

Living in the Gray: Why Today’s Supported Decision-Making-Type Models Eliminate Binary Solutions to Court-Ordered Guardianships

ALEXANDRA WALLIN*

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I. INTRODUCTION

“Just because people have a disability does not mean they need a guardianship. Many times they may need just a little help,” Margaret “Jenny” Hatch, an adult woman with Down Syndrome, wrote in a letter to others who may be in the same situation she was in prior to 2013.¹

In 2012, Jenny’s parents filed a claim in a Virginia trial court to seek appointment as Jenny’s guardians, which would give them the ability to make all decisions on Jenny’s behalf.² Prior to the court appointing Jenny’s parents as her temporary guardians,³ Jenny lived with friends and worked a full-time job.⁴ However, when the court appointed Jenny’s parents as

1. *Jenny’s Letter—Text Version*, JENNY HATCH JUST. PROJECT, http://jennyhatchjusticeproject.org/jennys_words [<https://perma.cc/JSG7-RFLP>]. Jenny is often portrayed as a “hero to the disabled.” *Jenny Hatch*, JENNY HATCH JUST. PROJECT, <http://jennyhatchjusticeproject.org/jenny> [<https://perma.cc/CWC7-TWT5>].

2. *The Justice for Jenny Trial*, JENNY HATCH JUST. PROJECT, <http://jennyhatchjusticeproject.org/trial> [<https://perma.cc/EB22-JS55>]; see VA. CODE ANN. § 64.2-2002(A) (2019) (“Any person may file a petition for the appointment of a guardian, a conservator, or both.”). Under Virginia guardianship laws, a court appoints a conservator who is responsible for maintaining the financial and estate affairs of an “incapacitated person.” VA. CODE ANN. § 64.2-2000 (2019). Additionally, under Virginia law, a “guardian” refers to a court-appointed person who has sole responsibility of managing the affairs of the incapacitated person, and the definition of a guardian refers to “limited guardians” as well. *Id.* For general distinctions between guardianships and conservatorships, see *infra* notes 55–57 and accompanying text. Virginia guardianship statutes define incapacitated person as:

[A]n adult who has been found by a court to be incapable of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that the individual lacks the capacity to (i) meet the essential requirements for his [or her] health, care, safety, or therapeutic needs without the assistance or protection of a guardian or (ii) manage property or financial affairs or provide for his [or her] support or for the support of his [or her] legal dependents without the assistance or protection of a conservator.

§ 64.2-2000. Furthermore, by itself, an individual’s display of poor judgment is not sufficient evidence that the individual meets the “incapacity” definition under Virginia guardianship law. *Id.* For a general summary of the status of supported decision-making in Virginia, see *Virginia*, NAT’L RESOURCE CTR. FOR SUPPORTED DECISION-MAKING, <http://supporteddecisionmaking.org/state-review/virginia> [<https://perma.cc/X45D-EXEX>].

3. See *infra* note 189.

4. *The Justice for Jenny Trial*, *supra* note 2. For a timeline of Jenny’s life leading up to the court-appointed guardianship, see *Jenny Hatch: A Timeline*, WASH. POST, <http://apps.washingtonpost.com/g/page/local/jenny-hatch-a-timeline/250/> [<https://perma.cc/4B2C-ZFKA>].

her guardians, they placed her into a group home where her cell phone and laptop were taken away, and she was forbidden from seeing her friends.⁵

Jenny received two different medical examinations to determine her intellectual competency and adaptive living skills.⁶ One doctor noted, “[W]ith appropriate support’ [Jenny] would not meet the statutory definition of incapacity, and ‘with support’ she could manage her property and financial affairs.”⁷ The court, giving deference to Jenny,⁸ appointed Jenny’s friends as her limited guardians for one year; this meant her friends would help Jenny make and implement decisions, a model called “supported decision-making” (SDM).⁹ Once the year expired, Jenny could successfully live independently using her SDM network.¹⁰ The court acknowledged that “there [were] no less restrictive alternatives available,” which exemplifies how a court should properly prioritize a person’s interests.¹¹ Thus, Jenny’s case is an excellent model of how guardianship cases should ensue. Unfortunately, this is not the case for most individuals with disabilities;¹²

5. *The Justice for Jenny Trial*, *supra* note 2. Jenny was also no longer able to work at her job, which is significant because the employment rate for individuals with disabilities is significantly lower compared to individuals without a disability. Shannon Smith, *The Rehabilitation Act of the Contingent Workforce: Effects of the Extension of Anti-Discrimination Legislation to the Contingent Workforce*, 11 GEO. J.L. & PUB. POL’Y 683, 689 (2013); *see also* SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 99 (2009) (explaining how the employment rate for individuals with disabilities has decreased since the Americans with Disabilities Act of 1990 was enacted).

6. *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 2 (Va. Cir. Ct. Aug. 2, 2013).

7. *Id.*; *see also infra* Section III.C.

8. During a guardianship proceeding, the proposed ward’s choice should be “afforded great deference.” Bruce S. Ross, *Conservatorship Litigation and Lawyer Liability: A Guide Through the Maze*, 31 STETSON L. REV. 757, 761 (2002) (citing CAL. PROB. CODE § 1810 (West 2019)).

9. *Ross*, slip op. at 3–5. This trial court was the first court to order an SDM instead of guardianship. BURTON BLATT INST. SYRACUSE UNIV., SUPPORTED DECISION-MAKING: AN ACTION FOR AGENDA 3 (2014), <http://bbi.syr.edu/newsevents/news/2014/02/Supported%20Decision%20Making-2014.pdf> [<https://perma.cc/LD78-CKUE>].

10. *Ross*, slip op. at 3–7; *see discussion infra* Section IV.B.2.

11. *Ross*, slip op. at 7; *see also discussion infra* Part III.

12. Restoring one’s rights is often a very difficult process. Some states have statutory evidence requirements to prove the individual now has sufficient capacity to maintain his or her own affairs. Jenica Cassidy, *Restoration of Rights in the Termination of Adult Guardianship*, 23 ELDER L.J. 83, 102 (2015); *see, e.g.*, GA. CODE ANN. § 29-4-42(b) (2019) (“A petition for termination must be supported either by the affidavits of two persons who have knowledge of the ward, one of whom may be the petitioner, or of a physician licensed to practice medicine . . . , a psychologist . . . , or a licensed clinical social worker, setting forth the supporting facts and determinations.”). However, most state statutes do not provide explicit guidance on how a judge should determine whether the individual now has this level of capacity, so “courts are left with broad discretion on the appropriate methods and sufficient evidence to determine capacity and restoration.” Cassidy, *supra*, at 103; *see* IND. CODE § 29-3-12-1(b) (2019) (“The court shall terminate the guardianship

the majority of individuals in this population are never able to gain their independence back, stripping them of their most basic rights.¹³

This Comment addresses current court systems' insistence upon granting guardianships at the expense of the individual's rights and focuses on the importance of legally recognizing SDM as a less restrictive guardianship alternative. After providing adequate background on disability information and guardianship laws, Part II examines SDM as a viable alternative, its status in the United States, and its international recognition. Part III dives into why the United States' current binary legal systems violate an individual's constitutional and human rights, how state court variance in determining capacity level fosters a tendency to appoint guardians, and how school systems play a role in the guardianship problem. Finally, Part IV proposes that the federal government should ratify the Convention on the Rights of Persons with Disabilities (CRPD); thus, each state would be required to legally recognize SDM-type models. Additionally, as a more attainable solution, the Department of Education should require special education programs to provide information on all available support options before the student reaches age eighteen.

of an incapacitated person upon: (1) adjudication by the court that the protected person is no longer an incapacitated person; or (2) the death of the protected person.”). Some state statutes, however, require frequent assessments by the court to determine the necessity of the ordered guardianship, regardless of whether a restoration petition has been filed or not. *See, e.g.*, CONN. GEN. STAT. § 45a-660(c) (2019) (“The court shall review each [guardianship] not later than one year after the [guardianship] was ordered, and not less than every three years after such initial one-year review.”); MO. REV. STAT. § 475.082(1) (2019) (“At least annually, the court shall inquire into the status of every adult ward and protectee under its jurisdiction for the purpose of determining whether the incapacity or disability may have ceased or changed and to insure that the guardian or conservator is discharging the guardian’s or conservator’s responsibilities and duties . . .”).

13. An individual may wish to restore his or her rights for three reasons: (1) the individual successfully regained decisional ability, (2) the individual developed decision-making support systems, or (3) additional evidence has surfaced to show the person does not meet the requirements to necessitate a guardian. ERICA WOOD ET AL., NAT’L CTR. ON LAW & ELDER RIGHTS, GUARDIANSHIP TERMINATION AND RESTORATION OF RIGHTS 5 (2018), <https://ncler.acl.gov/Files/Guardianship-Termination-Rest-of-Rights-Slides.aspx> [<https://perma.cc/A6KM-P8LB>]. However, restoration of rights is extremely rare because there are far too many barriers an individual has to overcome in order to successfully gain his or her rights back. *Id.* at 12. Barriers these individuals face include: lack of awareness, inadequate court access, irregular court review, inability to acquire legal representation, insufficient legal and judicial education, deficient focus on supports, deficient clinical evidence, and opposition from guardians. *Id.* at 13.

II. BACKGROUND

The World Health Organization estimates that approximately 15% of the world's population has some type of disability,¹⁴ and this number "is expected to rise due to global increases in life expectancy and advancements in medical treatments."¹⁵ Accordingly, this population is the largest minority in the world.¹⁶

In the United States, 25% of all adults and 40% of adults sixty-five years or older have some type of disability.¹⁷ Given the substantial number of individuals with a disability, it is discouraging that it took until 1990,¹⁸

14. *Disability and Health*, WORLD HEALTH ORG. (Jan. 16, 2018), <https://www.who.int/en/news-room/fact-sheets/detail/disability-and-health> [<https://perma.cc/85XK-QHZ5>]. There are two broad disability types: intellectual disabilities and developmental disabilities. Karen Andreasian et al., *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. REV. 287, 291 (2015). Intellectual disabilities generally impact thought processes and include cognitive aspects of a developmental disability. *Id.* (citing *Frequently Asked Questions on Intellectual Disability*, AM. ASS'N ON INTELL. & DEVELOPMENTAL DISABILITIES, <https://www.aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability> [<https://perma.cc/X2QU-93DC>]). Developmental disabilities encompass disabilities that result from language, physical, learning, or behavioral impairments. *Id.* (citing *Facts About Developmental Disabilities*, CENTERS FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html> [<https://perma.cc/DY9A-CXX9>]). The CRPD defines "persons with disabilities" as persons who have a long-term physical, intellectual, sensory, or mental impairment. Amy Raub et al., *Constitutional Rights of Persons with Disabilities: An Analysis of 193 National Constitutions*, 29 HARV. HUM. RTS. J. 203, 205 (2016).

15. Raub et al., *supra* note 14, at 203 (citing *Disability and Health*, *supra* note 14).

16. *Disability and Health*, *supra* note 14.

17. CDC: *1 in 4 US Adults Live with a Disability*, CENTERS FOR DISEASE CONTROL & PREVENTION (Aug. 16, 2018, 1:00 PM), <https://www.cdc.gov/media/releases/2018/p0816-disability.html> [<http://perma.cc/GZ9P-4U7A>]. For a breakdown on percentage of individuals with a disability per age range, see *U.S. Disability Statistics by State, County, City and Age*, DISABLED WORLD (June 14, 2018), <https://www.disabled-world.com/disability/statistics/scc.php#age> [<https://perma.cc/AT8H-UYFW>].

18. Compared to other equality movements, such as civil rights movements for race or gender, the disability civil rights and discrimination movement came much later. RUTH COLKER, *WHEN IS SEPARATE UNEQUAL?: A DISABILITY PERSPECTIVE* 11 (2009). During the 1960s, Congress began enacting civil rights legislation for race and gender equality. *Id.* However, "[i]t was not until 1990 that legislation comparable to the 1964 Civil Rights Act was enacted in the disability context." *Id.* Before the ADA was enacted in 1990, Congress enacted the Rehabilitation Act of 1973. For an overview of the importance of the Rehabilitation Act, see generally LENNARD J. DAVIS, *ENABLING ACTS: THE HIDDEN STORY OF HOW THE AMERICANS WITH DISABILITIES ACT GAVE THE LARGEST US MINORITY ITS RIGHTS* 1–19 (2015). The most crucial section of this act is section 504, which states that:

No otherwise qualified handicapped individual in the United States, as defined in Section 705(20) of this title, shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355 (codified as amended at 29 U.S.C. § 794(a) (2012)).

when Congress enacted the Americans with Disabilities Act of 1990 (ADA), for this population to officially be protected against discrimination—and yet these individuals are still fighting an uphill battle to maintain their rights.¹⁹

Although the ADA has provided individuals with disabilities protection from discrimination, these individuals continue to face many setbacks in their lives.²⁰ Part II of this Comment will delve into the ADA mandates and its impact on court cases; discuss what guardianships are and how guardianship laws have typically looked over the last decade, both internationally and in the United States; provide background on SDM as a guardianship alternative; explain how other countries and the United States have addressed SDM as an alternative; and describe the significance of reaching the age of majority within school systems.

19. Although individuals with disabilities still fight daily struggles to become fully integrated and thrive within society, and there is much room to grow to integrate these individuals, the treatment of this population has come a long way over the last half century. In 1947, Willowbrook State School opened as an institution for mentally disabled individuals; however, this institution quickly became understaffed, living conditions were despicable, and treatment of these individuals was deplorable—students were sexually and physically abused, often walked around naked due to a lack of clothing and staff supervision, used for human experiment purposes, and crammed into small rooms with way too many other students. Matt Reimann, *Willowbrook, the Institution That Shocked a Nation into Changing Its Laws*, TIMELINE (June 14, 2017), <https://timeline.com/willowbrook-the-institution-that-shocked-a-nation-into-changing-its-laws-c847acb44e0d> [<https://perma.cc/FUS7-XQHN>]. After a few news stories concerning the school's condition and a class action lawsuit, Willowbrook *finally* closed in 1987. *Id.* The lessons acquired from the deplorable nature of Willowbrook heavily influenced policies—the Protection and Advocacy System of the Developmental Disabilities Assistance, the Civil Rights Institutionalized Persons Act of 1980, the Bill of Rights Act, and the Education for All Handicapped Children Act—that were enacted to protect individuals with disabilities. *Id.*

20. While society has generally become more accepting of individuals with disabilities, this population has been categorically set apart from the rest of society, even dating back to when the Europeans settled colonies in North America and several charters specifically left out individuals with disabilities. SUSAN DUDLEY GOLD, *LANDMARK LEGISLATION: AMERICANS WITH DISABILITIES ACT 21* (2011). In the mid-1600s, “poorhouses” were established to shelter individuals in this population. *Id.* Institutions for individuals with disabilities were used in full force by the 1820s, and influential leaders, like P.T. Barnum, only exacerbated this separation by putting these individuals on display for show. *Id.* at 27. By the 1930s, the Nazis’ persecution of individuals with disabilities intensified conditions for this population. *Id.* However, individuals with disabilities began to find their voice and place in the 1960s when this population joined the civil rights movement against discrimination based on disability. *Id.* at 35; *see supra* note 18.

A. *The Americans with Disabilities Act*

The ADA is a fundamental law protecting individuals with disabilities from discrimination, and it was one of the first laws that laid a groundwork to establish these individuals' rights.²¹

The ADA, a Congress-enacted civil rights law, establishes “a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”²² The ADA defines a disability as: (1) having “a physical or mental impairment that substantially limits one or more of the major life activities of such an individual;”²³ (2) maintaining “a record of such an impairment;”²⁴ or (3) “being regarded as having such an impairment” (regarded as prong).²⁵ The ADA prohibits discrimination in

21. As President George H.W. Bush stated when signing the law, the ADA “takes a sledgehammer to [a] wall . . . which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp.” *Remarks of President George Bush at the Signing of the Americans with Disabilities Act*, EEOC, https://www.eeoc.gov/eeoc/history/35th/videos/ada_signing_text.html [<https://perma.cc/R5X3-6TAY>]; see also *The Olmstead Supreme Court Decision in a Nutshell*, OLMSTEAD RTS., <https://www.olmsteadrights.org/about-olmstead/#Before%20Olmstead> [<https://perma.cc/WKF7-9G88>]. Additionally, the ADA, specifically Title II, has proven over time to have an intricate relationship with sovereign immunity cases. See generally Derek Warden, *A Helping Hand: Examining the Relationship Between (1) Title II of the ADA's Abrogation of Sovereign Immunity Cases and (2) the Doctrine of Qualified Immunity in § 1983 and Bivens Cases to Expand and Strengthen Sources of "Clearly Established Law" in Civil Rights Actions*, 29 GEO. MASON U. C.R.L.J. 43 (2018).

22. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(b)(1) (2012).

23. *Id.* § 12102(1)(A). Under this ADA prong, when the work performed is the “major life activity” at issue, the plaintiff is required to show that:

[T]he employer thought that he [or she] was impaired in his [or her] ability to do the job that he [or she] held, but also that the employer regarded him [or her] as substantially impaired in performing either a class of jobs or a broad range of jobs in various classes as compared with the average person having comparable training, skills, and abilities.

Laurel M. Cohn, Annotation, *When Is Individual Regarded as Having, or Perceived to Have, Impairment Within Meaning of Americans with Disabilities Act (42 U.S.C.A. § 12102(2)(C))*, 148 A.L.R. Fed. 305 (2019); see also *Thornton v. United Parcel Serv., Inc.*, 565 F. Supp. 2d 273, 282 (D. Mass. 2008) (dismissing an ADA claim because Thornton was unable to provide evidence he was disabled during the time he suffered any adverse employment occurrences).

24. 42 U.S.C. § 12102(1)(B) (2012).

25. *Id.* § 12102(1)(C). An “offer of accommodation,” however, is not sufficient enough to fit the “regarded as” prong. *Thornton v. McClatchy Newspapers, Inc.*, 261 F.3d 789, 798 (9th Cir. 2001) (“[W]hen an employer takes steps to accommodate an employee’s restrictions, it is not thereby conceding that the employee is disabled under the ADA or that it regards the employee as disabled.”). For a suggestion on why a bright bright-line rule that denies ADA protection in “regarded-as” cases incorrectly applies the ADA, see Lawrence D. Rosenthal, *Reasonable Accommodations for Individuals Regarded as Having Disabilities Under the Americans with Disabilities Act? Why “No” Should Not Be the Answer*, 36 SETON HALL L. REV. 895, 956–66 (2006).

all public life areas, including: employment, private entity and public services, public accommodations, telecommunications, and other miscellaneous provisions.²⁶

Since the ADA's enactment, there have been many significant cases expanding the ADA to further ensure individuals with disabilities are not discriminated against.²⁷ Most notably, nine years after ADA enactment, the Supreme Court heard *Olmstead v. L.C. ex rel. Zimring*.²⁸ In *Olmstead*,

26. 42 U.S.C. § 12101 (2012). For a discussion on how integration into the working economy has the potential to impact society's view towards individuals with disabilities, which stems from discrimination and stereotyping, see Mark C. Weber, *Beyond the Americans with Disabilities Act: A National Employment Policy for People with Disabilities*, 46 BUFF. L. REV. 123 (1998).

27. See, e.g., Pa. Dep't of Corr. v. Yeskey, 524 U.S. 206, 206 (1998) (finding that the plaintiff could bring a suit against the state prison for denying his placement in a first offender program because he had a hypertension medical history, thus expanding the ADA to apply to state prisons); Helen L. v. DiDario, 46 F.3d 325, 333, 339 (3d Cir. 1995) (finding a state welfare department regulation violated the ADA because it forced specific patients to receive necessary care services in a segregated nursing home instead of in a community-based program with attendant care). After the ADA's enactment, the heavily litigated due process theory focused on whether the way a state allocates its resources encourages unnecessary segregation. See Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 29–32 (2012) (analyzing this due process theory in light of case law following the ADA enactment).

28. 527 U.S. 581 (1999). Starting in the 1800s, institutions and other similar facilities became an increasing solution to support individuals with disabilities or other mental health conditions. *The Olmstead Supreme Court Decision in a Nutshell*, supra note 21. However, in 1955, deinstitutionalization began. *Deinstitutionalization: A Psychiatric "Titanic,"* FRONTLINE (May 10, 2005), <https://www.pbs.org/wgbh/pages/frontline/shows/asylums/special/excerpt.html> [<https://perma.cc/8ESC-R57X>]. Deinstitutionalization refers to the policy of moving individuals with mental disabilities out of "large state institutions and then closing part of all of those institutions." *Id.* There were 558,239 mentally disabled patients in psychiatric hospitals across the United States in 1955; by 1994, this number dropped to 71,619 patients, which was a 486,620 reduction in the number of institutionalized patients. *Id.*; see E. FULLER TORREY, *OUT OF THE SHADOWS: CONFRONTING AMERICA'S MENTAL ILLNESS CRISIS* app. at 206–07 (1997) (providing a state-by-state chart with the number of patients in mental hospitals in 1955 versus the number in 1994). Another significant driving force behind deinstitutionalization was the passage of Medicaid in 1965, which provided an incentive for states "to move patients out of state mental hospitals and into nursing homes and general hospitals because the program excludes coverage for people in 'institutions for mental [disabilities].'" Deanna Pan, *Timeline: Deinstitutionalization and Its Consequences*, MOTHER JONES (Apr. 29, 2013), <https://www.motherjones.com/politics/2013/04/timeline-mental-health-america/> [<https://perma.cc/DEX8-YYG3>]. Later, the Mental Health Systems Act of 1980 was enacted to provide a complete reconstruction of mental health centers, thereby improving the services for individuals with mental illness. See Mental Health Systems Act of 1980, 42 U.S.C. §§ 9401, 9501 (2012). In 1981, President Ronald Regan's Omnibus Budget Reconciliation Act repealed all but two sections of the Mental Health Systems Act

two individuals with disabilities were inappropriately placed into an institution when they should have been placed in a less restrictive community-based treatment program, so they brought an action under the ADA Title II for inappropriate institutionalization.²⁹ The Supreme Court considered whether the State’s claim—that these individuals were placed in a community-based facility because of a lack of funds—was unreasonable and, consequently, whether the individuals were discriminated against.³⁰

The Court in *Olmstead* turned to the language of the ADA and its explicit identification of “unjustified ‘segregation’ of persons with disabilities as a ‘form of discrimination.’”³¹ The Court applied this conclusion to inappropriate institutionalization and subsequently concluded that a state must provide a patient with community-based treatment when: (1) professionals determine this treatment type is appropriate; (2) the patient does not oppose the treatment;³² and (3) placement in this facility may be reasonably accommodated.³³ Accordingly, the Court ruled that these individuals met the ADA Title II qualifications for community-based treatment.³⁴ Thus, the State’s inappropriate placement of these individuals into restrictive living environments violated the ADA.³⁵

of 1980 and created a block for grants to states, so the federal government no longer had a role in providing services to the mentally disabled. *National Institute of Mental Health (NIMH)*, NAT’L INSTITUTES MENTAL HEALTH, <https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-institute-mental-health-nimh> [<https://perma.cc/6JE3-LGQ6>] (last updated Feb. 17, 2017). Then, Congress enacted the ADA in 1990, which helped to further increase this population’s integration within society. *See supra* notes 21–26 and accompanying text. Despite the deinstitutionalization period progress, in 2010, there were “43,000 psychiatric beds in the United States, or about [fourteen] beds per 100,000 people—the same ratio as in 1850.” Pan, *supra*.

