lengths to defend their autonomy and avoid seeking clarification of things they don't understand. As a result, they can often appear to have greater decisional capacity than they actually possess.¹⁸⁷ Latent limitations of understanding present very serious risks where decisional supporters rely exclusively upon the stated preferences of the person with an intellectual disability. As a baseline example of how this can be a problem, research suggests that significant numbers of adults with intellectual disability have an incomplete understanding of death.¹⁸⁸ Thus, an expressed preference of an individual with an intellectual disability to forego life-saving treatment must, in the absence of evidence to the contrary, be considered in light of a probable imperfect understanding of the finality of the consequence of that decision. On the contrary, an evident joy of life in a person with an intellectual disability can be viewed as evidence that the individual, to be quite blunt, does not want to be dead.¹⁸⁹

VI. Striking a Balance Between Advocacy and Protection

It is important to point out that the discussion that follows is based upon a presumption of a guardian appropriately appointed to make decisions on behalf of a person who has been demonstrated to lack capacity to make those decisions for him or herself. This is not always the case. Guardianship appointments

186. Brown & Gill, *supra* note 182, at 342; ROBERT B. EDGERTON, *THE CLOAK OF COMPETENCE: STIGMA IN THE LIVES OF THE MENTALLY RETARDED* 131–32 (University of California Press rev. & updated 1993). Edgerton offers insight into how adults with mild to moderate intellectual disability become so strongly committed to avoiding the stigma of their diagnosis after an institutional experience that leaves “the patient without privacy, without clear identity, without autonomy of action, without relatives, friends, or family, in a regimented and impersonal institution where everything combines to inform him that he is, in fact, mentally inadequate.” *Id.* at 132.

187. Ellis, *supra* note 163, at 1792.

188. See John McEvoy et al., *Concept of Death and Perceptions of Bereavement in Adults with Intellectual Disabilities*, 56 J. INTELL. DISABILITY RES. 191, 199 (2012).

189. *In re R.H.*, 622 N.E.2d 1071, 1080 (Mass. 1993) (finding evidence that an individual with Down syndrome under her mother's guardianship would choose to undergo life-saving dialysis if she had capacity based, in part, on a finding that “she has always engaged in a variety of activities strongly suggestive of a desire to enjoy and prolong life”).

that are unnecessary and overbroad are the subject of substantial literature, and calls for reform are ongoing.¹⁹⁰ In fact, there is a strong argument that an undue guardianship of an individual with intellectual disability constitutes a civil rights violation.¹⁹¹ The comments below are restricted to guardianships that are necessary and appropriate.

One of the lessons that comes from the foregoing analysis is that there is often tension between maximizing individual self-determination and making decisions promoting the best interest of the individual with an intellectual disability. This is further complicated by the vast range in functional ability that lies between those with the mildest intellectual disability and those with the most severe.¹⁹² The very label of intellectual disability evokes stigma and can obscure the reality that this diverse cohort of our population has rich potential, talent, and ability that benefits society. Balancing the rules of advocate and protector can be incredibly frustrating, even for those with a strong grasp of the distinction between the two. The history of guardianship in the United States is a vivid illustration of a strong inclination toward protectiveness, often at the expense of advocacy.

Although the tenets of person-centeredness promote shifting focus to the person's strength and away from the disability, a diagnosis can be instructive, particularly for attorneys and judges with limited experience in this area. It is reasonable to presume that there is almost always some specific competence in a person diagnosed with an intellectual disability, particularly with those falling in the mild to moderate range. Even a person whose communication is so compromised that he or she cannot express the most basic choice has some way of showing preference. For instance, a person may not be able to provide informed consent to take a medication he or she has never taken. But, after some

190. See Margaret "Jenny" Hatch et al., *Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship*, 3 INCLUSION 65 (2015).

191. *Id.* In addition to the general analysis, *Unjustified Isolation Is Discrimination* contains a first-hand account of a woman's life during the year she spent under an organizational guardianship.

192. Ellis writes:

The severity of intellectual impairment within the class of people we label as having [intellectual disability] varies greatly. It has been observed that within the class of people who have [intellectual disability], individuals at the highest level of functioning have less in common with those at the lowest level of functioning than they have in common with people who have no intellectual handicap at all.

Ellis, *supra* note 163, at 1783.

experience, he or she may be able to provide feedback on whether the medication is effective or what side effects he or she experiences, and make an informed choice among available alternatives. Similarly, while an individual may not be able to competently choose whether or not to go to a medical specialist, he or she might be able to choose which doctor among those available he or she would prefer to see.

As the court advised in *In re M.R.*, the amount of decisional support needed increases with the gravity and irreversibility of the decision.¹⁹³ For example, the same person who is competent to choose where and with whom to live may not be able to make an informed decision to consent to or forego a medical procedure. The problem is that there is no single test for specific competency. Because there are many variables that impact decision-making, it really is a distinct set of skills from person to person that can change over time. The level of intellectual disability is a guidepost for judges and guardians *ad litem*. Where the individual has a mild or moderate impairment, it is likely prudent to find out what types of decisions he or she can make independently or with informal support.¹⁹⁴ Where appropriate, specific types of decisions can even be reserved to the individual in the guardianship order.

A final point is this: although a guardian is appointed in a protective capacity, some guardians have little or inaccurate understanding of what that means. Recall the stories of caregivers who avoided medical screenings because of their concerns about their loved one's ability to withstand the procedure, or their own fears of what would happen in the face of a diagnosis. These are often family members who believe that they are protecting their loved one and advocating for his or her best interest. In reality, this is neither protection nor advocacy and can lead directly to adverse results, even death.

When a recommendation for routine medical screening challenges a guardian's belief about what is best for the ward, or what the ward can withstand, the guardian, without further support or direction, may make a decision that violates his or her protective mandate. This can happen while the guardian believes, in all sincerity, that he or she is acting in the best interest of his or her family member. Front-end guidance from the court, either directly or through mandatory training, can be powerful in

193. *In re M.R.*, 638 A.2d 1274, 1281 (N.J. 1994).

194. See, e.g., Tina M. Campanella, *Supported Decision-Making in Practice*, 3 INCLUSION 35 (2015) (describing an emerging model for assisting persons with intellectual disability in making decisions without utilizing a formal guardianship).

combating this type of well-intentioned mischief. The rule of thumb is simple: absent guidance from a doctor to the contrary, a person with an intellectual disability should receive the same wellness care, screenings, and treatments as would a member of the general population with the same resources. This is the very protection for which a guardian is appointed. Making that expectation clear in a courtroom setting may be, by itself, the single most powerful protection that can be given.