29. *Olmstead*, 527 U.S. at 593–94.

30. *Id.* at 594–96; *see also Helen L.*, 46 F.3d at 333 (“The ADA and its attendant regulations clearly define unnecessary segregation as a form of illegal discrimination against the disabled.”).

31. *Olmstead*, 527 U.S. at 600 (citing 42 U.S.C. § 12101(a)(2), (5)).

32. A court may consider various factors when determining whether the individual does not oppose the integrated setting. U.S. DEP’T OF JUSTICE, STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND *OLMSTEAD V. L.C.* 4 (2011), https://www.ada.gov/olmstead/q&a_olmstead.pdf [<https://perma.cc/2276-FJG5>] (explaining that one of the most relevant factors to consider is whether the individual was provided with informed consent).

33. *See Olmstead*, 527 U.S. at 595–96. For a summary of the lawsuit and Justice Ginsburg’s opinion of the court, *see The Olmstead Supreme Court Decision in a Nutshell*, *supra* note 28.

34. *Olmstead*, 527 U.S. at 602–03; *see also Sch. Bd. of Nassau Cty. v. Arline*, 480 U.S. 273, 288 (1987) (“[C]ourts normally should defer to the reasonable medical judgments of public health officials.”).

35. *Olmstead*, 527 U.S. at 607.

Furthermore, the Court provided two different rationales in recognizing the isolation that flows from inappropriate institutionalization.³⁶ First, inappropriate institutionalization, or situations where the individual would benefit from community settings, “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in life.”³⁷ “Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”³⁸ Thus, *Olmstead* expanded the ADA’s requirements to prohibit discrimination based on inappropriate institutionalization.³⁹

In 2008, the ADA Amendments Act of 2008 (ADAAA) was enacted to address problems that still existed concerning the ADA’s definition of a disability.⁴⁰ The ADAAA altered ADA language to broaden the “regarded

36. *Id.* at 600.

37. *Id.* at 601–02. Since the Supreme Court heard this case, many states have implemented various mechanisms to help fight against unnecessary segregation that flow directly from institutionalization. *See, e.g.*, DISABILITY RIGHTS CAL., PRINCIPLES: HOME AND COMMUNITY SERVICES AND OTHER SUPPORTS FOR PEOPLE WITH MENTAL HEALTH DISABILITIES (2017), <https://www.disabilityrightsca.org/system/files/file-attachments/103901.pdf> [<https://perma.cc/Q7GX-WGV5>].

38. *Olmstead*, 527 U.S. at 601.

39. *Id.* at 602–03. Presently, individuals and their families can even take a “self-assessment” based upon the *Olmstead* ruling to determine how the Court’s ruling can help an individual live within their community. *Assess How Olmstead May Assist You To Live in the Community*, OLMSTEAD RIGHTS., <https://www.olmsteadrights.org/self-helptools/assessment/> [<https://perma.cc/3BEV-NNQQ>]. Other litigation has piggybacked off of the *Olmstead* precedent and many states continue to address *Olmstead* issues. For a look at the *Olmstead* activity in 2017 in various states, see KEVIN MARTONE, NAT’L LOW INCOME HOUS. COAL., OLMSTEAD IMPLEMENTATION, https://nlihc.org/sites/default/files/AG-2018/Ch06-S04_Olmstead-Implementation_2018.pdf [<https://perma.cc/V5G5-KB4X>].

40. ADA Amendments Act of 2008, Pub. L. No. 110-325, § 2(a), 122 Stat. 3553, 3553 (codified as amended at 42 U.S.C. § 12101 (2012)). The ADAAA overruled a series of cases regarding mitigating measures. *See* Hillary K. Valderrama, Comment, *Is the ADAAA a “Quick Fix” or Are We Out of the Frying Pan and Into the Fire?: How Requiring Parties to Participate in the Interactive Process Can Effect Congressional Intent Under the ADAAA*, 47 HOUS. L. REV. 175, 200 (2010). One main problem with the ADA prior to the 2008 amendments was how the narrow definition of a disability increasingly denied individuals with specific impairments, who had been subjected to adverse actions because of their disabilities, their ADA rights simply because they did not meet the statute’s definition. *Questions and Answers About the Department of Justice’s Notice of Proposed Rulemaking to Implement the Americans with Disabilities Act Amendments Act of 2008*, U.S. DEP’T JUST. C.R. DIVISION (Jan. 30, 2014), https://www.ada.gov/nprm_adaaa/adaaa-nprm-qa.htm [<https://perma.cc/J7SU-PA7Z>]. After the ADAAA’s enactment, the Equal Employment Opportunity Commission provided final regulations in March 2011. Nancy Lee Jones,

as” prong.⁴¹ Under the ADAAA, an individual would have an easier time establishing coverage under this third prong by proving discrimination “on the basis of disability” instead of “because of the disability of an individual.”⁴² This altered language aimed to transform ADA discrimination cases to focus on whether the *discriminatory act* itself met the ADA definition, rather than whether the *plaintiff’s disability* met the ADA definition.⁴³ The ADAAA made additional changes to close up ambiguity gaps in the ADA, including altering ADA sections regarding employment discrimination, defining “major life activities,” and a plaintiff’s inability to bring a “regarded as” claim for common ailments.⁴⁴ However, even after the ADAAA’s enactment, there remain a multitude of other ambiguities under the ADA and its case law.⁴⁵

Disability and the Disabled-Issues, Laws and Programs, in THE AMERICANS WITH DISABILITIES ACT (ADA): PROVISIONS AND PROTECTIONS 1, 57 (John Kiviniemi & Cécile Sanjo eds., 2012).

41. *The ADA Amendments Acts of 2008 Frequently Asked Questions*, U.S. DEP’T LAB., <https://www.dol.gov/ofccp/regs/compliance/faqs/adafaqs.htm> [<https://perma.cc/M435-N5FE>]. The ADAAA altered the “regarded as” prong by (1) “expanding the definition of ‘major life activities;’” (2) “redefining who is ‘regarded as’ having a disability;” (3) “modifying the regulatory definition of ‘substantially limits;’” (3) “specifying that ‘disability’ includes any impairment that is episodic or in remission if it would substantially limit a major life activity when active;” and (4) “prohibiting consideration of the ameliorative effects of ‘mitigating measures’ when assessing whether an impairment substantially limits a person’s major life activities, with one exception.” *Id.* For a discussion on the “regarded-as” prong, see *supra* note 25 and accompanying text.

42. Valderrama, *supra* note 40, at 201–02 (quoting 42 U.S.C. § 12112(a) (2012)); see also Kate S. Arduini, Note, *Why the Americans with Disabilities Act Amendments Act Is Destined to Fail: Lack of Protection for the “Truly” Disabled, Impracticability of Employer Compliance, and the Negative Impact It Will Have on Our Already Struggling Economy*, 2 DREXEL L. REV. 161, 188–89 (2009).

43. See 42 U.S.C. § 12112(a); Valderrama, *supra* note 40, at 199–202. The necessity to change the focus of discrimination cases arose because employers were increasingly able to prevail on summary judgment motions based solely on the ADA’s disability definition. Valderrama, *supra* note 40, at 204 (citing Amy L. Allbright, *2007 Employment Decisions Under the ADA Title I—Survey Update*, 32 MENTAL & PHYSICAL DISABILITY L. REP. 335, 336 (2008)).

44. For a brief summary of the major changes the ADAAA made to the ADA, see Valderrama, *supra* note 40, at 199–202. The ADAAA also overruled a few key Supreme Court cases. See generally *Toyota Motor Mfg. v. Williams*, 534 U.S. 184 (2002), *superseded by statute*, ADA Amendments Acts of 2008, Pub. L. No. 110-325, 122 Stat. 3554; *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999), *superseded by statute*, ADA Amendments Acts of 2008, Pub. L. No. 110-325, 122 Stat. 3554. Most notably, the ADAAA overruled *Sutton’s* “mitigating measures” holding and *Toyota’s* “substantial limitation” ruling. Valderrama, *supra* note 40, at 199–200.

45. E.g., *Ambiguity of ADA Compliance Guidelines Poses Challenges for Deployers*, ATM MARKETPLACE (Nov. 20, 2011), <https://www.atmmarketplace.com/articles/ambiguity-of-ada-compliance-guidelines-poses-challenges-for-deployers/> [<https://perma.cc/8AF4-4LN4>]. Though the ADA has provided substantial protection for this population, it may not be providing enough protection when the individual does not meet the *cookie-cutter* situation to properly invoke the ADA. See, e.g., *Carothers v. County of Cook*, 808 F.3d

In light of the ADA and subsequent antidiscrimination statutes, the United States has been overzealous in guarding this population from external harm.⁴⁶ The propensity to overprotect has consequently fostered an environment where individuals with disabilities struggle to equally exercise their basic rights.⁴⁷ For example, these individuals often experience limited access to education,⁴⁸ work marginalization,⁴⁹ inadequate health

1140, 1147–48 (7th Cir. 2015) (holding that defendant inmate’s anxiety condition, which prevented her from interacting with other detainees, did not fit the ADA’s disability definition because the anxiety did not prevent her from performing a wide range of jobs); *Scavetta v. Dillon Cos.*, 569 F. App’x 622, 625–26 (10th Cir. 2014) (determining that employee pharmacist’s rheumatoid arthritis did not substantially limit her so as to pull her under the ADA’s protection because the impact of her condition affected her major bodily functions in general, rather than affecting her ability to work); *Hirsch v. Nat’l Mall & Serv., Inc.*, 989 F. Supp. 977, 984 (N.D. Ill. 1997) (holding that a deceased man’s unlawful termination claim, brought by his wife, was not enough to constitute a disability even though it was the disabling illness itself, non-Hodgkin’s lymphoma, that killed him). See generally Peter David Blanck & Mollie Weighner Marti, *Attitudes, Behavior and the Employment Provisions of the Americans with Disabilities Act*, 42 VILL. L. REV. 345 (1997).

46. Individuals with disabilities are considered some of the most vulnerable members of society for various reasons. These individuals are “disproportionately represented among the world’s poorest and at greater risk of suffering from violence, disaster, catastrophic health expenses, and many other hardships.” Stephen Hawking, *Disability and Vulnerability*, UNITED NATIONS DEV. PROGRAMME (Dec. 3, 2014), <http://hdr.undp.org/en/content/disability-and-vulnerability> [<https://perma.cc/FQ3G-SYGB>]. Additionally, “[p]eople with disabilities are vulnerable because of the many barriers [they] face: attitudinal, physical, and financial.” *Id.*; see also Shar Grainger, *Are Physically Disabled People More Vulnerable in Society?*, NEWS24 (Aug. 4, 2016, 2:46 PM), <https://www.news24.com/MyNews24/are-physically-disabled-people-more-vulnerable-in-society-20160804> [<https://perma.cc/FH3G-DQQN>] (explaining how violence, abuse, safety, security, hostility, victimization, various limitations, and harassment contribute to this population’s vulnerability).

47. For a discussion on how the ADA falls short in aiding society to eliminate discrimination caused by employment structural barriers, see generally Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1 (2004).

48. The main barriers individuals with disabilities experience with regards to education include inclusion, inadequate resources, lack of cooperation between parents or guardians and the school itself, and overworked and underqualified teachers. *5 Possible Barriers to Education for Students with Disabilities*, SUSAN L. SANDYS (Apr. 19, 2018), <https://susansandys.com/5-possible-barriers-to-education-for-students-with-disabilities/> [<https://perma.cc/VB79-RKER>]; see also GPE Secretariat, *Children with Disabilities Face the Longest Road to Education*, GLOBAL PARTNERSHIP FOR EDUC. (Dec. 3, 2016), <https://www.globalpartnership.org/blog/children-disabilities-face-longest-road-education> [<https://perma.cc/PBF4-BPX4>] (examining educational barriers and restraints individuals with disabilities face across the world).

49. See Samuel R. Bagenstos, *Has the Americans with Disabilities Act Reduced Employment for People with Disabilities?*, 25 BERKELEY J. EMP. & LAB. L. 527, 528–29–30 (2004) (discussing how many “scholars have provocatively argued not only that the

care services,⁵⁰ social isolation,⁵¹ and civil rights violations⁵²—including restrictions on their rights to vote, marry, have children, or to exercise legal capacity.⁵³ In seeking to curb these abuses, legal systems are a good place to start, specifically by swapping overprotective approaches for methods that promote autonomy and liberties.⁵⁴

B. Guardianships

One current area of disability law that needs improvement pertains to guardianships, or conservatorships as some states call them.⁵⁵ The term “guardianship” is widely used to refer to a situation where an adult serves as a decision-maker, the guardian, for another adult, the ward, who has a disability.⁵⁶ Some states use the term “conservatorship” to refer to this

employment position of people with disabilities has deteriorated, but also that the ADA has in fact *caused* that deterioration”).

50. For a discussion on the health care services disparity between individuals with disabilities and services for individuals without disabilities, see Jessica L. Roberts, *Health Law as Disability Rights Law*, 97 MINN. L. REV. 1963, 1990–97 (2013). “Research reveals that people with disabilities endure numerous types of inequities with respect to their health.” *Id.* at 1991.

51. Though most individuals have access to free education under the IDEA, “many students [with disabilities] remain segregated in self-contained classrooms or in separate schools, with limited or no opportunities to participate academically and socially in general education classrooms and school activities. Many do not have access to the same academic and extracurricular activities and services provided to other students.” *Public Policy and Legal Advocacy*, ARC, <https://www.thearc.org/what-we-do/public-policy/policy-issues/education> [<https://perma.cc/6VTH-CE4L>]; see *infra* Section III.A.2.

52. See Jake Offenhartz, *State Finds Success Academy Violated Civil Rights of Disabled Students*, GOTHAMIST (Feb. 27, 2019, 5:45 PM), http://gothamist.com/2019/02/27/state_finds_success_academy_violate.php [<https://perma.cc/4NKN-VDD6>] (“State education officials have determined that Success Academy, the controversial charter network with [forty-seven] schools across the city, is violating the civil rights of kids with disabilities—and doing so with the tacit approval of the New York City Department of Education.”); *infra* Section III.C.

53. Raub et al., *supra* note 14, at 206–08. Not only does this population face the challenges mentioned above, the gaps the ADAAA set to fill has not necessarily created a positive change for these individuals. See Linda Hamilton Krieger, *Sociolegal Backlash, in BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS* 340, 359 (Linda Hamilton Krieger ed., 2003) (“[I]n recent years, Title VII [claims have] undeniably been subject to sociolegal capture, at least in certain significant respects. Over the course of the 1980s and 1990s, courts progressively heightened standards of proof for plaintiffs asserting Title VII claims.”).

54. See Raub et al., *supra* note 14, at 206.

55. For a discussion on different ways of viewing guardianships and the ways guardianship laws may be considered and altered, see generally Leslie Salzman, *Using Domestic Law to Move Toward a Recognition of Universal Legal Capacity for Persons with Disabilities*, 39 CARDOZO L. REV. 521 (2017).

56. *Guardianship*, BLACK’S LAW DICTIONARY (10th ed. 2014).

same situation.⁵⁷ This Comment will use the term guardianship as a reference to this surrogate decision-making model.

The basic definition of a guardianship is the legal appointment of an individual who makes legal decisions on another individual's behalf.⁵⁸ Specifically, an adult guardianship “allows a court system to appoint decision-making powers to another person on behalf of an individual with a disability or elderly person to provide protections to that individual based on a theory of [the individual's] inability to make sound legal decisions.”⁵⁹ Guardianships, more often than not, are procedures involuntarily forced by the ward's state.⁶⁰

Guardianship proceedings are governed by state law,⁶¹ thus, the burden of proof varies between jurisdictions.⁶² While most states have adopted a higher “clear and convincing evidence” standard when determining an individual's capacity level, not all states have made this shift.⁶³

57. See, e.g., CAL. PROB. CODE §§ 1510(a), 1800.3 (West 2019). *But see* Kenneth Rosenau & Evan Greenstein, *Guardianship and Conservatorship: Frequently Asked Questions*, LAWHELP.ORG/DC (Jan. 17, 2017), <https://www.lawhelp.org/dc/resource/guardianship-and-conservatorship-frequently-a> [<https://perma.cc/6SE7-MNWD>] (“A guardian [in D.C.] is a person appointed by the court to make healthcare and other mostly non-monetary decisions. . . . A conservator is a person appointed by the court to take care of someone's finances . . .”).

58. Robert Dinerstein, Esmé Grant Grewal & Jonathan Martinis, *Emerging International Trends and Practices in Guardianship Law for People with Disabilities*, 22 ILSA J. INT'L & COMP. L. 435, 436 (2016). *Compare* *Guardian*, *supra* note 56 (“Someone who has the legal authority and duty to care for another's person or property, [especially] because of the other's infancy, incapacity, or disability.”), *with* *Guardian ad litem*, BLACK'S LAW DICTIONARY (10th ed. 2014) (“A guardian, [usually] a lawyer, appointed by the court to appear in a lawsuit on behalf of an incompetent or minor party.”).

59. Dinerstein, Grewal & Martinis, *supra* note 58, at 436. This Comment specifically discusses guardianships for individuals with disabilities; however, a lot of guardianships are sought and appointed for elderly individuals, and this population faces similar autonomy struggles as those with disabilities. See, e.g., Norman Fell, *Guardianship and the Elderly: Oversight Not Overlooked*, 25 U. TOL. L. REV. 189, 189, 195 (1994); *Elderly Conservatorship and Guardianship*, SENIORLIVING.ORG, <https://www.seniorliving.org/law/conservatorship/> [<https://perma.cc/J2F7-89PG>].

60. *Guardianship*, *supra* note 56.

61. Guardianship proceedings usually occur in the state's probate court. ERIC Y. DROGIN & CURTIS L. BARRETT, *EVALUATION FOR GUARDIANSHIP* 5 (2010).

62. Sarah Katz, *The Value of Permanency: State Implementation of Legal Guardianship Under the Adoption and Safe Families Act of 1997*, 2013 MICH. ST. L. REV. 1079, 1097; see also *infra* notes 78–84 and accompanying text.

63. Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 279, 293–94 (2011). Iowa, New York, and Texas statutes provide that the standard to determine whether a guardian

Guardianships are very common among individuals with disabilities because “[m]any parents follow the advice they received from an educator, doctor[,] or attorney.”⁶⁴ Parents often leave these meetings with professionals “without a clear understanding of why guardianship was needed or what it accomplished.”⁶⁵ Because guardianship laws in the United States usually provide for the most common situation, imposed guardianships are often significantly overbroad so as to take away the individual’s rights.⁶⁶

1. Guardianships at an International Level

Generally, most countries have some integrated system to recognize guardianships within their national and provincial legal systems.⁶⁷ At a broader international level, the Convention on the Rights of Persons with Disabilities (CRPD) helped instigate an evolution of guardianship law reform and remains one of the most significant international documents.⁶⁸

is necessary is a “clear and convincing evidence” standard. *See* IOWA CODE ANN. §§ 633.556(1), 633.570(1) (West 2019); N.Y. MENTAL HYG. LAW § 81.12(a) (West 2019); TEX. EST. CODE ANN. § 1101.001 (West 2019). Some states do not even reference required burden of proof standards within state statutes. *See, e.g.*, MISS. CODE ANN. § 93-13-251 (2019).

64. Dustin Rynders, *Supporting Adults with Disabilities to Avoid Unnecessary Guardianship*, 55 HOUS. LAW., Jan.–Feb. 2018, at 26, 26.

65. *Id.*

66. Dinerstein, Grewal & Martinis, *supra* note 58, at 436; *see also* Cassidy, *supra* note 12, at 85 (“Once a guardianship is in place, it can be difficult to modify or terminate, even when such guardianship is no longer necessary.”).

67. Dinerstein, Grewal & Martinis, *supra* note 58, at 436.

68. *See id.* at 436–38, 443. There are two other international agreements, in addition to the CRPD, that instigated an evolution of guardianship law reform: the Hague Convention on the International Protection of Adults and the Yokohama Decision. *Id.* at 437. The Hague Convention, which the United States was not a contracting party of, established the standards for how a country deals with problems regarding an adult and his or her property in an international suit when the person does not necessarily have the legal capacity to adequately express his or her own interests. HAGUE CONFERENCE ON PRIVATE INT’L LAW, 35. CONVENTION ON THE INTERNATIONAL PROTECTION OF ADULTS art. 1 (2000), <https://assets.hcch.net/docs/c2b94b6b-c54e-4886-ae9f-c5bbef93b8f3.pdf> [<https://perma.cc/F7EG-CBQH>]; *see* Dinerstein, Grewal & Martinis, *supra* note 58, at 437. The Yokohama Declaration was not actually a formal declaration used between nations but rather was written with the hope that countries across the world would adopt the declaration’s underlying principles. Dinerstein, Grewal & Martinis, *supra* note 58, at 439. The Yokohama Declaration, similar to the Hague Convention and the CRPD, addressed modern thinking SDM for individuals with disabilities; specifically, it supported new ways of guardianship law application, most notably SDM, and encouraged each country around the world to enact legislation that would further respect an adult’s wishes, beliefs, and values. *Id.* at 440. The Yokohama Declaration provides that “a person must be assumed to have the mental capacity to make a particular decision unless it is established that he or she lacks capacity,” and that “a person is not to be treated as unable to make a decision unless all practicable steps to help him or her do so have been taken without success.” INT’L GUARDIANSHIP NETWORK,

The CRPD, which was adopted in 2006 and became effective in 2008, was “the first comprehensive human rights treaty of the [twenty-first] century and [was] intended as a human rights instrument with an explicit, social developmental dimension.”⁶⁹ Now, as then, a country may elect to sign or ratify the treaty.⁷⁰ CRPD ratification legally binds the country to implement the Convention, whereas signing the Convention only requires the country to not engage in any activity that violates the CRPD.⁷¹ The United States was among 161 countries to sign the CRPD in 2009.⁷² As of 2016, 181 countries had ratified the CRPD—the United States was and still is not one of them.⁷³

The CRPD specifically advocates for and ensures individuals with disabilities are given equal and full enjoyment to every human right and essential freedom.⁷⁴ CRPD Article 12 is particularly important because it maintains that “persons with disabilities have the right to recognition

YOKOHAMA DECLARATION 2 (2010), https://www.international-guardianship.com/pdf/IGN-Yokohama_Declaration_2010.pdf [<https://perma.cc/E3TS-DBNC>].

69. DIV. FOR SOC. POLICY & DEV., UNITED NATIONS DEP’T OF ECON. & SOC. AFFAIRS, THE UNITED NATIONS AND DISABILITY: 70 YEARS OF THE WORK TOWARDS A MORE INCLUSIVE WORLD 2 (2018), https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/01/History_Disability-in-the-UN_jan23.18-Clean.pdf [<https://perma.cc/R9PJ-HFWH>]. For a summary of the United Nations work leading up CRPD ratification, see generally *id.*

70. *Ratify the Convention on the Rights of Persons with Disabilities (CRPD)*, CHANGE.ORG, <https://www.change.org/p/ratify-the-convention-on-the-rights-of-persons-with-disabilities-crpd> [<https://perma.cc/X846-PDQZ>].

71. G.A. Res. 61/106, annex I, U.N. Doc. A/Res/61/106, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006) [hereinafter CRPD], <http://www.un.org/esa/socdev/enable/documents/tccconve.pdf> [<https://perma.cc/57DN-CCPR>]; *Chapter Four: Becoming a Party to the Convention and the Optional Protocol—Joining the Convention*, UNITED NATIONS—DISABILITY, <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-four-becoming-a-party-to-the-convention-and-the-optional-protocol.html> [<https://perma.cc/QDH6-PPDU>].

72. UNITED NATIONS ENABLE, CRPD AND OPTIONAL PROTOCOL SIGNATURES AND RATIFICATIONS (2017), <http://www.un.org/disabilities/documents/maps/enablemap.jpg> [<https://perma.cc/5BFN-KDGD>]; see also GUARDIANSHIP SUMMIT, BEYOND GUARDIANSHIP: SUPPORTED DECISION-MAKING BY INDIVIDUALS WITH INTELLECTUAL DISABILITIES: BRIEFING PAPER FOR ROUNDTABLE DISCUSSION 1, 3 (2011), <http://supporteddecisions.org/wp-content/uploads/2015/09/Glen.Beyond-Guardianship.Briefing-Paper.pdf> [<https://perma.cc/F2MA-NRLM>].

73. UNITED NATIONS, UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD) (2016), http://www.un.org/disabilities/documents/COP/cosp9_infographic.pdf [<https://perma.cc/ZUF9-DH28>].

74. Dinerstein, Grewal & Martinis, *supra* note 58, at 439.

everywhere as persons before the law.”⁷⁵ Consequently, the CRPD created a new tension in the United States between guardianships and SDM: the necessity to maintain an individual’s autonomy⁷⁶—in order to avoid CRPD violation—and the state’s interest in protecting these individuals, who are arguably more vulnerable than others, from harm.⁷⁷

2. Guardianships in the United States

In the United States, each individual state has power over guardianship legal systems;⁷⁸ thus, the Uniform Law Commission (ULC) stepped in to help deal with state guardianship law inconsistencies.⁷⁹ The ULC’s purpose is to draft model legislation that a state may choose to enact, with the hope that all states enact the model legislation to streamline guardianship laws between jurisdictions.⁸⁰ Though some states do not enact this model legislation in its entirety, states frequently use some of the model legislation in its revised or enacted provisions.⁸¹

In 2017, the ULC completed the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA).⁸² The UGCOPAA provides that a state court must clearly find that the individual with disabilities cannot have his or her needs met by any other less restrictive option besides a guardianship, encourages “person-centered planning,”⁸³ and requires the

75. CRPD, *supra* note 71, at 10 art. 12.

76. Autonomy refers to an individual’s “right to control [his or] her decisions and actions.” Jalayne J. Arias, *A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity*, 39 AM. J.L. & MED. 134, 136 (2013).

77. Dinerstein, Grewal & Martinis, *supra* note 58, at 439; *see also supra* note 46 and accompanying text.

78. Dinerstein, Grewal & Martinis, *supra* note 58, at 436. Because guardianship laws are governed by state laws, there is a discrepancy in guardianship terms used throughout the United States. *See id.*

79. David M. English, *Amending the Uniform Guardianship and Protective Proceedings Act To Implement the Standards and Recommendations of the Third National Guardianship Summit*, 12 NAT’L ACAD. ELDER L. ATTORNEYS J. 33, 34 (2016). One model act the ULC drafted is the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), which addresses how to deal with resolving jurisdictional disputes involving multiple states and ultimately providing that one state will have jurisdiction at a time. *Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act Law and Legal Definition*, U.S. LEGAL, <https://definitions.uslegal.com/u/uniform-adult-guardianship-and-protective-proceedings-jurisdiction-act/> [<https://perma.cc/HF2Y-GBLG>].

80. English, *supra* note 79, at 34.

81. *Id.*

82. UNIF. LAW COMM’N, THE UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT 1 (2018), <https://www.guardianship.org/wp-content/uploads/2018/04/UGCOPAA-Summary-Oct-2017.pdf> [<https://perma.cc/A2KQ-9KLA>].

83. Person-centered planning is a model that includes the individual, as well as planners, to empower individuals with a disability by focusing on their specific needs and

individual's values and preferences are prioritized, even when placed under a guardianship.⁸⁴ New Mexico⁸⁵ and Maine⁸⁶ are the only states that have enacted this model legislation.⁸⁷

In 2004, the United States enacted another significant piece of legislation: the Individuals with Disabilities Education Improvement Act of 2004 (IDEA).⁸⁸ One IDEA purpose is to ensure every child with a disability has access to free, public education.⁸⁹ Additionally, the IDEA allows parents or guardians to be involved in the student's education and developmental progress.⁹⁰ Once a student with a disability turns eighteen, the student's educational rights are no longer shared with his or her parent as the student is legally an adult.⁹¹ However, under some state laws, the adult student may continue to share his or her educational rights when the student is

allowing the individuals to define their life directions. *Person Centered Planning Education Site*, CORNELL U. ILR SCH. EMP. & DISABILITY INST., <http://www.personcenteredplanning.org> [<https://perma.cc/X3MJ-FJ2P>]; see also A. Frank Johns, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 UTAH L. REV. 1541, 1561–62 (discussing person-centered planning involves and the supporters' required training).

84. See UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 309 (UNIF. LAW COMM'N 2017).

85. See S.B. 19, 53d Leg., 2d Reg. Sess. (N.M. 2018).

86. See H.B. 91, 128th Leg., 1st Reg. Sess. (Me. 2018).

87. *Guardianship, Conservatorship, and Other Protective Arrangement Act*, UNIFORM L. COMMISSION, <http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act> [<http://perma.cc/C7V3-FM6X>].

88. Individuals with Disabilities Education Act of 2004, Pub. L. No. 108-446, 118 Stat. 2647 (codified as amended at 20 U.S.C. § 1400 (2012)). Before the IDEA was enacted, the "treatment of children with disabilities within the public education system [was] horrific." COLKER, *supra* note 18, at 27. Until the turn of the nineteenth century, these individuals did not receive any type of education, mainly because "they were feared and shunned by society." *Id.* (citing ROBERT L. OSGOOD, *THE HISTORY OF INCLUSION IN THE UNITED STATES* 18 (2005)).

89. See 20 U.S.C. § 1400(c)(1). There are six main IDEA principles: (1) each child with a disability must be provided access to free, appropriate education (FAPE); (2) every child is entitled to undergo an evaluation concerning each area related to the asserted disability; (3) an individualized education program will be created for the child; (4) the child shall be provided educational services in the least restrictive environment as possible; (5) the child and his or her parents' input must be considered throughout the child's education process; and (6) the child's parents have the right to question their child's educational program plan. OKLA. STATE DEP'T OF EDUC. SPECIAL EDUC. SERVS. & OKLA. PARENTS CTR., INC., *THE SUPER 6 GUIDEBOOK: SIX PRINCIPLES OF IEDA 3* (2013) [hereinafter *SUPER SIX GUIDEBOOK*], <http://oklahomaparentscenter.org/wp-content/uploads/2013/07/Super-6-6-Principles-of-IDEA.pdf> [<https://perma.cc/SC4S-KF7V>].

90. 20 U.S.C. § 1436(e) (2012).

91. See *infra* note 96.

deemed legally incompetent,⁹² has been unable to provide informed consent, and has a competent adult appointed to represent the student's educational interests.⁹³

C. Supported Decision-Making as a Viable Alternative to Guardianships

Until recently, an individual's ability to make decisions and guardianship status were binary conceptions: either (1) "an individual [was] fully capable of making decisions in his or her life and [did] not require a guardian;" or (2) "the individual [was] not capable of making any decisions and therefore need[ed] a guardian."⁹⁴ However, in recent years, the "legal concept of guardianship has evolved to include the idea of limited decision-making capacity—where an individual may be able to retain some decision-making autonomy despite having the need for a legal guardian."⁹⁵ With this viewpoint shift, a guardianship is no longer the only viable option for an individual once he or she reaches the age of majority.⁹⁶ Accordingly, there has been

92. See generally Hatice Uyanik, Karrie A. Shogren & Peter Blanck, *Supported Decision-Making: Implications from Positive Psychology for Assessment and Intervention in Rehabilitation and Employment*, 27 J. OCCUPATIONAL REHABILITATION 498 (2017) (analyzing the limited number of current studies concerning the positive impacts of SDM-type models and the need to continue to examine SDM models potential); Bruce J. Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health Law*, 1 PSYCHOL. PUB. POL'Y & L. 6, 9–23 (1995) (discussing the cognitive and social psychological effects that directly flow from labelling an individual incompetent).

93. See, e.g., D.C. CODE § 38-2571.04 (2019) ("A child with a disability who has reached [eighteen] years of age shall be presumed to be competent, and all rights under IDEA shall transfer to the student, unless: (1) [t]he student has been adjudged incompetent under law; (2) . . . the student has been determined to not have the ability to provide informed consent and another competent adult has been appointed to represent the educational interests of that student . . . ; or (3) (A) [t]he student has designated, in writing . . . another competent adult to be the student's agent to: (i) [m]ake educational decisions; (ii) [r]eceive notices; and (iii) [p]articipate in meetings and other procedures related to the student's educational program on behalf of the student.").

94. Bryan Y. Lee, Note, *The U.N. Convention on the Rights of Persons with Disabilities and Its Impact Upon Involuntary Civil Commitment of Individuals with Developmental Disabilities*, 44 COLUM. J.L. & SOC. PROBS. 393, 395 (2011).

95. *Id.*; see Soumitra Pathare & Laura S. Shields, *Supported Decision-Making for Persons with Mental Illness: A Review*, 34 PUB. HEALTH REVIEWS, Dec. 2012, at 1, 3 (providing a review of SDM models viability for individuals with mental illness).

96. "Majority" is the "status of one who has attained the age ([usually eighteen]) at which one is entitled to full civic rights and considered legally capable of handling one's own affairs." *Majority*, BLACK'S LAW DICTIONARY (10th ed. 2014); see, e.g., ARIZ. REV. STAT. § 1-215 (2019) ("'Adult' means a person who has attained eighteen years of age.").

an increasing goal within the disability community to prioritize the individual's autonomy and self-determination.⁹⁷

Although a guardianship can be an acceptable option for one individual, other support options exist that may function as less restrictive alternatives for others.⁹⁸ Guardianship alternatives implement legal planning tools that can completely replace a guardian's necessity. SDM is one example of a less restrictive guardianship alternative.⁹⁹ The goal of SDM is to increase the individual's self-determination and maintain his or her decision-making autonomy.¹⁰⁰ SDM is best defined as:

97. Many psychologists have determined that autonomy and self-determination are fundamental for individuals and social groups to thrive. See, e.g., HUMAN AUTONOMY IN CROSS-CULTURAL CONTEXT: PERSPECTIVES ON THE PSYCHOLOGY OF AGENCY, FREEDOM, AND WELL-BEING 1 (Valery I. Chirkov, Richard M. Ryan & Kennon M. Sheldon eds., 2011).

98. Arlene S. Kanter & Yotam Tolub, *The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law for People with Disabilities in Israel and Beyond*, 39 CARDOZO L. REV. 557, 595 (2017). Guardianship alternatives include: “[P]owers of attorney, health care proxies or medical powers of attorney, advance directives, [] legal representation agreements,” direct bank deposit systems, and representative payee regimes. *Id.*; Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 9 (2012); see L. MARK RUSSELL, ALTERNATIVES: A FAMILY GUIDE TO LEGAL AND FINANCIAL PLANNING FOR THE DISABLED 63 (Catherine L. Caldwell & Doug Utigard eds., 1983); Debbie Reslock, *Why You Need a Health Care Proxy and How To Choose One*, FORBES (June 2, 2017, 12:09 PM), <https://www.forbes.com/sites/nextavenue/2017/06/02/why-you-need-a-health-care-proxy-and-how-to-choose-one/#f8458c96e779> [http://perma.cc/A53V-V93R]; *Living Wills and Advance Directives for Medical Decisions*, MAYO CLINIC (Dec. 15, 2018), <https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303> [https://perma.cc/7UPY-TDDA]; see also White & Case, L.L.P., *Power of Attorney—Do You Need One?*, LEARNING DISABILITIES ASS’N AM. (Dec. 11, 2018), <https://ldaamerica.org/power-of-attorney-do-you-need-one/> [https://perma.cc/E3AX-AUH5]. But see *Supported Decision-Making*, PARTNERS RESOURCE NETWORK (Sept. 27, 2016), <http://prntexas.org/supported-decision-making/> [https://perma.cc/ZVY5-8MLA] (“A power of attorney grants another person the authority to make decisions and handle matters without input from the individual. A supported decision-making agreement does not give the supporter the power to make decisions.”).

99. Sean Burke, *Person-Centered Guardianship: How the Rise of Supported Decision-Making and Person-Centered Services Can Help Olmstead’s Promise Get Here Faster*, 42 MITCHELL HAMLINE L. REV. 873, 882 (2016).

100. *Id.* at 880.

[A] process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.¹⁰¹

The SDM model's objective is to employ various tools that allow the individual with a disability to understand and make his or her own choices.¹⁰² Typically, an SDM model involves signing a formal agreement that identifies the people,¹⁰³ called the support network, who will support the individual's personal decisions.¹⁰⁴

1. Supported Decision-Making at an International Level

SDM models have taken on various forms throughout the world but nonetheless provide another viable alternative, fostering a shift away from rights-capturing models to autonomy-prioritizing models. Many countries recognize different SDM-type models, including: parts of Australia,¹⁰⁵

101. TEX. EST. CODE ANN. § 1357.002 (West 2019).

102. NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, SUPPORTED DECISION-MAKING: FREQUENTLY ASKED QUESTIONS 3 [hereinafter SDM: FAQ], <http://www.supporteddecisionmaking.org/sites/default/files/supported-decision-making-frequently-asked-questions.pdf> [<https://perma.cc/Y5KZ-EHJW>]. An SDM Pilot Project performed by the Center for Public Representation and Nonotuck Resources Associates revealed that most decisions individuals made using an SDM network were regarding health and dental care related decisions. ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT 13 (2016), http://supporteddecisions.org/wp-content/uploads/2016/11/Evaluation-Year-2-Report_HSRI-2016_FINAL-2-1.pdf [<https://perma.cc/ART9-FWV2>]. Other frequent decision categories included, in order of most frequent to least frequent: financial decisions; social and leisure; employment, volunteer, and day supports; relationship; legal matters; living arrangements; mental health and behavioral health; and SDM arrangements. *Id.*

103. People who are members of the individual's network, the supporters, "are selected by the person with the disability. They can be family members, coworkers, friends, and past or present providers. The individual should select supporters who know and respect his or her will and preferences, and who will honor choices and decisions the individual makes." *About SDM: What Is Supported Decision-Making*, CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/about-sdm/> [<https://perma.cc/523V-DPVT>].

104. SDM: FAQ, *supra* note 102, at 3.

105. For South Australia's policy regarding SDM, see GOV'T OF S. AUSTL. DEP'T FOR CMTYS. & SOC. INCLUSION, SAFEGUARDING PEOPLE WITH DISABILITY SUPPORTED DECISION-MAKING AND CONSENT POLICY (2015), http://dhs.sa.gov.au/__data/assets/pdf_file/0014/13415/safeguarding-people-with-disability-supported-decision-making-and-consent.pdf [<https://perma.cc/ZRY5-ZYQA>].

Bulgaria,¹⁰⁶ Canada,¹⁰⁷ the Czech Republic,¹⁰⁸ Israel,¹⁰⁹ Ireland,¹¹⁰ New Zealand,¹¹¹ Norway,¹¹² and Sweden.¹¹³

A majority of the recognized SDM models have close ties to the CRPD Article 12's declaration that individuals with disabilities have an equal recognition before the law.¹¹⁴ Article 12's significance also stems from: (1) acknowledgment of "the importance of legal capacity as an inalienable right of a person;" (2) recognition "that some [individuals] might need

106. Since its comprehensive guardianship law reform in 2012, the Bulgarian Center for Not for Profit Law has proposed legal capacity legislation to the National Assembly, which would have passed had there not been a change in the government, but there has since been another change in the government and there is a good chance this legislation will be considered again for enactment. Kristin B. Glen, *Introducing a "New" Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 87, 91 (2018). For a look at what kickstarted, along with the CRPD ratification, Bulgaria's need to address its guardianship laws, see *Stanev v. Bulgaria*, App. No. 36760/06, 2012 Eur. Ct. H.R. 46.

107. Canada was the first country to pioneer SDM legislation with the Representation Agreement Act, which allows an individual with a disability to control the individual's own decisions with the help of decision-maker(s). Burke, *supra* note 99, at 881. Canada's legislation created a "more flexible understanding of legal capacity," which shifted "the power dynamic within the relationship and [ability to] craft a more thorough process that necessarily includes the person with disabilities in the decision." *Id.*

108. For a description of the 2012 laws enacted that introduce SDM as a guardianship alternative, allow individuals to utilize advance directives, and require legal capacity restrictions to be implemented only as a resort option, see *Czech Republic Enacts Legal Capacity Law Reform*, MENTAL DISABILITY ADVOC. CENTRE (Feb. 21, 2012), <http://www.mdac.info/en/news/czech-republic-enacts-legal-capacity-law-reform> [<http://perma.cc/E47Q-CJQ6>].

109. Israel legally recognizes SDM as a guardianship alternative, and its legislation has served as a model for other countries that are considering enacting similar laws following the CRPD. Kanter & Tolub, *supra* note 98, at 559; see also Suzanne Cannon, *Bizchut Leading Legislation*, BIZCHUT (Feb. 17, 2016), <http://bizchut.org.il/en/555> [<http://perma.cc/7E3J-AYWB>].

110. For information on the changes Ireland made to its laws after CRPD ratification, see Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT'L L. 124, 133–34 (2014).

111. In New Zealand, the threshold utilized to determine incapacity is very high and any type of intervention must be the least restrictive option. Dinerstein, Grewal & Martinis, *supra* note 58, at 449.

112. There are two intervention levels used in Norway: (1) another person who supports the individual with a disability to express his or her preferences, and (2) an "assistive representative" whose decision will ultimately prevail over the individual with a disability's decision in an extenuating situation. Pathare & Shields, *supra* note 95, at 14 tbl.1.

113. Sweden completely banned incapacity findings and uses guardianship alternatives when appropriate. Dinerstein, Grewal & Martinis, *supra* note 58, at 449.

114. *Id.* at 443. Countries often use the CRPD's goal of providing equal recognition of legal capacity for all individuals as a backdrop for such legislative changes. *Id.*

support in exercising their legal capacity;” (3) identification of “safeguards . . . designed to make sure that a person’s legal capacity was not abused”; and (4) promotion of individual choice—the hallmark of autonomy underlying legal capacity.¹¹⁵ Article 12 does not attempt to eliminate guardianships but rather presents that guardianships and SDM models should coexist together.¹¹⁶

2. *Supported Decision-Making in the United States*

While the United States has not joined the significant number of nations to ratify the Convention, CRPD Article 12 has served as the foundation for the global SDM-recognition movement.¹¹⁷ Nonetheless, in 2012, the United States Agency for International and Developmental Disability—part of the Administrative Community for Living—formed the National Resource Center on Supported Decision-Making (The Center).¹¹⁸ The Center initiated a five-year project to further address gaps that existed in SDM research.¹¹⁹ Many states’ individual protection and advocacy agencies began to seriously discuss and experiment with SDM as a guardianship alternative such that SDM became widely discussed at national conferences and in

115. *Id.* at 444.

116. *Id.* at 444–45.

117. Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of Supported Decision-Making Project*, 39 CARDOZO L. REV. 495, 499 (2017).

118. *Id.* at 501. The Center specifically works with SDM experts and has “applied SDM in groundbreaking legal cases, developed evidence-based outcome measures, successfully advocated for changes in law, policy[,] and practice to increase self-determination and demonstrated SDM to be a valid, less-restrictive alternative to guardianship.” *About, NAT’L RESOURCE CTR. FOR SUPPORTED DECISION-MAKING*, <http://www.supporteddecisionmaking.org/about> [<https://perma.cc/H9EZ-NQ97>].

119. Dinerstein, Grewal & Martinis, *supra* note 58, at 458 (citing to News Staff, *Burton Blatt Institute Receives \$2.5 Million Grant*, SYRACUSE UNIV. NEWS (Oct. 19, 2015), <http://news.syr.edu/burton-blatt-institute-receives-2-5-million-grant-60460/> [<http://perma.cc/6WRQ-YKTT>]). The five-year project aimed to provide increased SDM knowledge and implementation through: (1) “[p]ublication, outreach, and training intended to change attitudes in the legal, educational, medical, and professional fields so that families, practitioners, and providers recognize and consider SDM as an appropriate decision-making option;” (2) “[i]dentifying local, state, and national policies and practices that are barriers to the use of SDM, and advocating for necessary and appropriate modifications;” (3) “[c]onducting and sponsoring research into SDM, including identifying best practices;” and (4) “[h]olding annual symposia bringing together American and international experts to discuss the state-of-the-art in SDM and strategize ways to increase acceptance and use of SDM.” *Id.* at 457–58 (citing Jonathan G. Martinis, *Supported Decision-Making: Protecting Rights, Ensuring Choices*, 36 A.B.A. COMMISSION ON L. & AGING 107, 110 (2015)); see also *Community Living and Supported Decision-Making*, BURTON BLATT INST. SYRACUSE U., http://bbi.syr.edu/projects/Community_Living_DRRP/index.html [<https://perma.cc/HM8R-N72S>].

legal journals.¹²⁰ Subsequently, many states have heavily considered the constitutionality and justice of its guardianship laws.¹²¹

Only a few states have successfully enacted legislation to legally recognize SDM.¹²² The Texas legislature created a pilot program in 2009, which aimed to promote SDM within the disability community.¹²³ In 2015, Texas became the first state to enact a statute that legally recognized SDM.¹²⁴ In 2016, Delaware passed a similar SDM statute,¹²⁵ and in 2018, the District

120. Glen, *supra* note 117, at 501. Protection and Advocacy Systems specifically “work at the state level to protect individuals with disabilities by empowering them and advocating on their behalf.” *State Protection and Advocacy Agency Systems*, ADMIN. FOR COMMUNITY LIVING (Oct. 3, 2019), <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> [<https://perma.cc/QGC6-C93B>]. In the United States and its territories, there are fifty-seven Protection and Advocacy Systems that are all “dedicated to the ongoing fight for the personal and civil rights of individuals with disabilities.” *Id.*; see, e.g., *Success Stories*, DISABILITY L. CTR., <http://disabilitylawcenter.org/successstories/> [<https://perma.cc/564P-T66X>].

121. See, e.g., Andreasian et al., *supra* note 14, at 289–90; Desiree C. Hensley, *Due Process Is Not Optional: Mississippi Conservatorship Proceedings Fall Short on Basic Due Process Protections for Elderly and Disabled Adults*, 86 Miss. L.J. 715, 722 (2017); see also *In re Dameris L.*, 956 N.Y.S.2d 848, 856 (Sup. Ct. 2012) (finding Dameris L.’s SDM network was the individual’s least restrictive option that would allow her to properly exercise her legal capacity, so her guardianship was terminated).

122. Although a majority of states have not enacted SDM laws, many states have drafted SDM legislation, but these laws have not been passed into enactment. For a state-by-state breakdown of guardianship laws, resources, and proposed legislation, see *In Your State*, NAT’L RESOURCE CTR. FOR SUPPORTED DECISION-MAKING, <http://www.supporteddecisionmaking.org/states> [<https://perma.cc/2YYL-NCEB>].

123. Dinerstein, Grewal & Martinis, *supra* note 58, at 455. The Texas pilot program “trained volunteers to support people in making, ‘life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person.’” *Id.* (quoting Volunteer-Supported Decision-Making Advocate Pilot Program, TEX. GOV’T CODE ANN. § 531.02446 (West 2009) (repealed 2013)).

124. Glen, *supra* note 117, at 502. Texas Estates Code chapter 1357, cited as “the Supported Decision-Making Agreement Act,” functions to “recognize a less restrictive substitute for guardianship for adults with disabilities who need assistance with decisions regarding daily living.” TEX. EST. CODE ANN. §§ 1357.001–.003 (West 2019). Texas’s SDM laws require that in order to utilize the SDM option, a formal agreement must be completed and signed by the supporter, the individual, and a witness or notary. See TEX. COUNCIL FOR DEVELOPMENTAL DISABILITIES, SUPPORTED DECISION-MAKING AGREEMENT (2015), <http://www.t added.texas.gov/wp-content/uploads/2015/08/Supported-Decision-Making-Agreement-Oct15.pdf> [<https://perma.cc/3WBT-9GTM>].

125. Glen, *supra* note 117, at 502. Delaware’s Supported Decision-Making Act specifically states that every adult should: “be able to live in the manner they wish”; “be able to be informed about and, to the best of their ability, participate in the management of their affairs”; “receive the most effective yet least restrictive and intrusive form of support,

of Columbia enacted similar legislation.¹²⁶ As of 2017, at least five other states have considered enacting similar SDM statutes.¹²⁷

In some situations, an individual with an appointed guardian has a positive change in his or her need for a guardian. This is where guardianship restoration laws come into play. However, an individual who wishes to reverse a guardianship, after regaining his or her capacity, is fighting an uphill battle.¹²⁸ The American Bar Association (ABA) Commission on Law and Aging performed a pioneering study from 2013 to 2014 that intended to gain a better understanding of adult guardianship restoration laws statuses.¹²⁹ The study looked at case law, statutes, and different stakeholder experiences.¹³⁰

assistance, or protection when they are unable to care for themselves”; and have their “values, beliefs, wishes, cultural norms, and traditions” respected when managing the adult’s affairs. DEL. CODE ANN. tit. 16, § 9402A(b) (West 2017).

126. An SDM agreement “means an agreement between a supported person and a supporter entered into pursuant to this chapter.” D.C. CODE § 7-2131 (2019). Under D.C. guardianship laws, SDM refers to:

[A] process of supporting and accommodating an adult with a disability in order to: [a]ssist the adult with a disability in understanding the options, responsibilities, and consequences of life decisions; and . . . [e]nable the adult with a disability to make life decisions, without impeding the self-determination of the adult with a disability or making decisions for the adult with a disability.

Id.

127. New York piloted a project in 2016, called Supported Decision-Making New York (SDMNY), that laid a viable supported decision-making model foundation. Glen, *supra* note 117, at 503. One year after the project started, it found that special education and third-party acceptance were areas that need advancing. *Id.* at 518. As this project continues, those involved in the project note that, “the greatest lesson has been the ways in which facilitating SDM has increased the confidence, capacity, and self-determination” of the individuals with disabilities. *Id.* at 519; *see also Massachusetts SDM Pilot*, CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/current-sdm-pilot/> [<https://perma.cc/MH93-38ZK>] (explaining a second SDM pilot project to help expand SDM model use across Massachusetts).

128. Cassidy, *supra* note 12, at 115–17. Restoration laws create the following struggles for individuals when they seek to regain their independence back: lack of awareness regarding these individuals’ restoration rights, negative societal views towards restoration, the individual seeking restoration has the burden of proving they no longer need a guardianship, courts rely too much on psychological assessments that only provide a snapshot of that person’s capacity to determine the individual’s capacity, and original proceeding capacity assessments are often insufficient. *Id.*; *see also supra* note 12.

129. *See* Cassidy, *supra* note 12, at 84–122.

130. *Id.* at 86. The study provided an online question to judges and found that “petitions for restoration are uncommon, but do occur with moderate success. Of the 152 judicial respondents who completed the online questionnaire, 73% have presided over petitions for restoration with 24% presiding over more than 10 petitions.” *Id.* at 83. As for the attorney questionnaire that was part of the study, “[47%] of the 412 attorney questionnaire respondents have filed at least one petition for restoration within the last 10 years. Of those, 96% reported having success with at least some of the petitions.” *Id.* Additionally, “[o]f the collected cases that indicate the disability population of the protected individual, 51% of cases were to restore an older individual.” *Id.*

The United States has yet to fully acknowledge guardianships as an area of law that needs improvement, setting the United States far behind many other countries that have already implemented effective guardianship law reforms. Roughly thirty-eight states reference “less restrictive alternatives,” either through case law or statute, and only two states have actually enacted statutes that legally recognize SDM.¹³¹ Not only has the United States still not ratified the CRPD,¹³² but advocates have made conscious efforts to raise awareness on this issue and force the United States government to make a shift in its legal system to further promote an individual’s rights.¹³³

D. Reaching the Age of Majority

Although there is a substantial push to improve the laws impacting individuals with disabilities, the federal government has a history of slowly passing statutes to establish support for this population.¹³⁴ IDEA enactment was a crucial stride within the disability community because it provided the groundwork requiring that every individual with a disability has access to free, appropriate public education.¹³⁵ While a child is attending a special

131. See generally HALDAN BLECHER, LEAST RESTRICTIVE ALTERNATIVE REFERENCES IN STATE GUARDIANSHIP STATUTES (2018), https://www.americanbar.org/content/dam/aba/administrative/law_aging/06-23-2018-lra-chart-final.authcheckdam.pdf [<https://perma.cc/3EXG-6FGU>]. But see H.B. 101, 61st Leg., 2016 Gen. Sess. (Utah 2016) (taking a step backwards by providing that counsel is not required for the potential ward in some situations).

132. See *infra* notes 288–91 and accompanying text.

133. The ABA wrote a resolution that “urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that supported decision-making be identified and fully considered as a less restrictive alternative before guardianship is imposed; and urges courts to consider supported decision-making as a less restrictive alternative to guardianship.” A.B.A., COMMISSION ON DISABILITY RIGHTS SECTION OF CIVIL RIGHTS AND SOCIAL JUSTICE SECTION OF REAL PROPERTY, TRUST AND ESTATE LAW COMMISSION ON LAW AND AGING: REPORT TO THE HOUSE OF DELEGATES (2017), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf [<https://perma.cc/C3ET-28AN>]; see also NAT’L CTR. ON LAW & ELDER RIGHTS, ANNUAL UPDATE ON GUARDIANSHIP LAWS AND PRACTICES 2, <https://ncler.acl.gov/pdf/Annual%20Update%20on%20Guardianship%20Laws%20and%20Practices.pdf> [<https://perma.cc/N4U5-3RNV>] (providing a summary of state guardianship legislative changes in 2017).

134. See *supra* notes 18, 19, 21 and accompanying text.

135. Individuals with Disabilities Education Act of 2004, Pub. L. No. 108-446, § 614 (d)(1)(A), 118 Stat. 2647 (codified as amended at 20 U.S.C. § 1400(c) (2012)). In 1975, the Education for Handicapped Children Act of 1975 was enacted and became “the first legislation to protect the educational rights of students with disabilities.” *What Is Special Education?*, SPECIAL EDUC. GUIDE, <https://www.specialeducationguide.com/pre-k-12/what-is-special-education/> [<https://perma.cc/5DAT-MNPS>]. This Act was later named the IDEA. *Id.*;

education program,¹³⁶ the minor child and his or her family will meet to design an individualized education program (IEP),¹³⁷ which is a “written statement for each child with a disability that is developed, reviewed, and revised in accordance” with the IDEA.¹³⁸ Once a child reaches the age of majority, notice will be given to both the individual and his or her parents that all rights the parents previously held will be transferred to the student.¹³⁹ Additionally, parents are no longer required to attend IEP meetings, unless the child requests the parents to attend.¹⁴⁰ However, the IDEA provides an exception to this rule:

If, under State law, a child with a disability who has reached the age of majority under State law, who has not been determined to be incompetent, but who is determined not to have the ability to provide informed consent with respect to the educational program of the child, the State shall establish procedures for appointing the parent of the child, or . . . another appropriate individual, to represent the educational interests of the child.¹⁴¹

In most states, the local educational agency is required to notify the student, at least one year before the student turns eighteen, of the rights that will be transferred to him or her, and the IEP will include a statement that the individual has been informed of such rights.¹⁴² While most state

see also U.S. OFFICE OF SPECIAL EDUC. PROGRAMS, HISTORY: TWENTY-FIVE YEARS OF PROGRESS IN EDUCATING CHILDREN WITH DISABILITIES THROUGH IDEA, <https://www2.ed.gov/policy/speced/leg/idea/history.pdf> [<https://perma.cc/VFD6-3W8P>] (“Congress enacted the *Education for All Handicapped Children Act* (Public Law 94-142), in 1975, to support states and localities in protecting the rights of, meeting the individuals needs of, and improving the results for . . . youth with disabilities and their families.”).

136. These programs that provide education for individuals with disabilities are typically called special education programs. *See Teaching Special Education*, TEACH, <https://teach.com/become/what-can-i-teach/special-education/> [<https://perma.cc/B29C-54DJ>] (explaining special education programs as those “designed for those students who are mentally, physically, socially[,] and/or emotionally delayed”).

137. For an overview of what an IEP is, what is contained in an IEP, and the purposes of an IEP, see *Contents of the IEP*, CTR. FOR PARENT INFO. & RESOURCES (Nov. 9, 2017), <https://www.parentcenterhub.org/iepcontents/> [<https://perma.cc/Z6MJ-L48A>].

138. 20 U.S.C. § 1414(d)(1)(A)(i) (2012).

139. *Id.* § 1415(m)(1).

140. *See* PACER’S NAT’L PARENT CTR. ON TRANSITION & EMP’T, PREPARE YOUR CHILD FOR AGE OF MAJORITY AND TRANSFER OF RIGHTS 1 (2012), <https://www.pacer.org/transition/resource-library/publications/NPC-19.pdf> [<https://perma.cc/BQ4S-UUTK>].

141. 20 U.S.C. § 1415(m)(2) (2012); *see* 34 C.F.R. § 300.517(b) (1999) (providing regulations that implement the IDEA).

142. *See, e.g.*, CAL. EDUC. CODE § 56043(g)(3) (Deering 2019) (“Beginning not later than one year before the pupil reaches 18 years of age, the individualized education program shall contain a statement that the pupil has been informed of the pupil’s rights under this part, if any, that will transfer to the pupil upon reaching 18 years of age”); N.J. ADMIN. CODE § 6A:14-3.7(e)(14) (2019) (“Beginning at least three years before the student reaches age 18, a statement that the student and the parent have been informed of the

provisions require that safeguard notifications are sent to both the individual and his or her parents, this notification is not required in some states when the individual is deemed incompetent under state law.¹⁴³

While the United States has enacted legislation, such as the ADA and IDEA,¹⁴⁴ to protect individuals with disabilities and ensure they have equal status under American law, the United States has taken the desire to protect this population to an extreme level.¹⁴⁵ This seemingly harmless protection-based focus comes at the expense of these individuals' rights.

III. THE PROBLEM WITH GUARDIANSHIPS: STRIPPING INDIVIDUALS OF THEIR FUNDAMENTAL RIGHTS

The initial reason behind creating guardianship laws was the states' view that it had a responsibility to safeguard the property and personal interests of an individual with impaired capacity.¹⁴⁶ Hence, the main issue with a guardianship is not the guardianship itself because this option often effectively protects an individual; the problem is that most guardianships

[educational] rights under this chapter that will transfer to the student on reaching the age of majority.”).

143. See, e.g., CAL. EDUC. CODE § 56041.5 (Deering 2019) (“When an individual with exceptional needs reaches the age of 18, with the exception of an individual who has been determined to be incompetent under state law, the local educational agency shall provide any notice of procedural safeguards required by this part to both the individual and the parents of the individual. All other rights accorded to a parent under this part shall transfer to the individual with exceptional needs. The local educational agency shall notify the individual and the parent of the transfer of rights.”); MD. CODE ANN., EDUC. § 8-412.1(a) (West 2019) (“When a child with a disability reaches the age of 18 years, all rights accorded to parents under the federal Individuals with Disabilities Education Act shall transfer to the child if the child has not been adjudged incompetent under State law”).

144. Cf. CHRIS KUCZYNSKI, RECENT CASES UNDER THE AMERICANS WITH DISABILITIES ACT AND THE REHABILITATION ACT, <https://www.nhsaa.org/site/handlers/filedownload.ashx?moduleinstanceid=172&dataid=457&FileName=Primex%20Recent%20ADA%20caselaw%20-%20nationwide%202016%20handout.pdf> [<https://perma.cc/3MPE-AUDS>] (providing summaries of recent cases regarding the ADA's definitions, claims under the different ADA prongs, and other ADA related cases).

145. See *supra* note 46.

146. Shih-Ning Then, *Evolution and Innovation in Guardianship Laws: Assisted Decision-Making*, 35 SYDNEY L. REV. 133, 136 (2013). For far too long, even tracing back to Ancient Rome, “society treated people with intellectual disabilities as if they were unable to take care of or make decisions for themselves.” SUZZANE M. FRANCISCO & JONATHAN G. MARTINIS, SUPPORTED DECISION-MAKING TEAMS: SETTING THE WHEELS IN MOTION (2017), <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf> [<https://perma.cc/9JV4-NX42>].

are too broad or unnecessary.¹⁴⁷ A guardianship should only be preserved in situations where the individual's protection is the main priority and it is the individual's least restrictive option.¹⁴⁸

Although the main purpose of implementing a guardianship is to protect the individual's personal interests, state legal systems have a tendency to excessively grant guardianships at the expense of the individual's rights.¹⁴⁹ Specifically, the current binary legal system in the United States, which recognizes only two support options—a guardianship or nothing—costs individuals with disabilities their ADA, constitutional, and human rights. Moreover, a lack of a standardized system to determine capacity and the failure to adequately inform an individual's family once the child turns eighteen only exacerbates these violations. Therefore, there is a need to shift away from a binary solution legal system that tends to diminish these individuals' autonomy and rights.

A. How Guardianships May Violate the ADA

As in Jenny's case, the parents or childhood guardians of an individual with disabilities will often seek appointment as his or her guardians.¹⁵⁰

147. Rynders, *supra* note 64, at 27; see also Jamie L. Leary, *A Review of Two Recently Reformed Guardianship Statutes: Balancing the Need to Protect Individuals Who Cannot Protect Themselves Against the Need to Guard Individual Autonomy*, 5 VA. J. SOC. POL'Y & L. 245, 246 (1997) ("The struggle inherent in the guardianship process, then, is to achieve a balance between protecting the [disabled] person and preserving [his or] her autonomy.").

148. Rynders, *supra* note 64, at 27. "Least restrictive alternative" describes: [A] course of action or an environment that allows the ward to live, learn, and work with minimum restrictions on him/her. . . . [The] ward is provided a kind of setting which places minimal limits on the ward's rights and personal freedoms so as to enable the ward to meet his/her personal needs.

Least Restrictive Alternative (Guardianship) Law and Legal Definition, U.S. LEGAL, <https://definitions.uslegal.com/least-restrictive-alternative-guardianship/> [<https://perma.cc/J6DR-K49M>].

149. Yet another issue arises with the insistence upon granting guardianships: inadequate state laws that do not provide for a straightforward guardianship termination process. A majority of states provide specific restoration of rights laws to create a guardianship termination option. See, e.g., HAW. REV. STAT. § 560:5-318(b) (2019) ("On petition of a ward, a guardian, or another person interested in the ward's welfare, the court may terminate a guardianship if the ward no longer needs the assistance or protection of a guardian."). However, the issue is that when a guardianship is granted, it is seemingly difficult to get the guardianship reversed to restore the individual's rights. See *supra* notes 12–13 and accompanying text.

150. *The Justice for Jenny Trial*, *supra* note 2; see also FRANCISCO & MARTINIS, *supra* note 146 ("Today, it is still expected that someone else . . . will be appointed to make decisions for [these individuals]. In fact, that is often the advice parents get when their child with disabilities turn 18: become their guardian/conservator as soon as possible."); Ryan King—Updated, NAT'L RESOURCE CTR. FOR SUPPORTED DECISION-MAKING, <http://>

More often than not, a parent will seek guardianship once the individual turns eighteen and the parent no longer has the ability to make decisions for his or her child.¹⁵¹ As demonstrated in Jenny's situation, the guardian has the power to determine where the individual lives and with whom the individual associates.¹⁵² This creates major ADA violations in situations where the individual is inappropriately placed into an institution,¹⁵³ perpetually isolated, and not fully integrated within society.¹⁵⁴

supporteddecisionmaking.org/impact-stories/ryan-king-updated [https://perma.cc/2WXU-A49V] (“When Ryan King turned 18, his parents were told they HAD to become his guardians. Ryan certainly didn’t want a guardian and they didn’t think he needed one.”). For examples of common rationales parents often have for the necessity of a guardian, see Dorothy Squatrito Millar, *Guardianship Alternatives: Their Use Affirms Self-Determination of Individuals with Intellectual Disabilities*, 48 EDUC. & TRAINING IN AUTISM & DEVELOPMENTAL DISABILITIES 291, 298 (2013).

151. See *supra* note 139 and accompanying text. There are many resources available for parents that explicitly provide the process of how to seek a guardianship in order to protect the child. See, e.g., Melissa Stuart, *When Your Child Turns 18: A Guide to Special Needs Guardianship*, FRIENDSHIP CIRCLE (Oct. 16, 2012), <https://www.friendshipcircle.org/blog/2012/10/16/when-your-child-turns-18-a-guide-to-special-needs-guardianship/> [https://perma.cc/NV45-VDD3]. But see Anna Stewart, *When Your Kid with Significant Needs Turns 18*, ESME, <https://esme.com/resources/special-needs/when-your-kid-with-significant-needs-turns-18> [https://perma.cc/67JA-REP4] (providing information on general services that should be acquired before and after the individual turns eighteen). These documents likely stem from parents’ fear that they will no longer be able to protect their child once the child turns eighteen.

152. See *supra* note 5 and accompanying text; see also *infra* notes 191, 192, 198 and accompanying text.

153. See C. Joseph Boatwright II, *Solving the Problem of Criminalizing the Mentally Ill: The Miami Model*, 56 AM. CRIM. L. REV. 135, 143 (2019) (explaining how institutionalization, and later the deinstitutionalization movement, added to the “criminalization of mental illness”). Institutionalization that is not warranted is not the only problem with institutionalization; the issue is that institutions are often not able to provide adequate care and conditions for individuals with disabilities. See, e.g., *Wyatt v. Aderholt*, 503 F.2d 1305, 1311–19 (5th Cir. 1974) (holding that this particular mental institution’s staff and the hospital’s patient records were inadequate and the admitted patients had a constitutional right to treatment); *Wyatt v. Stickney*, 334 F. Supp. 1341, 1343–34 (M.D. Ala. 1971) (finding that a state mental hospital’s treatment program for these institutionalized patients were inadequate and did not provide for an improved physical environment). But see *Williams v. Wasserman*, 164 F. Supp. 2d 591, 638 (D. Md. 2001) (holding that confining these plaintiffs with traumatic brain injuries in a more restrictive institution when doing so was recommended by a physician did not violate the ADA).

154. See *supra* Section II.A.

1. *Inappropriate Institutionalization as a Major Guardianship Consequence*

In *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court determined that inappropriate institutionalization is discrimination based on disability.¹⁵⁵ In Jenny’s case, she had been living on her own prior to the court’s guardianship order.¹⁵⁶ Jenny’s guardians placed her in an isolated living center, contrary to her desire, with all of her electronic devices taken away, and she was unable to exit the building without first receiving permission.¹⁵⁷ Any person without a disability put in Jenny’s isolated situation “would either be able to lodge a charge of kidnapping, or be a prisoner convicted of a crime”; however, “because [Jenny] is a person with a disability—and only because of that—is it completely legal, even though she has done nothing wrong.”¹⁵⁸ Thus, the court’s original guardianship order, which led to inappropriately placing Jenny in a restricted home, caused a domino effect that eventually instigated the violation of Jenny’s ADA rights.¹⁵⁹

Similar to *Olmstead*, where the court concluded that unjustified isolation in an institution was discrimination based on disability, placing Jenny in the group home that restricted her access to the outside world was a form of confinement violating her ADA rights.¹⁶⁰ As the court in *Olmstead*

155. 527 U.S. 581, 597 (1999). The ADA, and regulations that followed, do not condone terminating institutional settings for an individual who is unable to deal with or benefit from a community setting. *Id.* at 602. The ADA further provides that “‘qualified individuals with a disability’ may not ‘be subjected to discrimination’” and “‘qualified individuals’ is defined under the ADA as ‘persons with disabilities who, ‘with or without reasonable modifications to rules, policies, or practices, meet the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.’” *Id.* at 602 (quoting Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12131(2), 12132 (2012)).

156. *The Justice for Jenny Trial*, *supra* note 2.

157. Susan Mizner, *Disability Is No Excuse to Deprive One of Civil Liberties*, ACLU (Aug. 5, 2013, 3:15 PM), <https://www.aclu.org/blog/disability-no-excuse-deprive-one-civil-liberties> [<https://perma.cc/G6NJ-G8HH>].

158. *Id.* Jenny herself even noted, “I felt like a prisoner but I didn’t do anything wrong. I was told I had rights at the group home. But that wasn’t true. . . . It was like I didn’t matter. Like I didn’t exist.” *Jenny’s Letter—Text Version*, *supra* note 1.

159. The Virginia trial court appointed a guardianship in a situation where Jenny’s least restrictive option was not a guardianship, as later determined during her trial proceeding. *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 2, 7 (Va. Cir. Ct. Aug. 2, 2013); *The Justice for Jenny Trial*, *supra* note 2. Furthermore, Jenny’s appointed guardians placed her into a group home, which put Jenny in a situation that restricted her access to the world she knew prior to the guardianship—where she could live on her own and choose with whom she wished to engage. See *The Justice for Jenny Trial*, *supra* note 2.

160. *Olmstead*, 527 U.S. at 597. The right to appropriate treatment services that must be provided to the individual in the least restrictive environment is not a new concept. This concept was recognized as a fundamental right to this population even before the ADA was

considered, the ultimate impact of institutionalization is the individual's segregation that flows from confinement, which fosters degrading stereotypes and a deprivation of community life engagement opportunities.¹⁶¹ Jenny was fortunate enough to regain her freedom and ADA rights, but too many other individuals are unable to reverse their guardianships and are trapped under these rights-capturing circumstances.¹⁶²

2. Guardianships Cause Perpetual Isolation

Even though an individual under a guardianship might not necessarily be physically confined and segregated within an institution, a guardianship creates a legal construct similar to the actual isolation an individual might experience while institutionalized.¹⁶³ Guardianships consequently restrict an individual's ability to make his or her own decisions, thereby eliminating the individual's opportunities to interact with others.¹⁶⁴ As in *Olmstead*, many individuals who are placed in confined living situations would benefit from a living and care situation that is less restrictive.¹⁶⁵ Thus, the *Olmstead* court's integration mandate is similarly triggered when a guardianship "fail[s] to provide assistance with decision[-]making in the least restrictive 'setting.'"¹⁶⁶

enacted and *Olmstead* was heard. See ISSAM B. AMARY, THE RIGHTS OF THE MENTALLY RETARDED-DEVELOPMENTALLY DISABLED TO TREATMENT AND EDUCATION 24 (1980).

161. *Olmstead*, 527 U.S. at 600; see also Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 194 (2010).

162. See *supra* note 11 and accompanying text.

163. Salzman, *supra* note 161, at 194.

164. *Id.* The restricted and isolated nature of an overly broad or unnecessary guardianship blatantly violates the Supreme Court's holding in *Olmstead*. The Supreme Court's holding in "*Olmstead* represent[ed] a critical first step toward achieving the goal of community integration for individuals with disabilities, a goal envisioned by the drafters of the ADA." Joanne Karger, Note, "*Don't Tread on the ADA:*" *Olmstead v. L.C. ex. rel. Zimring and the Future of Community Integration for Individuals with Mental Disabilities*, 40 B.C. L. REV. 1221, 1249 (1999). Even though the Court's ruling was a significant step towards recognizing community segregation, these individuals are still fighting to uphold their *Olmstead* and ADA rights. See *supra* notes 45, 48–52 and accompanying text.

165. Salzman, *supra* note 161, at 194. For how public entities should deal with budget cuts while simultaneously ensuring that an individual is not inappropriately institutionalized, see U.S. DEP'T OF JUSTICE, *supra* note 32.

166. Salzman, *supra* note 161, at 194. The integration mandate requires public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d) (2019). The Department of Justice noted that the "most integrated setting" is defined under ADA and *Olmstead* as "a setting that enables individuals with disabilities to interact with non-disabled

While the Court in *Olmstead* does not use this exact language or completely extend its ruling to say that failing to use the least restrictive option violates the integration mandate, there is a substantial policy argument to do so.¹⁶⁷

Yet again, the tension between protection and autonomy surfaces.¹⁶⁸ Assuming society is committed to ensuring all individuals with a disability have their basic needs met at a minimum, inappropriately placing individuals in a restrictive decision-making setting results in a failure to maximize their autonomy.¹⁶⁹ Furthermore, society often comes to reflect standards promulgated by the legal system, specifically in regard to individual capacity and the proficiency to provide assistance to those with limited decision-making capacity.¹⁷⁰ As such, society will ideally feel obligated to completely integrate these individuals into the mainstream community.¹⁷¹

persons to the fullest extent possible.” *Id.* pt. 35 app. B. Conversely, segregated settings have institutional-like qualities, which include primarily providing interactive congregations for individuals with disabilities, controlled daily activities that often limit the freedom to engage in community activities, and settings that offer regular daily activities with only other individuals with disabilities. U.S. DEP’T OF JUSTICE, *supra* note 32.

167. Salzman, *supra* note 161, at 195. For discussion of why exacerbation of disabilities is also a form of discrimination the ADA must be extended to cover as a new discrimination type, see generally Derek Warden, *A Worsened Discrimination: How Exacerbation of Disabilities Constitutes Discrimination by Reason of Disability Under Title II of the ADA and § 504 of the Rehabilitation Act*, 46 S.U. L. Rev. 14 (2018).

168. See *supra* text accompanying note 77.

169. Salzman, *supra* note 161, at 195. Since the Supreme Court heard *Olmstead*, other state and lower federal courts have generally applied the *Olmstead* ruling to cover situations where an individual, who is living within the community, is at risk for becoming institutionalized. *From Olmstead to the Present*, OLMSTEAD RTS., <https://www.olmsteadrights.org/about-olmstead/#From%20Olmstead%20to%20the%20Present> [http://perma.cc/G7Y2-94VY].

170. Society’s view of this population has been continuously important in moving towards fully integrating these individuals. Since its formation in 1950, the Arc, an organization working to improve the lives of individuals with disabilities across the United States, has been “committed to altering perceptions of children with intellectual and developmental disabilities and to educate parents and others regarding the potential of people with intellectual and developmental disabilities.” *History of the Arc*, ARC, <https://www.thearc.org/who-we-are/history> [https://perma.cc/EK78-9TDA].

171. Salzman, *supra* note 161, at 195. Currently, students with disabilities are not always fully accepted by their peers, which negatively impacts these individual’s psyche and development. See Daniel Schaefer, *Any IDEA?: Examining the Barriers Faced by the Disabled in the American Education System*, MEDIUM (Dec. 6, 2016), <https://medium.com/age-of-awareness/any-idea-examining-the-barriers-faced-by-the-disabled-in-the-american-education-system-f1d6f81d65cb> [https://perma.cc/T34Z-FAA3] (“On top of the physical barriers of inaccessible buildings and lack of resources, the disabled face a general lack of acceptance from their peers and of understanding from their teachers and administrators. Disabled students face bullying more frequently than their non-disabled counterparts, and often lack the resources they need to handle such situations . . .”).

3. A Failure to Fully Integrate

Courts grant a guardianship because, while it is not necessarily the best option, no help or support appears worse.¹⁷² This binary legal choice does not pass the “integration regulation” applied by the Supreme Court in *Olmstead* and issued by the Attorney General.¹⁷³

The integration regulation under the ADA requires state and local governments to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁷⁴ Additionally, the ADA specifically prohibits state and local governments from discriminating on the basis of disability, while requiring them to make “reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability.”¹⁷⁵

The current binary legal system does not create an avenue for courts to implement an option that would place the individual in the appropriate setting, which would maximize the individual’s integration.¹⁷⁶ Additionally, the ADA requires states to make reasonable changes to practices when it is necessary to avoid discrimination.¹⁷⁷ However, a state that only legally recognizes a substituted decision-making option does not avoid discrimination when other viable alternatives better prevent unnecessary or overly broad guardianships.¹⁷⁸ Almost all states, except Texas and Delaware,¹⁷⁹ are simply not providing

172. See Julia Freeman-Woolpert, *Guardianship: Balancing Liberty and Protection*, DISABILITY RTS. CTR.-N.H. (2006), <http://www.drcnh.org/libertyprotection.html> [<https://perma.cc/2KHT-NGKL>].

173. Bagenstos, *supra* note 27, at 32 (citing Americans With Disabilities Act of 1990, 42 U.S.C. § 12134 (2012)).

174. General Prohibitions Against Discrimination, 28 C.F.R. § 35.130(d) (2019).

175. 28 C.F.R. § 35.130(b)(7) (2019); see 42 U.S.C. § 12131 (2012).

176. See Glen, *supra* note 106, at 1 (noting the opportunity “to enhance and improve the dignity, autonomy, and self-determination of persons who are routinely deprived of the[ir] right[s], most commonly through systems of substituted decision-making, like guardianships and conservatorships”).

177. See *supra* note 175 and accompanying text. *But see, e.g.*, *Williams v. Sec’y of the Exec. Office of Human Servs.*, 609 N.E.2d 447, 452 (Mass. 1993) (“[N]othing in the ADA requires that a specific proportion of housing placements provided by a public mental health service be in ‘integrated’ housing.”).

178. See *supra* text accompanying notes 174–75.

179. See *supra* Section II.C.2. Some states have altered their guardianship laws to list SDM as a least restrictive option but do not provide explicit recognition for such models unlike Texas and Delaware statutes. See, e.g., ME. REV. STAT. ANN. tit. 18-C, § 5-102(14), (32) (2018) (effective Sept. 1, 2019) (providing only a definition for SDM and listing it as

appropriate, less restrictive integration options.¹⁸⁰ Consequently, most states are in danger of causing ADA violations because these binary legal systems prevent courts from catering to each person’s support needs—further promoting discrimination based on disability.¹⁸¹

B. Guardianships Cause a Violation of Constitutional Rights

The states’ perpetuation of ADA violations results in an even more serious abuse: the encroachment on the constitutional rights of individuals with disabilities.¹⁸²

The United States Constitution Fourteenth Amendment guarantees that each state will not enforce or make a law abridging the immunities or privileges of any United States citizen.¹⁸³ Furthermore, the Fourteenth Amendment provides that each state must not deprive any United States citizen “of life, liberty, or property” without due process of law.¹⁸⁴ Under the Fourteenth Amendment, each citizen will not be deprived of equal protection of laws

a least restrictive alternative); MO. ANN. STAT. § 475.075(13)(4) (West 2019) (listing SDM agreements as a least restrictive alternative to be tried before a guardian is appointed).

180. Among all different results for individuals with disabilities, “[i]ntegration is overwhelmingly the preferred remedy in the disability area.” COLKER, *supra* note 18, at 25.

181. See Salzman, *supra* note 161, at 160 (“[B]y limiting an individual’s right to make decisions, guardianship imposes a form of segregation that is not only bad policy, but, in given circumstances, is also a violation of the integration mandate of the ADA.”).

182. See Susan G. Haines & John J. Campbell, *Defects, Due Process, and Protective Proceedings: Are Our Probate Codes Unconstitutional?*, 14 QUINNIPIAC PROB. L.J. 57, 60 (1999). For a discussion on constitutional procedures during guardianship proceedings, see A. Frank Johns, *Ten Years After: Where Is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?*, 7 ELDER L.J. 33, 59–68 (1999).

183. U.S. CONST. amend. XIV, § 1.

184. *Id.* Advocates for individuals with disabilities have continuously “pursued several avenues for establishing a right to treatment in the least restrictive environment. Courts held that there was no such right under the Due Process Clause of the Constitution because, given the voluntary nature of the care, it could not be said that the State was denying liberty.” Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits After Olmstead v. L.C.*, 24 HARV. J.L. & PUB. POL’Y 695, 707 (2001). Cases over the last few decades since the ADA’s enactment have reflected this refusal. See, e.g., *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 445–46 (1985) (declining to extend heightened protection under the due process clause to individuals with disabilities); *Pennhurst State Sch. & Hosp. v. Halderman*, 451 U.S. 1, 31–32 (1981) (refusing to find an explicit right to treatment in a least restrictive setting under the Developmental Disabilities Assistance and Bill of Rights Act).

in any state.¹⁸⁵ Additionally, the Fifteenth Amendment grants United States citizens a right to vote that must not be denied.¹⁸⁶

Although these Constitutional Amendments, among others, preserve an individual's fundamental rights as a United States citizen, state legal systems excessively rely upon guardianship models that strip individuals of these rights.¹⁸⁷ In balancing these individuals' protective needs and empowering basic rights, the scale is heavily skewed towards overprotecting the individual.¹⁸⁸ Subsequently, excessively granting guardianships violates the individual's constitutional rights because these practices bypass other viable options, deny the right to vote unnecessarily, and refuse other fundamental rights.

1. Guardianships and Viability of Less Restrictive Options

In a majority of states, there are two broad guardianship types: a plenary guardianship and a limited guardianship.¹⁸⁹ Around 90% of ordered guardianships in the United States are plenary or "full" guardianships.¹⁹⁰ Plenary guardianships, which are substituted decision-making models, comprehensively take away the individual's legal capacity and most basic rights—including the right to vote.¹⁹¹ A limited guardian "allows a partially disabled or incompetent person to delegate limited powers and authority

185. U.S. CONST. amend. XIV, § 1; *see also* David Ferleger, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763, 766 (2010) ("Equal protection forbids discrimination against [disabled] individuals unless necessitated by a compelling state interest, an interest absent in non-criminal institutionalization. On groundwork language in *Olmstead*, I suggest that the narrow class of involuntarily institutionalized individuals with intellectual disabilities is a suspect or quasi-suspect class under the Equal Protection Clause.").

186. *See* U.S. CONST. amend. XV.

187. For an example of how state guardianship proceedings deprive individuals with disabilities of their fundamental rights, *see* Hensley, *supra* note 121, at 724–58.

188. While the deinstitutionalization period in the 1970s and 1980s, and the litigation that came along with it, relied upon due process theories, there has been a shift away from constitutional theories and towards ADA antidiscrimination theories. Bagenstos, *supra* note 27, at 6.

189. Additionally, some states allow for "temporary guardians" in emergency situations. *See, e.g.*, ARK. CODE ANN. § 28-65-218 (2018) ("[I]f the court finds that there is imminent danger to the life or health of the incapacitated person or of loss, damage, or waste to the property of an incapacitated person and that this requires the immediate appointment of a guardian . . . the court may, with or without notice, appoint a temporary guardian . . . [which] shall not exceed ninety (90) days.").

190. Rynders, *supra* note 64, at 27.

191. *Id.*

to the limited guardian.”¹⁹² The National Probate Court Standards declares that a court “should always consider, and utilize, where appropriate, limited guardianships.”¹⁹³ While these standards might have initially been adequate to reduce unnecessary or overly broad guardianships, solely relying on this standard is not sufficient in a modern world that can fill in the gap between options that provide overprotection and zero protection.

There are certainly situations when a plenary guardianship is necessary, and failure to appoint a guardian would in fact impact that individual’s ability to function on a daily basis.¹⁹⁴ In such situations, a plenary guardian would protect this individual’s personal and financial interests, while supporting the individual’s constitutional rights. In some situations, an individual lacks decision-making capacity and is consequently not able to exercise some constitutional rights.¹⁹⁵ The guardian’s duty is to act on the individual’s behalf.¹⁹⁶ When an individual is unable to singly exercise his or her constitutional rights, a guardian may actually empower this individual by making constitutionally empowering decisions.¹⁹⁷

192. *Limited Guardianship*, 1 TRUST SERVICES AUDIT MANUAL SCOPE app. B (2017). These standards were developed in 1994 by the Commission on National Probate Court Standards to address the problems that resulted from a lack of judicial governance and procedural protections. Paula L. Hannaford & Thomas L. Hafemeister, *The National Probate Court Standards: The Role of the Courts in Guardianship and Conservatorship Proceedings*, 2 ELDER L.J. 147, 147 (1994).

193. NAT’L PROB. CT. STANDARDS § 3.3.10 (2013).

194. *See, e.g., In re Mark C.H.*, 906 N.Y.S.2d 419, 435 (Sur. Ct. 2010) (“In the instant case, the court finds, based on the evidence before it, that Mark is a person with developmental disabilities of such magnitude that he is in need of a guardian of the person . . .”).

195. The decision-making ability minimum threshold can be defined as “act[ing] in a way that at least one other person who has personal knowledge of an individual can reasonably ascribe to [that individual]’s actions”: personal intention or will; memory; coherence of the person’s identity through time; and communicative abilities to that effect. MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 66 (2010), <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> [<https://perma.cc/Q3AZ-BWU6>]. As such, these abilities should guide an individual’s competency for different decision-making processes. *Id.*

196. *See, e.g., MINN. STAT. § 524.5-313* (2019) (“The duties and powers of a guardian or those which the court may grant to a guardian include, but are not limited to: . . . the duty and power to exercise supervisory authority over the ward in a manner which limits civil rights and restricts personal freedom only to the extent necessary to provide needed care and services.”).

197. However, even though a guardianship may be the least restrictive option that maximizes the individual’s constitutional rights, a court should generally err on the side of appointing a limited guardian rather than jumping to a plenary guardianship. *Limited Guardianship*, *supra* note 192, at app. B.

2. *How Constitutional Rights Are Impacted by a Failure to Recognize Least Restrictive Options*

Even though a guardianship may be the least restrictive option in some situations, constitutional issues arise when a guardianship is unnecessary or overly broad. According to a U.S. House of Representatives Subcommittee report in 1987:

The typical ward has fewer rights than the typical convicted felon By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen.¹⁹⁸

The consequences of appointing a guardian are extreme, as it can completely purge the ward of his or her rights.¹⁹⁹ Thus, a guardianship should *only* be ordered when it is in the individual's best interest to have someone other than him or herself to make daily and life decisions—when it is the least restrictive option.²⁰⁰

One major hindrance with the current legal system is that state courts often order a plenary guardianship when a limited guardianship would be adequate.²⁰¹ The result of such actions is an overly broad guardianship that takes away more of the individual's rights than necessary.²⁰² While the court

198. *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace: Hearing Before the H. Select Comm. on Aging*, 100th Cong. 1, 4 (1987) (statement of Claude Pepper, Chairman, H. Select Comm. on Aging).

199. *See supra* notes 190–91 and accompanying text.

200. In the event that a guardianship is necessary, this guardian “should only have the powers that the person . . . is not able to exercise.” Megan S. Wright et al., *Severe Brain Injury, Disability, and the Law: Achieving Justice for a Marginalized Population*, 45 FLA. ST. U. L. REV. 313, 364 (2018).

201. *See supra* note 197 and accompanying text.

202. The tendency to appoint either form of a guardian creates situations where guardianships are unnecessarily granted and a less restrictive option, which would not take away the individual's constitutional rights, would have been appropriate. A 2011 study found that there were roughly 1.5 million, maybe even somewhere between 1 million and 3 million, active guardianships at that time in the United States. Michele J. Feinstein & David K. Webber, *Voting Under Guardianship: Individual Rights Require Individual Review*, 10 NAT'L ACAD. ELDER L. ATTORNEYS J. 125, 143 (2014) (citing Brenda K. Uekert & Richard Van Duizend, *Adult Guardianships: A “Best Guess” National Estimate and the Momentum for Reform*, in *FUTURE TRENDS IN STATE COURTS 2011*, at 107, 109 (Carol R. Flango et al. eds., 2011)). This number has likely increased as well due to an increasing use of guardianships for elderly individuals. These statistics briefly show how state court systems have a general tendency to appoint a guardian during guardianship proceedings.

may determine the individual is unable to make all decisions due to his or her incompetence, there is a high likelihood the individual has the capacity to make *some* decisions, which would mean the individual has the capability to exercise several constitutional rights.

a. The Effect on Constitutional Voting Rights

During a guardianship proceeding, individuals with disabilities are frequently stripped of their constitutional right to vote without any consideration as to whether the individual has the capacity to exercise this right.²⁰³ The issue here is that a guardianship order or competency determination “has nothing to do with someone’s ability to vote.”²⁰⁴ Just because a person cannot do one “thing,” does not mean the person cannot do another.²⁰⁵ In a democratic society that heavily values the right to vote, it is inconceivable that an individual—who is fully capable to vote—would be denied this right solely because he or she was categorically restricted when deemed “incapacitated.”²⁰⁶ This result is discrimination based on

203. Henry G. Watkins, *The Right to Vote of Persons Under Guardianship—Limited or Otherwise*, 44 ARIZ. ATT’Y MAG., Nov. 2007, at 34, 34. In twenty-five states, an individual placed under a guardianship retains the right to vote, unless the court expressly limits this right. *Guardianship, Mental Incapacity and the Right to Vote*, SPECIAL NEEDS ANSWERS, <https://specialneedsanswers.com/guardianship-mental-incapacity-and-the-right-to-vote-16317> [<https://perma.cc/3Y7Y-MJYA>]. Eleven other states’ laws do not have any disability-related restrictions for an individual’s right to vote. *Id.* Nine states, however, completely ban an individual’s right to vote when the individual is placed under a guardianship. *Id.* California recently passed a law that allows the individual to simply *say* that he or she would like to retain his or her right to vote during a guardianship proceeding, but this new law does not make it any easier for an individual to restore his or her right to vote when this right was previously taken away with the ordered guardianship. See S.B. 589, 2015–2016 Leg., Reg. Sess. (Cal. 2015); Disability Rights Cal. & ACLU of Cal., *YOUR VOTING RIGHTS UNDER CONSERVATORSHIP (SB 589)* (2016), <https://www.disabilityrightscal.org/system/files?file=file-attachments/559001.pdf> [<https://perma.cc/YF7T-XREY>]; see also Caroline Modarressy-Tehrani, *One Disabled Man’s Fight To Restore His Right To Vote*, VICE NEWS (Oct. 29, 2016, 11:09 PM), https://news.vice.com/en_us/article/8xv4pz/disability-activist-voting-rights [<https://perma.cc/D3E9-V8TL>].

204. Pam Fessler, *Disabled and Fighting for the Right To Vote*, NPR (Sept. 4, 2016, 6:00 AM), <https://www.npr.org/2016/09/04/492430780/disabled-and-fighting-for-the-right-to-vote> [<https://perma.cc/8NBK-SDUW>].

205. *Id.*

206. Feinstein & Webber, *supra* note 202, at 126; see Voting Rights Act of 1965, Pub. L. No. 89-110, 79 Stat. 437 (1965) (codified as amended at 52 U.S.C. § 10101 (2012)); see also *Shelby County v. Holder*, 570 U.S. 529, 530 (2013) (finding that section 4(b) of the Voting Rights Act of 1965 was unconstitutional as the forty-year-old statute was no longer necessary); *Arizona v. Inter Tribal Council of Ariz., Inc.*, 570 U.S. 1, 15 (2013) (holding that Arizona’s voter registration requirements, which required each voter to provide specific documentary citizenship proof, was unconstitutional); *Leser v. Garnett*, 258 U.S. 130, 130 (1922) (ruling that the Nineteenth Amendment was constitutionally established).

disability.²⁰⁷ Thus, these individuals will continue to face improper marginalization as binary legal systems continue to thrive.²⁰⁸

b. Infringement upon Other Constitutional Rights

Voting rights are just one example of how guardianship violates an individual's constitutional rights.²⁰⁹ A plenary guardianship strips an individual of his or her right to: property, marry, choose whom to live with, choose where to live, and decide whether to have medical treatment.²¹⁰ The Due Process Clause requires the court to weigh each interest during the guardianship proceeding—most notably the individual's interests, the risk of unnecessarily depriving the individual of these interests, and the state's financial and efficiency interests.²¹¹

207. Furthermore, a state's constitutional provision or enacted statutes that restricts an individual's right to vote due to his or her mental capacity will likely be deemed invalid because it violates the Equal Protection Clause under the United States Constitution. Feinstein & Webber, *supra* note 202, at 202.

208. However, these laws would still need to protect “the integrity of elections by excluding those incapable of understanding the nature of voting or participating meaningfully in the electoral process.” *Id.* at 126. States have enacted various statutory requirements that the individual must meet in order to provide the individual with the ability to exercise his or her right to vote, while protecting the election process. *See, e.g.*, Cal. S.B. 589 (“A person is presumed competent to vote regardless of his or her conservatorship status. A person shall be deemed mentally incompetent, and therefore disqualified from voting, if, during the course of any of the proceedings set forth below, the court finds by clear and convincing evidence that the person cannot communicate, with or without reasonable accommodations, a desire to participate in the voting process”); *see also* Feinstein & Webber, *supra* note 202, at 145–48 (providing a state-by-state breakdown of whether the state allows for individualized inquiry for incapacity and guardianship and whether the individual's right to vote is automatically revoked).

209. Courts have also ruled on whether specific state laws or ordinances are invalid because the law was unconstitutional and, thus, invalid as a result of the law discriminating against individuals with disabilities. *See, e.g.*, *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 446, 448 (1985) (finding that a Texas ordinance requiring a corporation to obtain a permit that allowed the corporation to build a group home for individuals with disabilities was subject to the rational basis standard and the ordinance was invalid because there was no rational basis to believe that the group home would create a threat to the city's legitimate interests).

210. Hensley, *supra* note 121, at 727.

211. *Id.* at 728–29. This list is by no means inclusive of all rights stripped from an individual when he or she is placed under a guardianship.

Under the Fourteenth Amendment,²¹² the individual has a right to counsel, at a minimum.²¹³ The problem with counsel during guardianship proceedings develops when the individual's parents hire the counsel, so the parents are essentially the "client."²¹⁴ This problem is further aggravated because most state guardianship laws do not promote a clear role for the attorney in a guardianship proceeding.²¹⁵ As a result, the attorney may not actually be a zealous advocate for the individual's rights and interests.²¹⁶ Likewise, the current binary legal system prevents the representing attorney from advocating for the individual's least restrictive option.²¹⁷

212. U.S. CONST. amend. XIV.

213. See, e.g., Mark D. Andrews, Note, *The Elderly in Guardianship: A Crisis of Constitutional Proportions*, 5 ELDER L.J. 75, 90 (1997) ("In Illinois, every alleged incompetent has a statutory guarantee of representation by counsel."); Winsor C. Schmidt, *Guardianship for Vulnerable Adults in North Dakota: Recommendations Regarding Unmet Needs, Statutory Efficacy, and Cost Effectiveness*, 89 N.D.L. REV. 77, 110 (2013) ("Procedural due process safeguards in guardianship are meaningless without counsel to exercise the safeguards. . . . '[O]ver twenty-five states require the appointment of counsel, generally making counsel available without charge to indigent respondents." (quoting PAMELA B. TEASTER ET AL., PUBLIC GUARDIANSHIP: IN THE BEST INTERESTS OF INCAPACITATED PEOPLE? 20 (2010))).

214. These attorney-client relationships also get dicey because the attorney needs to be a zealous advocate for the individual's needs, and not the needs that a third party has influenced the individual to express. Raymond C. O'Brien, *Attorney Responsibility and Client Incapacity*, 30 J. CONTEMP. HEALTH L. & POL'Y 59, 73 (2013); see also MODEL RULES OF PROFESSIONAL CONDUCT r. 1.14 (AM. BAR ASS'N 2018) ("When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of . . . mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client. . . . Information relating to the representation of a client with diminished capacity is protected by Rule 1.6 [relating to client confidentiality]."). The attorney "must distinguish between a lack of capacity for execution of legal documents and when a client is being unduly influenced by a third party." O'Brien, *supra*, at 72.

215. See R. MARK DAVIS, 4 WARREN'S HEATON ON SURROGATE'S COURT PRACTICE § 50.02 (2019) ("Unlike with a court evaluator, the statutes do not set out the duties of the counsel for the alleged incapacitated person.").

216. Phoebe Ball, *Guardianships, Civil Liberties, and the Role of Lawyers*, 33 GPSOLO, July–Aug. 2016, at 42, 45. In some jurisdictions, the lawyer takes on a role that is similar to the role of a guardian ad litem. *Id.* at 44. In more than half of jurisdictions, the state requires that counsel is appointed for the incapacitated person, but the attorney's role is not clear. *Id.* Even in states where the attorney's role is clear in providing for an individual's due process rights, attorneys might feel that they need to act in the client's best interest rather than the incapacitated individual's best interest. *Id.*

217. Additionally, the National Guardianship Association Standard Rule of Practice specifically provides that a guardian must "promptly inform the court of any change in capacity of the person that warrants an expansion or restriction of the guardian's authority." NAT'L GUARDIANSHIP ASS'N, STANDARDS OF PRACTICE 5 (4th ed. 2013), <https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standards-with-Summit-Revisions-2017.pdf> [<https://perma.cc/S7RB-MKDL>]. However, this requirement is not so easy to uphold when the individual's interest is at conflict with the individual's parents' interest.

Under a guardianship, the individual is no longer able to choose where to live or whom to marry.²¹⁸ In Jenny’s case, her court-appointed guardians chose her place of residence, a group home, even though she had previously been living in a normal residential home with friends.²¹⁹ Jenny was also no longer able to exercise her basic right to choose with whom she associated; a freedom that most people take for granted.²²⁰ A guardianship is an extreme option, as demonstrated in Jenny’s case,²²¹ and should only be exercised when no other guardianship alternative would sufficiently protect the individual.²²²

C. *The Existence of Only Two Options: A Human Rights Violation*

Almost every jurisdiction in the United States has failed to close the gap between the two extreme support options, which deprives individuals with disabilities of their basic human rights.²²³

218. See *supra* text accompanying notes 190, 210. In Illinois, for example, statutory law does not specifically address competency-based determinations regarding an individual’s right to become married. DROGIN & BARRETT, *supra* note 61, at 15; see also 750 ILL. COMP. STAT. § 5/301(1) (2019) (“The court shall enter its judgment declaring the invalidity of a marriage . . . entered into under the following circumstances: (1) a party lacked capacity to consent at the time the marriage was solemnized, [] because of mental incapacity . . .”). However, case law in Illinois provides that:

[T]here is no clear dividing line between competency and incompetency, and each case must be judged by its own peculiar facts; the parties must have sufficient mental capacity to enter into the status, but proof of mental capacity must be clear and definite; if the party possesses sufficient mental capacity to understand the nature, effect, duties, and obligations of the marriage contract into which he or she is entering, the marriage contract is binding, as long as they are otherwise legally competent to enter into the relation

Larson v. Larson, 192 N.E.2d 594, 597 (Ill. App. Ct. 1963).

219. *The Justice for Jenny Trial*, *supra* note 2.

220. *Id.*

221. See *id.*

222. See, e.g., *In re Dameris L.*, 956 N.Y.S.2d 848, 854–55 (Surr. Ct. 2012) (finding that SDM was the least restrictive option for the individual with a disability because she had previously been able to successfully live with the support of her husband and other individuals; SDM allowed her to choose who she married and to have children).

223. Because a guardianship is an extreme solution that puts the individual’s human right to legal capacity at risk, a “court must not deprive the adult of his or her rights unless there is no doubt about the inability of the adult to make his or her own choices.” Hensley, *supra* note 121, at 725. As previously discussed in this Comment, a plenary guardianship completely denies the individual of his or her basic right as an adult to make decisions. See *supra* note 191 and accompanying text. Stripping an individual of these basic rights “‘unperson[s]’ an adult, reducing his or her legal status to that of a child.” Hensley, *supra* note 121, at 727 (footnotes omitted) (first quoting Erica F. Wood, *History of Guardianship*,

Across the world, legal capacity is recognized as an inalienable human right.²²⁴ In the United States specifically, legal capacity is assumed for every adult.²²⁵ However, under state guardianship laws, legal capacity is often tied indivisibly to mental capacity, even though these two concepts are not the same.²²⁶ State laws generally provide a definition that allows a court to determine whether the individual has or lacks mental capacity.²²⁷ Consequently, when the court decides an individual meets the state’s definition for mental incapacity, the court often insufficiently lumps legal capacity into this determination and fails to functionally assess the individual’s legal capacity.²²⁸

However, legal capacity and mental capacity are two different concepts. Legal capacity refers to an individual’s meaningful participation in society, recognition as a rights holder, and right to legal agency.²²⁹ Mental capacity

in GUARDIANSHIPS OF ADULTS: ACHIEVING JUSTICE, AUTONOMY, AND SAFETY 17, 18 (2005); and then quoting Peter M. Horstman, *Protective Services for the Elderly: The Limits of Parens Patriae*, 40 MO. L. REV. 215, 231 (1975)). However, if the court has any doubt about the individual’s decision-making capacity, “the law must err on the side of protecting the right of an adult to make his or her own personal and property choices.” Hensley, *supra* note 121, at 725.

224. Legal capacity as a human right is derived from a few human rights instruments: the Universal Declaration of Human rights, Article 6; the CRPD; the Convention to End All Discrimination Against Women, Article 15; and the International Convention on Civil and Political Rights, Article 16. Glen, *supra* note 106, at 3–4; see G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948); CRPD, *supra* note 71; Convention on the Elimination of All Forms of Discrimination Against Women, art. 15, *opened for signature* Dec. 18, 1979, 1249 U.N.T.S. 13, 20 (entered into force Sept. 3, 1981); International Convent on Civil and Political Rights, art. 16, *opened for signature* Dec. 16, 1966, 999 U.N.T.S. 171, 177 (entered into force Mar. 23, 1976); see also *Human Rights Principles*, UNITED NATIONS POPULATION FUND (2005), <https://www.unfpa.org/resources/human-rights-principles> [http://perma.cc/5HHT-9WJ7].

225. Glen, *supra* note 106, at 5.

226. *Id.* Granting a guardianship based solely upon the court’s mental capacity determinations, and using discriminatory labels such as “unsoundness of mind,” is not a legitimate reason to deny legal capacity. *Id.* at 14. “Unsoundness of mind” is another term courts use to refer to “mental incapacity.” Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201, 1216 (2015); see, e.g., IDAHO CODE § 18-6101 (2019) (explaining how an “unsoundness of mind” determination may be “due to any cause including, but not limited to, mental illness, mental disability or developmental disability”).

227. See Glen, *supra* note 106, at 14; see also, e.g., CAL. PROB. CODE § 811 (Deering 2019) (providing a mental functions list that determine whether a person meets the State’s “incapacity” definition).

228. See Glen, *supra* note 106, at 14. For an in-depth look at functional assessments with regard to determining mental and legal capacity, see generally Committee on the Rights of Persons with Disabilities, *Convention on the Rights of Persons with Disabilities, General Comment No. 1*, U.N. Doc. CRPD/C/GC/1 (May 19, 2014).

229. Glen, *supra* note 106, at 4, 14. United States courts generally just look at cumulative evidence when determining an individual’s legal capacity. Meta S. David, Note, *Legal Guardianship of Individuals Incapacitated by Mental Illness: Where Do We Draw the*

refers to an individual's decision-making skills.²³⁰ CRPD Article 12 specifically provides that "perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity."²³¹ Thus, the propensity to lump together legal and mental capacity findings and court tendencies to appoint a guardian with an incapacity determination create human rights violations.²³² Current guardianship laws do not mandate comprehensive legal capacity assessments, thereby fostering a system that produces such violations.²³³

D. How the Current Framework for Determining Mental Capacity Increases the Guardianship Problem

Mental capacity is generally described in terms of "mental incapacity,"²³⁴ which refers to an individual who is no longer capable of taking care of him or herself.²³⁵ As guardianship laws are state-determined,²³⁶ the framework

Line?, 45 SUFFOLK U. L. REV. 465, 482 (2012). Thus, sweeping individuals into a broad category of needing a guardian, and lumping legal and mental determinations together, promote judge-made determinations that a guardianship is necessary, even when a guardianship is in fact not necessary or would be too broad.

230. Glen, *supra* note 106, at 14.

231. *Convention on the Rights of Persons with Disabilities, General Comment No. 1*, *supra* note 228, at 3.

232. A paradigm shift towards a system that entirely recognizes, and also empowers, an individual's human rights can also help support the United States in further aligning with the United Nations General Assembly Charter, which specifically maintains in the preamble a declaration to maintain "faith in fundamental human rights, in the dignity of worth of the human person." U.N. Charter pmbl.

233. *See infra* note 262 and accompanying text. For a list of functions California considers when making a capacity determination, which further shows how such functions are not always enough to warrant a substituted decision making option, see *supra* note 227 and accompanying text.

234. *See, e.g.*, OKLA. STAT. tit. 43A, § 10-103(A)(4) (2019) (providing the definition for incapacitated persons under state statutes); TENN. CODE ANN. § 34-1-101(14) (2019) (specifying a "person with a disability" as a meeting various needs, including an individual with a "mental or physical incapacity"). "Capacity" and "competency" are directly related concepts; capacity refers to "the ability to understand the nature and effect of one's act," and "[c]ompetency is a legal finding[, which is] . . . conducted to allow the court to determine an individual's mental capacity." OFFICE OF THE STATE LONG-TERM CARE OMBUDSMAN, CAPACITY VS. COMPETENCY, https://www.iowaaging.gov/sites/default/files/library-documents/Capacity%20vs%20Competency_fact%20sheet.pdf [<https://perma.cc/8VL6-ZGPN>].

235. Laura J. Whipple, Comment, *Navigating Mental Capacity Assessment*, 29 TEMP. J. SCI. TECH. & ENVTL. L. 369, 373 (2010).

236. *See supra* Section II.B.2.

for determining mental incapacity significantly varies.²³⁷ The lack of a streamlined structure to determine an individual’s incapacity further adds to the state court systems’ tendency to unnecessarily grant guardianships. Judge persistence in excessively granting guardianships stems from two capacity specific roots: (1) individual judge discretion, and (2) sweeping individuals into two broad capacity categories.

1. *The Problem with Individual Judge Discretion*

First, guardianship legal systems completely rely upon the presiding judge’s discretion.²³⁸ Such a system is unpredictable, unreliable, and increases the risk for inconsistency.²³⁹ Nevertheless, a bright-line rule to determine capacity level would also be ineffective.²⁴⁰ The problem with a bright-line rule is that the human mind and mental functions are extremely complex.²⁴¹ Consequently, the complex human psyche creates uncertainty as to whether an individual is functionally impaired enough to necessitate a guardian.²⁴² Either extreme option—complete judge discretion or a bright-line rule—

237. See George J. Demakis, *State Statutory Definitions of Civil Incompetency/Incapacity: Issues for Psychologists*, 19 PSYCHOL. PUB. POL’Y & L. 331, 333–39, tbl.1 (providing a detailed breakdown of each state’s incapacity definitions as of May 2012). Compare UTAH CODE ANN. § 75-1-201(22) (West 2019) (“‘Incapacitated’ or ‘incapacity’ is measured by . . . clear and convincing evidence that an adult’s ability to do the following is impaired to the extent that the individual lacks the ability, even with appropriate technological assistance, to meet the essential requirements for financial protection or physical health, safety, or self-care: (a) receive and evaluate information; (b) make and communicate decision; or (c) provide for necessities such as food, shelter, clothing, health care, or safety.”), with ARIZ. REV. STAT. ANN. § 14-5101(3) (2019) (“‘Incapacitated person’ means any person who is impaired by reason of mental illness, mental deficiency, mental disorder, physical illness or disability, chronic use of drugs, chronic intoxication or other cause, except minority, to the extent that he [or she] lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his [or her] person.”).

238. David, *supra* note 229, at 482. As guardianship laws are state determined, there is some variance as to the guardianship petition process. In a majority of states, guardianship proceedings take place in probate court. *E.g.*, *Private Guardianship for Adults with a Mental Disability*, VT. DEVELOPMENTAL DISABILITIES SERVICES DIVISION, <https://ddsd.vermont.gov/programs/public-guardian/private-guardianship-adults-mental-disability> [<https://perma.cc/J7UC-XL6Q>] (explaining that, in Vermont, the person “may file a petition with the probate division of the superior court requesting the appointment of a guardian”).

239. David, *supra* note 229, at 482.

240. *Id.*

241. *Id.* at 482–83.

242. *Id.* For a psychologist-focused perspective regarding the difficulties the human mind creates when making an incapacity determination, and consequently a guardianship determination, see Demakis, *supra* note 237, at 331–32, 341.

create challenging uncertainties, which perpetuate courts granting unnecessary or overly broad guardianships.²⁴³

2. *The Effect of Sweeping Individuals into Broad Categories*

Additionally, the legal recognition of only a surrogate decision-making option means that during a guardianship proceeding, an individual will be swept into a general category of needing help.²⁴⁴ This determination directs the court to appoint a guardian at the price of the individual's freedom and rights.²⁴⁵ Most state guardianship laws focus on determining whether the individual is "incapacitated," and consequently needs a guardian, or if the individual retains capacity, and is entitled to guardianship petition dismissal.²⁴⁶ Thus, the current guardianship system's predominant procedure restricts

243. See Salzman, *supra* note 161, at 170 (explaining how an incapacity determination starts a brutal sequence of events that eventually leads to "further isolation and loss of abilities" under a guardianship). Additionally, family members do not have a reference as to the behaviors that will push the court over the line towards an incapacity determination. David, *supra* note 229, at 483.

244. The main problem with this common practice is that an incapacity determination starts a "vicious cycle" that results in an individual's inability to manage his or her affairs, diminishing "the individual's opportunities to test his or her abilities." Salzman, *supra* note 161, at 170.

245. See Nina A. Kohn & Catheryn Koss, *Lawyers for Legal Ghosts: The Legality and Ethics of Representing Persons Subject to Guardianship*, 91 WASH. L. REV. 581, 587 (2016).

246. Salzman, *supra* note 161, at 175, 242. As exemplified in Jenny's case, the court will generally consider medical opinions regarding the proposed ward's condition, which may include an evaluation of the individual's medical history, mental illness diagnoses, or a psychological evaluation. *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 2 (Va. Cir. Ct. Aug. 2, 2013); David, *supra* note 229, at 479–80; see DROGIN & BARRETT, *supra* note 61, at 19–29. Although it may be necessary for a court to take these factors into consideration when determining capacity, consideration of medical documents alone does not result in an individualized option that caters to the individual's specific needs. Relying solely upon medical examinations is common, but the court must not only rely on this determination because physician expertise varies, interaction with the individual will likely vary, and knowledge of the individual's need for protection is limited. Cassidy, *supra* note 12, at 103. In 2006, the ABA Commission on Law and Aging, the National College of Probate Judges, and the American Psychological Association, recommended that a judge must consider the individual's medical condition, cognitive functioning, everyday functioning, risk of harm, level of supervision needed, ability to enhance functioning, and the consistency with preferences and values. DROGIN & BARRETT, *supra* note 61, at 6. Furthermore, these medical documents only help push the judge over the line of the individual needing help and, thus, should be appointed a guardian. Medical opinions alone do not allow the judge to adequately determine whether the individual is able to exercise basic rights—whether a person has the capacity to vote should not be based upon a physician's opinion of the individual's physical state.

the court's ability to cater to each individual's needs. Sweeping all individuals into two broad categories precludes legal recognition for additional options that would fall between complete autonomy and substituted decision-making options.²⁴⁷

E. Reaching the Age of Majority: The Role the Education System Plays in Perpetuating the Guardianship Problem

School systems have a particular role in an individual with a disability's path to autonomy because the school is present during the student's "transition" years.²⁴⁸ While schools may seem like an unusual place to focus on while discussing guardianships, every individual's access to a free education makes schools an ideal target for change.²⁴⁹

The IDEA laid a necessary foundation to empower individuals with disabilities because it requires that an appropriate education program be available to every eligible individual with a disability.²⁵⁰ However, the IDEA only provides the *groundwork* for these education programs,²⁵¹ and there is room to build from this foundation to further promote individuals' rights.

The IDEA serves additional purposes. Another IDEA principle is to prepare individuals with a disability for future education, employment, and independent living.²⁵² The IDEA also functions to provide students with "transition services" related to "training, education, employment, and, where appropriate, independent living skills."²⁵³ Thus, school systems have a special

247. See Salzman, *supra* note 161, at 242–43.

248. For a summary of what "transition" years are and what transition services should be included in a special education program, see *What Are Transition Services?*, PIONEER CENT. SCHOOLS, <https://www.pioneerschools.org/Page/364> [<https://perma.cc/HA7J-ERBY>]. While these transition years—the years leading up to an individual's eighteenth birthday—are some of the most exciting years for an individual with a disability, this time can also be extremely stressful because of the uncertainty that comes with this time period. AUTISTIC SELF ADVOCACY NETWORK, *TRANSITION TO ADULTHOOD: A HEALTH CARE GUIDE FOR YOUTH AND FAMILIES 1* (2014), <https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf> [<https://perma.cc/BP6D-XY7E>].

249. See *supra* note 135 and accompanying text.

250. Individuals with Disabilities Education Act of 2004, Pub. L. No. 108-446, § 601(c), 118 Stat. 2647 (codified as amended at 20 U.S.C. § 1400(c) (2012)).

251. "Special education programs" are the programs within school systems that are specifically designed for students with disabilities. See *supra* note 136.

252. 20 U.S.C. § 1414(d)(1)(A)(i)(VIII)(aa) (2012). For methods a teacher can use to best help the individual prepare for postadolescent life, see, for example, Thomas Armstrong, *7 Ways to Bring Out the Best in Special-Needs Students*, EDUC. WK. TCHR. (Apr. 9, 2013), https://www.edweek.org/tm/articles/2013/04/08/fp_armstrong.html [<https://perma.cc/2L9A-P2KV>].

253. 20 U.S.C. § 1414(d)(1)(A)(i)(VIII)(aa)–(bb) (2012). State laws regarding types of transition services required under law additionally vary state-to-state. See, e.g., ALASKA STAT. § 14.30.278 (2018) (explaining transition service objectives); CAL. EDUC. CODE § 56462

role in the guardianship process. Not only do teachers and other special education program staff interact with the student on a daily basis, they also provide services to enable the students to achieve his or her postsecondary transition goals.²⁵⁴ The very nature of a special education program is to prepare the individuals to “demonstrate the ability to ‘take care of themselves’ to the maximum of their abilities,” which allows these individuals to “overcom[e] the persistent paradigm that they cannot make decisions for themselves.”²⁵⁵

1. *The IDEA Fails to Provide Support Beyond Providing Basic Skills*

There are two main problems with the IDEA. First, it does not always offer the individual support beyond just providing basic skills.²⁵⁶ When the IDEA was originally enacted, its purpose was to provide individuals with disabilities a free, appropriate public education, including necessary post-secondary transition skills.²⁵⁷ Now that an increasing number of students with disabilities are eligible under the IDEA,²⁵⁸ education laws and

(Deering 2019) (providing a noninclusive list of required special education training transition services).

254. See discussion *supra* note 253 and accompanying text. For a discussion on special education teacher roles and teacher competencies to provide adequate transition services, see Tonisha L. Johnson, Transition Competencies: Secondary Special Education Teachers’ Perceptions of Their Frequency of Performance 25, 31–32 (2014) (unpublished Ed. D. dissertation, Georgia Southern University), <https://digitalcommons.georgiasouthern.edu/cgi/viewcontent.cgi?article=2257&context=etd> [<https://perma.cc/X26H-AHEW>].

255. Jonathan G. Martinis, One Person, Many Choices: Using Special Education Transition Service to Increase Self-Direction and Decision-Making and Decrease Overbroad or Undue Guardianship 12 (2015) (unpublished manuscript), http://jennyhatchjusticeproject.org/docs/publications/jhjp_publications_draft_article_guardianship.pdf [<https://perma.cc/C676-QC3N>]. Again, the issue is that “[w]hen denied self-determination, people can ‘feel helpless, hopeless, and self-critical.’” Rynders, *supra* note 64, at 27 (quoting EDWARD L. DECI, INTRINSIC MOTIVATION 208 (1975)). Thus, eliminating as many factors that prevent an individual from maximizing his or her self-determination abilities is crucial. See *id.*

256. See *infra* note 263 and accompanying text.

257. See *About IDEA*, INDIVIDUALS WITH DISABILITIES EDUC. ACT, <https://sites.ed.gov/idea/about-idea/> [<https://perma.cc/RV6G-B6UX>]. But see Dalun Zhang, Joy Ivester & Antonis Katsiyannis, *Teachers’ View of Transition Services: Results from Statewide Survey in South Carolina*, 40 EDUC. & TRAINING DEVELOPMENTAL DISABILITIES 360, 365 (2005) (“[T]he majority of schools in South Carolina report that they are not providing adequate employment skill development for their students.”).

258. See Martinis, *supra* note 255, at 11–13. In the United States, during the 2000–2005 school years, “the number of students ages 3–21 who received special education services . . . increased from 6.3 million, or 13 percent of total public school enrollment, to 6.7 million, or 14 percent of total public school enrollment.” *Children and Youth with Disabilities*, NAT’L

requirements must also change to promote these individuals' rights after they turn eighteen. Furthermore, these legal changes would help discourage the persistence of the current binary legal system.

2. *The IDEA Strips Individuals of Their Rights When Deemed Incompetent*

Second, the IDEA currently conditions that if an individual is deemed incompetent under state law,²⁵⁹ then, even once the individual turns eighteen, another person may represent the individual's educational needs.²⁶⁰ This further contributes to the court system's insistence upon appointing a guardian and is directly linked to how states define incompetency.

The IDEA leaves the incompetency determination up to the state's specific definition for incompetency.²⁶¹ Because most states only provide two determination options and lack an aggregated competency spectrum,²⁶² students have an increased chance of having their educational rights taken away once they turn eighteen. Though this right may seem insignificant to the average person, it is a crucial right for individuals with a disability because allowing these students to make their own educational decisions,²⁶³

CTR. FOR EDUC. STAT. (2019), https://nces.ed.gov/programs/coe/indicator_cgg.asp [<https://perma.cc/E4UZ-TWMS>]. Additionally, during the 2011–2012 and 2017–2018 school years, “the number of students served increased from 6.4 million to 7.0 million.” *Id.*

259. For a discussion on the problems with current state incapacity determinations, see *supra* Section III.D.

260. 34 C.F.R. § 300.520(b) (2018). For analysis of a study performed regarding students' control over adjustments during everyday life and their increased learning abilities, see generally James E. Martin et al., *Increasing Self-Determination: Teaching Students To Plan, Work, Evaluate, and Adjust*, 69 EXCEPTIONAL CHILD. 431 (2003).

261. 34 C.F.R. § 300.520(b) (providing that the individual's rights will be transferred to the parent at age eighteen, unless the child has “been determined to be incompetent” under state law).

262. In most states, there are only two determinations: competence or incompetence. Arias, *supra* note 76, at 147. These state guardianship law positions create additional problems in promoting individuals with disabilities' rights. Competency is not simply a black and white determination. Competency varies by issue, health status, external stressors, and even time of day. ACLU, BEYOND THE BINARY: USING A SUPPORTED DECISION-MAKING LENS IN EVALUATING COMPETENCE 1 (2019), https://www.aclu.org/sites/default/files/field_document/mo_tool_plain_language_-_evaluator_version.pdf [<https://perma.cc/AE28-S6VX>]. Thus, competency should not be considered a binary question; rather, competency should be a spectrum that is dependent upon the individual's circumstances and the given situation. *Id.*

263. In a society that fosters this population's dependency, it is important to increase these individuals' independence in any way possible. One research study revealed that self-determination has a positive impact on quality of life for individuals with mental disabilities. Michael Wehmeyer & Michelle Schwartz, *The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation*, 33 EDUC. & TRAINING MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES 3, 8 (1998). Additionally, this same study confirmed “what people with disabilities have emphasized and practitioners have presumed[,]”

with the teacher's support and guidance, is key to promoting the individuals' independence, self-determination, and autonomy.²⁶⁴ Furthermore, the IDEA's reliance upon state binary incapacity determination practices feeds directly into court system's current procedure of legally recognizing two support options.²⁶⁵

While historically it might have been more acceptable for courts to appoint guardians at the expense of individuals' rights because protecting the individual from harm was the priority,²⁶⁶ this practice of unnecessarily appointing a guardian is no longer appropriate when several viable alternatives exist.²⁶⁷ The United States' continued reliance upon binary legal systems, failure to alter the current mental capacity determination framework, and need to expand school systems' role under the IDEA produces frequent rights violations.

that people who can take greater control in their lives are more likely to have a higher quality of life." *Id.* at 11.

264. Promoting self-determination directly impacts an individual in many aspects of his or her life and is significantly related to an individual's psychological well-being, which includes a positive connection to the person's motivation and personality. Courtney Ackerman, *Self-Determination Theory of Motivation: Why Intrinsic Motivation Matters*, POSITIVE PSYCHOL. PROGRAM (Oct. 16, 2019), <https://positivepsychologyprogram.com/self-determination-theory/> [<https://perma.cc/3R84-Z962>].

265. See Arias, *supra* note 76, at 136–37.

266. However, in today's world, this practice is unacceptable. A significant number of countries around the world have started to make these changes, and the United States is simply failing American citizens with disabilities with its slow and seemingly insignificant legal changes. See *supra* notes 105–17 and accompanying text. For an interactive timeline of the SDM movement across the world, see *SDM International*, TIMEMAPPER (2018), http://timemapper.okfnlabs.org/sdm_timeline/sdm-international#0 [<https://perma.cc/N9DV-QTW4>].

267. Additionally, since deinstitutionalization began to shift how society viewed this population, there has been a movement towards "normalization." Normalization is defined as the "[u]tilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible." WOLF WOLFENBERGER ET AL., *THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES* 28 (1972). Along with this framework comes "life satisfaction, self-esteem, and personal competence[, which] are viewed as products of involvement with mainstream activities of society. Also, participation in atypical, segregated, or specialized environments and affiliation with other 'socially devalued persons' are considered detrimental to an individual's development." Sharon Landesman & Earl C. Butterfield, *Normalization and Deinstitutionalization of Mentally Retarded Individuals*, 42 *AM. PSYCHOLOGIST* 809, 810 (1987). Recognizing alternatives is also imperative in order to help foster this movement that has the potential to positively impact this population.

IV. SHIFTING TOWARDS A PERSON-CENTERED, SELF-DETERMINATION SYSTEM

There are four methods to help shift the United States away from a system that inevitably diminishes an individual's fundamental rights: (1) ratification of the CRPD, (2) state recognition of SDM models, (3) an altered mental capacity determination framework, and (4) Department of Education and IDEA requirements for school systems to provide students and families with information on every available support option.

A. CRPD Ratification

Having merely signed the CRPD, the United States is currently only prohibited from engaging in any activity that would violate the CRPD.²⁶⁸ As a *ratified* party to the Convention, the United States would be required to submit reports to the Committee on the Rights of Persons with Disabilities (Committee).²⁶⁹ The reports would explain the measures the United States has taken to comply with the Convention's obligations.²⁷⁰ Furthermore, becoming a party to the Convention requires the country to collect progress information, which would include statistical and research data.²⁷¹ This information would allow the United States to effectively construct policies to put the Convention into effect.²⁷² In general, the CRPD compels the country to create "national coordination mechanisms to collect and share information and best practices through the innovative mechanisms of the Committee."²⁷³

The United States has yet to ratify the CRPD for various reasons. One reason the Convention has not been ratified is the belief that the United

268. Glen, *supra* note 106, at 3. CRPD ratification would not only benefit Americans with disabilities, but ratification in the United States would, in a sense, benefit individuals with disabilities all over the world. As Judith Heumann, known for her advocacy for individual's with disabilities' rights and who suffered from polio and eventual paralysis, explains:

[I]t's equally important that disabled people have the same opportunities to travel, study[,] and work abroad as anyone else in our country. And as long as many countries don't have the same laws as we do and don't enforce them if they have them, opportunities for disabled people are more limited.

Judith Heumann, *Our Fight for Disability Rights—And Why We're Not Done Yet*, TED (Oct. 2016), https://www.ted.com/talks/judith_heumann_our_fight_for_disability_rights_and_why_we_re_not_done_yet [<https://perma.cc/2TBN-W4PL>].

269. For consideration of how the Committee is elected, see CRPD, *supra* note 71, art. 34.

270. *Id.* art. 35. These initial reports must be filed within the first two years after the country ratifies the Convention, and the country must submit subsequent reports every four years, at a minimum, or upon Committee request. *Id.*

271. *Id.* art. 31.

272. *Id.*

273. Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 157 (2012) (footnote omitted).

States “already has a wide range of federal laws that protect Americans with disabilities,” so ratifying the Convention would not benefit these individuals.²⁷⁴ Another reason the United States has failed to ratify the Convention is that ratifying this international law has “binding legal effects”; thus, CRPD ratification opponents argue that “the United States should make the law for itself” instead of having international laws establish control over domestic policy.²⁷⁵ Nevertheless, the United States is not adequately safeguarding these individuals and actually needs the Convention to push it towards autonomy-focused legal systems.²⁷⁶ The monitoring mechanism alone should be enough for the country to see the value in ratifying the Convention.²⁷⁷

Guardianship laws in the United States do not currently comply with CRPD Article 12, but being bound to the Article 12 would necessitate a complete change in state guardianship laws.²⁷⁸ Required compliance reports would motivate the United States to continue to promote this population’s rights and cause state governments to prioritize guardianship legislative changes.²⁷⁹ Ratifying the CRPD would not extinguish guardianship state

274. Steven Groves, Opinion, *The U.S. Doesn’t Need the U.N.’s Disability Treaty*, U.S. NEWS & WORLD REP. (Jan. 20, 2014, 8:00 AM), <https://www.usnews.com/opinion/articles/2014/01/20/the-us-doesnt-need-the-un-treaty-on-the-disabled> [<https://perma.cc/D56N-U8JY>].

275. PBS News Hour, *What Prevents the U.S. from Signing the U.N. Disabilities Treaty?*, PBS (Mar. 13, 2014, 8:16 PM), <https://www.pbs.org/newshour/show/prevents-u-s-signing-u-n-disabilities-treaty> [<https://perma.cc/DR44-78E3>].

276. The United States does, however, have a federal agency, called the National Council on Disability (NCD), that advises the President, Congress, and all other federal agencies “regarding policies, programs, practices, and procedures that affect people with disabilities.” *About Us*, NAT’L COUNCIL ON DISABILITY, <https://ncd.gov/about> [<https://perma.cc/9T66-DP3W>]. The NCD was responsible for recommending enactment of the ADA in 1990, and it has continued to play a significant role in advising the government, creating policy solutions, and understanding individuals with disabilities’ needs. *Id.*

277. See Arlene S. Kanter, *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities*, 34 SYRACUSE J. INT’L L. & COM. 287, 296 (2006).

278. Glen, *supra* note 273, at 162. The United Nations has provided many resources advocating for ratification of the Convention to ensure individuals with disabilities have equal recognition before the law in every country. The United Nations wrote that Parliamentary nations should “[p]ropose the development of a national framework for supported decision-making consistent with the United Nations Convention,” among a list of other crucial actions a party country must make. UNITED NATIONS ENABLE, CHAPTER SIX: FROM PROVISIONS TO PRACTICE: IMPLEMENTING THE CONVENTION 3 (2013), http://www.supporteddecisionmaking.org/sites/default/files/chapter_6_%20provisions%20to%20practice_%20implementing_convention.pdf [<https://perma.cc/8GD4-UFCC>].

279. Dinerstein, Grewal & Martinis, *supra* note 58, at 445.

laws or diminish the positive effects of current federal laws.²⁸⁰ Instead, the CRPD would directly require the United States to “(1) recognize the legal capacity of all persons, including those with intellectual disabilities, and (2) engage in ‘progressive implementation’ of Article 12,” which would create an obligation for the country to provide multiple decision-making support models.²⁸¹

B. Legal Recognition of Guardianship Alternatives

Legally recognizing other options would expand the court’s ability to cater to each individual’s specific needs and thus promote an individual’s rights and independence.²⁸² Additionally, legally recognizing alternatives would allow a court to further fulfill its obligations to ensure the least restrictive option is always utilized.²⁸³

Most states generally follow the principle that the state is required to adhere to the least restrictive alternative standard;²⁸⁴ however, it is difficult to fulfill

280. GUARDIANSHIP SUMMIT, *supra* note 72, at 3.

281. *Id.* Though guardianship laws are state governed in the United States, this should not be a hindrance for the country to maintain compliance with the CRPD once it is ratified. As demonstrated in Canada, the legislative changes “would likely fall primarily within the powers of provincial and territorial governments.” BACH & KERZNER, *supra* note 195, at 117. Compare *id.* at 44–46 (discussing guardianship laws and practices in Canada before the country underwent guardianship law reforms to recognize SDM-type options), with Glen, *supra* note 106, at 76–84 (explaining Canada’s disability rights movement), and Representation Agreement Act, R.S.B.C. 1996, c 450 (Can.) (“The purpose of this Act is to provide a mechanism (a) to allow adults to arrange in advance how, when[,] and by whom, [various] decisions . . . will be made if they become incapable of making decisions independently, and (b) to avoid the need for the court to appoint someone to help adults make decisions, or someone to make decisions for adults, when they are incapable of making decisions independently.”).

282. For example, Amanda, a participant in the Nonotuck and the Center for Public Representation’s initial SDM Pilot Project, signed an SDM agreement with a support network through the Pilot Project. *Meet Amanda: Amanda and Supported Decision-Making*, CTR. FOR PUB. REPRESENTATION, <https://supporteddecisions.org/stories-of-supported-decision-making/amandas-story/> [<https://perma.cc/7P5J-85UB>]. In 2009, prior to her participation in the Project, Amanda implemented her own SDM model when she needed a place to live; she used a caseworker and her friend’s support to make this decision. *Id.* Amanda needs assistance in understating issues prior to making decisions, and she is able to obtain such assistance through her SDM supporters. *Id.* Amanda chose her SDM network, which is common practice for such a model, and it includes her caregiver, best friend, respite worker, and mother. *Id.*

283. See *supra* notes 131, 148 and accompanying text.

284. Kohn & Koss, *supra* note 245, at 601. Some states have “least restrictive option” standards written into their statutes. See, e.g., N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2019) (“The legislature finds that it is desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention which assists them in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable.”).

this requirement when the state only provides legal recognition for a substituted decision-making option. SDM models, however, provide the judge with multiple support options to cater to different need levels, without having to succumb to a guardianship upon finding that the individual needs support.

1. *Enacting Legislation that Recognizes Supported Decision-Making Options*

States must amend current guardianship laws to legally recognize SDM models and purge legal systems of binary support options. Though it seems like a daunting task for each state to make these legislative changes, the ULC has already provided states with the UGCOPAA,²⁸⁵ and other model legislation, which can facilitate such legislative transformations.²⁸⁶ Using all or parts of this model language would help ensure that the state meets the CRPD requirements, while fostering a shift away from rights-capturing court systems.²⁸⁷

285. See *supra* note 84 and accompanying text. The UGCOPAA delivers model act language regarding legislative requirements to: provide guardians with clear, person-centered standards; limit a court's ability to use a more restrictive alternative than necessary; increase procedural rights; bar a guardian's restrictions for that individual; and alter current systems to provide protective arrangements, instead of a guardianship. A.B.A., UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT (UGCOPAA) & STATE ADVOCACY (2018), <https://www.americanbar.org/content/dam/aba/administrative/crsj/committee/ABA-UGCOPAA-presentation-2-28-18.pdf> [<https://perma.cc/ZSU7-G5HJ>].

286. Some states have already implemented such model legislation language. SCOTT SKINNER-THOMPSON, AIDS AND THE LAW § 13.06[F], at 13-77 (2020).

287. The United States's failure to ratify the CRPD further exhibits the country's failure to recognize individuals with a disability's basic human rights. See *supra* note 71 and accompanying text; see also *supra* Section III.C. In 2014, the U.S. Administration for Community Living (ACL), a committee within the U.S. Department of Health and Human Services that incorporates both the Administration on Aging and the Administration on Intellectual and Developmental Disabilities, initiated a five-year Supported Decision-Making Technical Assistance and Resource Center, which would conduct research and document successful SDM practices. Andreasian et al., *supra* note 14, at 330. The ACL additionally declared, citing to the CRPD, that every person is deemed to have legal capacity, thus differentiating an individual's cognitive and communicative abilities from his or her right to legal capacity. Dep't of Health & Human Servs. Admin. for Cmty. Living, *Supported Decision Making Grant Opportunity*, GRANTS.GOV (May 28, 2014), <http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168> [<http://perma.cc/GRZ5-SP38>].

Specifically, the ACL stated, "all people[,] regardless of their disability or cognitive abilities have the right to make decisions and have those decisions implemented," which has helped to create an outline of how to develop SDM models. *Id.* Even though the ACL has embraced the CRPD in its initiative to bring SDM to the United States to further promote an individual with disability's human rights, the United States has not ratified the CRPD. Therefore,

Not only do states have ULC model language to help facilitate these statute amendments, states can also use the SDM legislation enacted in Texas, Delaware, and the District of Columbia, as legislative and systematic examples.²⁸⁸ Texas specifically has been successfully implementing SDM practices under its SDM legislation for more than four years.²⁸⁹ Thus, states cannot simply use challenges in writing these legislative changes as an excuse to not enact such amendments.²⁹⁰

2. Putting Supported Decision-Making Models into Practice

Just as state guardianship laws vary, SDM models will look different for every individual. However, SDM models typically have three common elements: (1) guidelines emphasizing the individual's autonomy, capacity presumption, and decision-making rights similar to others; (2) recognition

there is no incentive for the United States to require that each state change its guardianship laws to provide legal recognition of SDM. Thus, an individual with a disability's human right to legal capacity is at risk until the United States ratifies the CRPD and requires each state to legally recognize SDM-type models as viable alternatives.

288. See *supra* Sections II.B.2, II.C.2; see also Eliana J. Theodorou, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973, 979 (2018) (providing the steps Texas took towards legislative changes).

289. Although Texas has made positive strides to improve guardianship laws, and consequently the lives of individuals with disabilities, Texas still has room to grow. In Texas, some individuals with disabilities are placed into a State Supported Living Center (SSLC). Jeryn Crabb, Comment, *Texas Can't Hold 'Em Anymore: Why Individuals with Intellectual and Developmental Disabilities Committed to State Supported Living Centers Need Judicial Review of Their Commitment Orders*, 48 TEX. TECH L. REV. 931, 952 (2016). However, despite the deinstitutionalization movement, Texas's legislation "has failed to ensure that involuntarily committed individuals are treated in the least restrictive environment appropriate for their needs." *Id.* The Texas Legislature passed Senate Bill 643 in 2009 to "increase oversight and protection for residents of the SSLCs by increasing training and standards for staff, requiring video surveillance in all common areas, and creating an office of ombuds [persons] to protect the rights of SSLC residents." *Id.*; see S.B. 643, 81st Leg., Reg. Sess. (Tex. 2009). This bill, however, failed to address how SSLCs would ensure residents are in the most integrated setting. See Crabb, *supra*, at 954. In 2013 and 2015, the Texas Legislature aimed to address this issue with Senate Bill 7, with Rider 39 to Senate Bill 1 attached, and Senate Bill 219. *Id.* at 953; see S.B. 219, 84th Leg., Reg. Sess. (Tex. 2015); S.B. 7, 83rd Leg., Reg. Sess. (Tex. 2013). Nonetheless, "not a single one of the major SSLC reform bills made it through the legislative labyrinth to become law," but the Senate Bill 1 Rider 39 was enacted and set a ten-year budget plan for the costs to maintain the SSLCs. Crabb, *supra*, at 954.

290. The responsibility to protect an individual with disabilities from harm seems to be the main reason SDM statutes have not been enacted in every state. See Johns, *supra* note 83, at 1544. But see *Indiana Judge Approves First Supported Decision Making Agreement*, NASDDDS (July 12, 2018), <https://www.nasddds.org/news/indiana-judge-approves-first-supported-decision-making-agreement/> [<https://perma.cc/7PFM-7AYL>] ("We are pushing to enact Supported Decision Making here in Indiana and have it recognized as a tool to use when planning for futures . . .").

that the individual has the capacity to use a decision-making process that does not completely remove the individual's decision-making rights; and (3) acknowledgement that the individual will need some assistance in his or her decision-making process.²⁹¹

At first glance, this support option does not appear to necessitate legal involvement because any person can set up a system where one person helps another person make decisions. However, the law plays a significant role with this option, which is why legally recognizing this alternative is imperative.²⁹² For example, under Texas law, the SDM option requires the individual and supporter to complete and sign a valid SDM agreement form that is witnessed or notarized.²⁹³ This witnessed or notarized document is, therefore, legally recognized under Texas's SDM statute, so the supporter and the individual will be bound to the agreement. This agreement does not require a court hearing or an attorney,²⁹⁴ but the agreement provides that the supporter may not make any decisions or take any actions in the individual's place.²⁹⁵

SDM models can be molded to fit the person's decision-making capabilities and any person can act as a supporter,²⁹⁶ but the law must step in and limit the supporter's assistance to ensure the individual retains his or her decision-making rights.²⁹⁷ Thus, the legal system's role is crucial to guarantee the

291. Dinerstein, *supra* note 98, at 10 (citing Michael Bach, *Securing Self-Determination: Building the Agenda in Canada*, TASH NEWSL., June–July 1998, at 8, 10). With the self-determination movement on its way, many organizations that promote an individual's autonomy have produced resources to help parents create self-determination focused models. See, e.g., *Resource Guide: Specific Materials for Promoting Self-Determination*, NAT'L GATEWAY TO SELF-DETERMINATION, <http://www.ngsd.org/everyone/resource-guide> [<https://perma.cc/AZY7-EKFD>]; *Supported Decision-Making Resource Library*, ACLU, <https://www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library> [<https://perma.cc/7253-V3RS>].

292. For an example of an SDM agreement under Wisconsin law, one of the only states that legally recognizes an SDM document, see WIS. STAT. § 52.20 (2019).

293. *Supported Decision-Making: Alternatives to Guardianship*, TEX. COUNCIL FOR DEVELOPMENTAL DISABILITIES, <http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/> [<https://perma.cc/KJR4-CLD6>].

294. *Id.*

295. *Id.*

296. See PELL & MULKERN, *supra* note 102, at 13.

297. SDM agreements specifically list what decisions the supporters will help the individual make, so it is crucial that the SDM agreement be legally recognized to limit potential supporters from overstepping their duties. See A.B.A., PRACTICAL TOOL FOR LAWYERS: STEPS IN SUPPORTING DECISION-MAKING 6, <http://supporteddecisionmaking.org/sites/default/files/docs/events/PRACTICALGuide.pdf> [<https://perma.cc/F734-NB34>].

SDM model does not limit an individual's decision-making rights, or, even worse, create a situation where the individual is provided with no support at all.²⁹⁸ Regardless of how the SDM model actually plays out, the goal of the SDM option is to allow the individual to retain his or her legal decision-making rights, while being provided support in making his or her decisions.²⁹⁹

3. *Potential Consequences and Setbacks*

The need to shift away from the current binary system stems from guardianships unnecessarily taking away an individual's rights. However, the push towards recognizing SDM does not come without its opposition and challenges.

One major consequence of this paradigm shift is an increase in unpredictability, where there would be no way to know which option the judge would decide is best for the individual.³⁰⁰ A potential guardian may also be further deterred from filing to seek legal recognition of a support option with the potential uncertainty in the individual's future.³⁰¹ Given that this is a significant pitfall to SDM recognition and mental capacity determinations, the benefits of individualizing solutions to each person's needs—using the increased toolbox—would reduce the number of unnecessary or overly broad guardianships. This enhanced support option toolbox would allow the judge to consider the person's entire circumstances when selecting

298. For other reasons why it is important to sign a written SDM agreement, even if these types of networks are already being implemented, see SDM: FAQ, *supra* note 102.

299. As previously discussed, some individuals already implement effective SDM networks; however, “guardianship laws and practice still dominate” because most legal systems do not have clear SDM policy frameworks. UNITED NATIONS ENABLE, *supra* note 278, at 2. Designating support networks can be very difficult, especially when the individual is not able to identify persons to be members of his or her SDM network. *Id.*; see also *supra* note 296 and accompanying text. Even more significantly, “people in institutional settings are often denied support, even when it is available.” UNITED NATIONS ENABLE, *supra* note 278, at 2.

300. See *supra* Section III.D.1.

301. However, this is not always the case, and additional support options actually help push parents to select the best option for their child. For example, the parents of Cory Carlotto, who participated in the Nonotuck and the Center for Public Representation's initial SDM Pilot Project, were appointed as Cory's guardians once he turned eighteen years old in 2009. *Cory, Pilot Project Participant*, CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/cory/> [<https://perma.cc/MP54-GNGR>]. Before Cory turned eighteen, “[h]is parents felt that he still needed protection, and since they could not find any alternative, they proceeded with guardianship, but always with the intention that one day they would be able to give Cory his rights back.” *Id.* In 2015, Cory and his parents completed a Representation Agreement, which identified the areas that Cory needed support in and who would be designated as his supporters; Cory now successfully uses an SDM. *Id.*

the option that best protects the individual from harm, while maintaining as many rights as possible.³⁰²

Another obstacle this paradigm shift will encounter is that even though there is a need to shift towards a system that protects an individual's rights, there will always be an overarching and necessary need to protect this individual from external harm.³⁰³ Making these state legislative changes, altering the way society views this population,³⁰⁴ and shifting court systems' tendency to protect the individual and grant a guardianship will not be easy. A major concern with increasing the use of SDM models is that this population will be exploited and harmed without another person's complete protection, such as a guardian.³⁰⁵ However, SDM-type alternatives do not completely rid the individual of any necessary protection.³⁰⁶ Rather, this option provides the individual with as much protection as he or she needs, whether that be through helping the individual make decisions or ensuring the individual's choices do not place him or her in a harmful situation.³⁰⁷

Furthermore, there are some financial costs that would make this paradigm shift difficult. Such alternatives may not be the most financially practical option for an individual.³⁰⁸ However, the financial costs of creating

302. Furthermore, once guardianship alternatives become widely used, parents may not even need to go to court if they decide that a guardianship alternative, which does not necessitate a judge order, would be the individual's best support option. *See supra* Section IV.B.2.

303. *See* GUARDIANSHIP SUMMIT, *supra* note 72, at 3.

304. The importance to rid society's negative views and biases towards individuals with disabilities is succinctly summed up in Justice Ginsburg's dissent in *Adarand Constructors, Inc. v. Peña*: "Bias both conscious and unconscious, reflecting traditional and unexamined habits of thought, keeps up barriers that must come down if equal opportunity and nondiscrimination are ever genuinely to become this country's law and practice." 515 U.S. 200, 274 (1995) (Ginsburg, J., dissenting) (footnote omitted). Thus, society as a whole must make changes to its view on individuals with disabilities and their defining capacity to help alter guardianship laws to prevent discrimination.

305. *See* Glen, *supra* note 106, at 32–33.

306. SDM: FAQ, *supra* note 102, at 2. Not only do SDM models protect the individual's needs, the SDM network usually has multiple supporters—often each having their own role for certain types of decisions. *Id.* Multiple supporters protect the individual from potential harm because many supporters "provide[] a check against abuse or manipulation by any one supporter." *Id.*

307. *See About SDM: What Is Supported Decision-Making*, *supra* note 103.

308. Accordingly, actually implementing such alternatives has potential challenges. *See* Burke, *supra* note 99, at 887. Other difficulties this alternative creates include: funding issues, deciding who makes the ultimate decision, limited resources available for the ward and supporter, making agreements and compromises, actually developing this type of system, and a tendency to retreat to a more restrictive option. *Id.* at 887–88.

an SDM are surely no greater than the financial costs of going to court to obtain a guardianship.³⁰⁹ SDM models can be equally as costly as guardianships, SDM “should thus be seen as a redistribution of existing resources, not an additional expense.”³¹⁰ Consequently, the United States should not be satisfied with maintaining guardianship laws as they stand now just because it is easy and financially comfortable to keep appointing guardians.

4. *A Decline of Rights Violations*

Ultimately, regardless of the opposition and setbacks that are likely to arise from the shift towards autonomy-centered practices, the benefits that would result from such changes would outweigh the potential setbacks.³¹¹ As a society that so heavily values freedom, the financial costs and ease should not be determining factors when it comes to ensuring that an individual has the ability to exercise his or her most basic rights.³¹² The setbacks and the opposition that may result are insignificant when considering this shift from a bird’s-eye view; the positive impact these changes would have on the individual’s psyche outweighs the problems that may arise from this paradigm shift.³¹³

With every set of laws, there will be pros and cons. However, these advantages and disadvantages can shift over time and, eventually, the advantages may start to outweigh the disadvantages.³¹⁴ This is exactly what has occurred

309. See A.B.A., WINGS ACTION TOOLS: PROMOTING OPTIONS LESS RESTRICTIVE THAN GUARDIANSHIP, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018_wings_lro_%20action_%20tool.pdf [<https://perma.cc/5CTP-YLVP>].

310. UNITED NATIONS ENABLE, *supra* note 278.

311. One significant advantage to SDM models is the fact that the individual retains support and maintains his or her independence. Kathy, a participant in the Center for Public Representation and Nonotuck Resources Associates initial Pilot Project, explained that SDM was the correct guardianship alternative for her because it allowed her to consult with her sisters before making decisions, but she was still able to make her own decision; thus, Kathy retained her independence by using an SDM model. See *Kathy’s Story, Pilot Project Participant*, CTR. FOR PUB. REPRESENTATION, <https://supporteddecisions.org/stories-of-supported-decision-making/kathys-story/> [<https://perma.cc/D754-T5NZ>].

312. See ARTHUR G. NEAL & HELEN YOUNGELSON-NEAL, CORE VALUES IN AMERICAN LIFE: LIVING WITH CONTRADICTIONS ch. 4 (2014).

313. See *generally id.* at 1 (“The core values of American life are deeply embedded in historical experiences and traditions.”). For a discussion on how allowing individuals to make decisions for themselves, which alters individuals’ view of themselves and enhances their confidence level, see Martinis, *supra* note 255, at 4–6, 14–16.

314. Dating back to the mid-1800s, this population tended to be marginalized and even abused. A. Frank Johns, *Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of Its Crumbling Linkage to Unprotected Older Americans in the Twenty-First Century—A March of Folly? Or Just a Mask of Virtual Reality?*, 27 STETSON L. REV. 1, 19 (1997). Thus, the mid-twentieth century guardianship movement in the United States focused on ordering guardianships, whether it was “for their own good or to protect others.” *Id.* at 28.

with guardianship laws. When guardianship laws were first enacted, the positive outcomes far outweighed the negative results, as protecting the individual came before all other interests; however, this is no longer the case in light of viable guardianship alternatives.³¹⁵ While altering guardianship laws to recognize SDM-type models is not a perfect solution, the positive effects will be substantially greater than the negative results.³¹⁶ Legally recognizing guardianship alternatives has the potential to promote an individual's rights, and this alone is enough of a reason to make these legislative changes.

Expanding legal recognition of guardianship alternatives would help ensure that an individual's ADA rights are not infringed upon. When a court determines that an individual needs help or support in his or her daily activities or decisions, the court will no longer be forced to appoint a guardian.³¹⁷ This will seamlessly allow the court to enforce a support option that would not put the individual in a confining environment, as the ADA prohibits.

Additionally, legal recognition of SDM across all states would safeguard an individual's constitutional rights to a far greater extent than current guardianship laws do. The availability of SDM, or another guardianship alternative, would decrease the tension between protecting an individual from harm and providing an option that advances the individual's constitutional rights.³¹⁸ A court's determination that an individual meets the state's incapacity determination, and that the individual needs some decision-making support, does not necessarily mean the individual lacks the capability to understand the nature of his or her vote.³¹⁹ Thus, the court may find an SDM network is the individual's best option, and this support system can assist the individual to appropriately exercise his or her voting rights.

315. SDM-type models are relatively newer guardianship alternatives. In an informational document provided by the American Bar Association in 1998, the "Alternatives to Guardianship" chart did not list SDM models and subsequent information. A.B.A., FACTS ABOUT LAW AND THE ELDERLY 12 tbl.3 (1998), http://www.supporteddecisionmaking.org/sites/default/files/aba_facts_about_law_and_the_elderly_0.pdf [<https://perma.cc/R5FU-53X9>].

316. For discussions on the psychological impacts of self-determination and autonomy-focused models, see *supra* notes 92, 97, 264 and accompanying text.

317. See *supra* Section III.B.1.

318. See Johns, *supra* note 83, at 1544; see also discussion *supra* Section II.C.

319. Some states have begun to recognize that these individuals should not be denied the right to vote when deemed incapacitated. See, e.g., ARIZ. REV. STAT. ANN. § 14-5101(3) (2019) ("In cases of limited guardianship only, a person is not deemed an incapacitated person for purposes of voting if the person files a petition and has a hearing and the judge determines by clear and convincing evidence that the person retains sufficient understanding to exercise the right to vote . . .").

5. *Altering the Current Framework for Mental Capacity Determinations*

Not only is it important for states to legally recognize guardianship alternatives, but states must provide a strong framework for determining mental capacity, without lumping it together with legal capacity determinations, using aggregated factors.³²⁰ While making a complete template to determine mental capacity would increase predictability within and among different courts, this idea would not allow a court to properly individualize a support option.³²¹

Moreover, CRPD ratification and nationwide SDM recognition can serve as a suitable solution to fix additional hinderances that mental capacity determinations create.³²² Expanding a court's support system toolbox would allow a judge to use discretion to appoint an option that promotes the individual's legal capacity, even when the judge determines the individual meets the state's incapacity definition. Such a system would consequently shift the legal system away from measuring an individual's "mental capacity" to affirming the individual's legal capacity, while concurrently providing the individual with legally recognized self-decision-making support.³²³ Therefore, the current system that blurs mental and legal capacity determinations into two broad capacity determinations would dissolve.

Recognizing alternatives would additionally allow judge discretion and variance to be in an individual's favor, despite judge unpredictability due to difficulties that the human mind creates.³²⁴ Currently, a finding of

320. This Comment refers to this new "framework" as more of a "spectrum" than a bright-line standard. See David, *supra* note 229, at 483 ("[I]t would be prudent to enact a statutory framework in order to inform concerned parties of these factors and to have clinical assessments made accordingly.").

321. The most significant problem that needs to be fixed is the negative consequences that come with an incapacity determination. An incapacity determination can make the "individual experience[] a sense of helplessness and loss of control, with critical implications for psychological well-being. 'A finding of incapacity may accentuate a patient's difficulties, making him or her feel even more stigmatized and lacking in control' and diminishing his or her motivations to act in the world . . ." Salzman, *supra* note 63, at 291–92 (footnotes omitted) (quoting Mary Donnelly, *From Autonomy to Dignity: Treatment for Mental Disorders and the Focus for Patient Rights*, 26 LAW CONTEXT 37, 49 (2008)). Furthermore, an individual's loss of legal capacity only adds to the challenges that come along with re-integration into social life. *Id.* at 292.

322. For example, in 2018, South Carolina made changes to its definition of incapacity by adding a "supports and assistance" element to ensure "that if a less restrictive alternative is available to guardianship or a protective order, then the court should not find an individual is incapacitated under the law, even if the first element in establishing incapacity is met." Sarah Garland St. Onge, *Guardianship and Protective Proceedings: Changes for 2019*, 30 S.C. LAW., Nov. 2018, at 32, 34–35. South Carolina's updated incapacity definition provides a comprehensive list of what constitutes "support[] and assistance." S.C. CODE ANN. § 62-5-101(23) (2019).

323. GUARDIANSHIP SUMMIT, *supra* note 72, at 3.

324. See *supra* note 242 and accompanying text.

incapacity likely causes the judge to err on the side of protecting the individual, which would trigger the judge to appoint a guardian.³²⁵ However, providing additional alternative options would allow the judge to make a more nuanced determination by considering the individual's personal limits and capabilities.³²⁶

Furthermore, this change would directly impact the problem that occurs within school systems once a student with disabilities reaches age eighteen.³²⁷ If varying capacity levels are attainable, then the student with disabilities is more likely to retain the right to make educational decisions.³²⁸ Even if individuals need support in making educational decisions,³²⁹ SDM would provide these individuals with a support network to facilitate decision-making, all without completely taking away their decision-making capacity. Thus, the current problems that state binary incapacity determinations create, which impedes on an individual's ability to make educational decisions and further encourages a system that tends to promote guardianships, will be significantly reduced.

325. See generally Johns, *supra* note 83, at 1542 (“The focus of *parens patriae* was the Crown’s (now state probate and guardianship judges’) exercise of its paternal royal prerogative over its subjects unable to protect themselves This continues to be the indictment of guardianship, where vulnerable citizens . . . have been condemned to a perverse legal system that protects property over the person.”).

326. Each person’s capacity level “naturally var[ies].” Glen, *supra* note 106, at 14. See generally Yael Braudo-Bahat, *Towards a Relational Conceptualization of the Right to Personal Autonomy*, 25 AM. U. J. GENDER SOC. POL’Y & L. 111, 131 (2017) (explaining that the autonomous process is perceived “as a dynamic, fluid[,] and external process”).

327. See *supra* notes 141, 143 and accompanying text.

328. With varying competency levels, an individual would not necessarily outright meet a state’s “incapacity” definition just because the individual needs help. Consequently, the individual would not unnecessarily be stripped of his or her education rights. See *supra* notes 92–93 and accompanying text.

329. When an individual’s education rights are taken away, the individual does not even have the opportunity to participate in his or her IEP meeting. With an SDM network, the individual would still maintain these educational rights, most notably his or her right to attend the mandatory IEP meetings, while using supporters to help make important education-related decisions.

C. *A More Attainable Solution: Providing Information on All Available Alternatives Before Reaching the Age of Majority*

With the potential setbacks and difficulties that may arise from requiring each state to legally recognize guardianship alternative models, like SDM, there is a more attainable solution. This potential solution will further encourage a shift towards self-determination-promoting court systems. The potential solution: provide information on *every* available support option to students and their families before the student turns eighteen.

With the IDEA mandate that all eligible individuals with a disability must be provided free, appropriate public education, schools are the ideal place to stop the guardianship problem before it even occurs.³³⁰ Schools and teachers have the potential to play a significant role in the guardianship process because the teacher, the student's parents, and frequently the student attend the student's IEP meetings until he or she reaches age eighteen.³³¹ This situation allows the teacher and school to provide information to the student and his or her family on every available support option as the student nears the age of majority. Once the student and his or her family receive extensive information on such options, the student and the student's family will be better equipped to make an informed decision as to the student's best path.³³² Currently, many parents are not aware that there are other options available for their child,³³³ so providing the student's family with this information can help push families towards implementing an option that caters to the student's support needs.³³⁴

330. Approximately five million children between the ages of three and twenty-one "receive special education and related services each year in the United States." SUPER SIX GUIDEBOOK, *supra* note 89, at 3. However, even though this population has increasing educational rights, another problem still remains: special education programs often segregate children with disabilities. Trevor Matthews, Note, *The Most Integrated Setting*: Olmstead, Fry, and the Segregated Public Schools for Students with Disabilities, 102 MINN. L. REV. 1413, 1416 (2018). According to U.S. Department of Education statistics from 2015, 146,581 students with disabilities ages six to eighteen attended separate, segregated-site school buildings. *Id.* at 1431 (citing *IDEA Section 618 Data Products: State Level Data Files*, U.S. DEP'T EDUC., <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html> [<https://perma.cc/LQ3S-G52J>]). ADA Title II, the integration mandate, has not been applied to school settings, but, in the future, this mandate must be extended to cover classroom settings as "[s]egregated-site schools are unquestionably limiting students' peer groups." *Id.* at 1435.

331. See *supra* note 138 and accompanying text.

332. Providing this information can actually have an empowering effect on the individual because allowing the individual to learn about all options that are available allows them to become an active participant in decisions that impact his or her own life.

333. See *supra* text accompanying notes 64–65.

334. "For far too long, parents have been told the only way to protect their youth/youth adult is to get guardianship." *Supported Decision Making and Alternatives to*

Providing information to parents and families will also encourage parents to try less restrictive alternatives before jumping right to a guardianship.³³⁵ Presently, the teacher and school often tell parents to obtain a guardianship as soon as the student turns eighteen.³³⁶ While this may be the correct option for one student, it is unlikely a guardianship recommendation is the correct alternative for every student in the program.³³⁷ Therefore, giving families this information is a starting place to inform families and encourage SDM-type model use when appropriate.

Furthermore, requiring schools and teachers to provide this information would compel them to familiarize themselves with guardianship alternatives and how each one functions, which can help the teacher and school better support the student in enabling them to successfully use an autonomy-focused alternative.³³⁸ Thus, this basic solution has the potential to kickstart a transformation that shifts court systems away from unnecessarily granting guardianship, which can result from potential guardians unnecessarily seeking guardianships, to systems that promote the individual's rights.

V. CONCLUSION

Individuals with disabilities have historically been viewed as a more vulnerable population within society, and consequently, states have generally shouldered the responsibility to protect this population from harmful or abusive situations.³³⁹ Thus, court systems within the United States have erred on the side of appointing a guardian as a way to ensure the individual is protected, but this general insistence upon granting guardianships has been at the expense of the individual's rights. While ordering guardianships might

Guardianship, SPAN PARENT ADVOC. NETWORK, <http://www.spanadvocacy.org/content/supported-decision-making-and-alternatives-guardianship> [<https://perma.cc/G47J-WGES>].

335. See generally Burke, *supra* note 99 (providing alternatives to traditional guardianship).

336. See *supra* notes 64, 160–61, 334 and accompanying text.

337. The complexities of the mind and each person's varying competency levels reflect why a guardianship is not the best option for every individual. See *supra* notes 251–52 and accompanying text.

338. See generally Kristie Pretti-Frontczak & Diane Bricker, *Enhancing the Quality of Individualized Education Plan (IEP) Goals and Objectives*, 23 J. EARLY INTERVENTION 92, 92 (2000) (“[H]igher quality IEP goals and objectives that are developed from a comprehensive assessment process, and directly linked to intervention and evaluation, are likely to contribute to the individualization of services and improved outcomes for young children.”).

339. See *supra* note 46.

have been effective in the early stages of providing these individuals with protection, even if protection cost the individuals access to their rights, there are too many other viable options to justify a guardianship as the only way to protect an individual.³⁴⁰

In a society that values freedom, independence, and self-determination, it is imperative that the United States progress past a binary system that errs on the side of appointing a guardian just because the individual needs protection. Instead, current practices must shift to err towards defending an individual's autonomy, while simultaneously protecting the individual from exploitation or harm.³⁴¹ Thus, the United States' failure to enact advanced guardianship laws will perpetuate courts' tendencies towards appointing guardians because legally recognizing only two support options broadly pushes individuals into one of two categories. Distributing these individuals into such broad categories places individuals under an unnecessary or overly broad guardianship, which threatens to strip individuals of their most basic rights.

Support needs are not one-size-fits-all models, and each individual's situation differs from the rest. It is essential that the United States ratify the CRPD and legally recognize additional protective alternatives as a way to cater to every person's needs, while empowering and maintaining the individual's capacity to exercise fundamental rights.³⁴² At a minimum, the Department of Education should require that special education school

340. See *supra* Section II.C. Additionally, as notably written in the *Scalia/Ginsburg* opera:

We must not stop in our mission to right every wrong—
Not until We the People and our Constitution are living
In a nation, in a place
That, regardless of station or race,
Is a nation where *all* of us truly belong!

Derrick Wang, *Scalia/Ginsburg: A (Gentle) Parody of Operatic Proportions*, 38 COLUM. J.L. & ARTS 237, 255–56 (2015) (footnotes omitted). Although the direct language of the opera relates to “station or race,” this statement can be extended to all persons—including those with disabilities.

341. For a summary of state legislative guardianship enactments in 2018, see generally A.B.A. COMM'N ON LAW & AGING, STATE ADULT GUARDIANSHIP LEGISLATION SUMMARY: DIRECTIONS OF REFORM—2018 (2018), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-adult-guardianship-legislative-summary.pdf [<https://perma.cc/PGA6-SSVT>].

342. According to a 2018 National Council on Disability report, “about 1.3 million Americans are subject to guardianship.” Shaun Heasley, *Federal Report Calls for Alternatives to Guardianship*, DISABILITY SCOOP (Mar. 23, 2018), <https://www.disabilityscoop.com/2018/03/23/federal-alternatives-guardianship/24893/> [<https://perma.cc/B3AD-X3XM>]. While a guardianship aims to protect the individual, the report found that current guardianship systems are often not able to provide adequate monitoring procedures for these models. *Id.* Furthermore, once the individual is placed under guardianship, it is very uncommon for the individual to attempt to restore his or her rights. *Id.*

systems offer students and families information on *every* available support option. This basic requirement would be a step towards ensuring an individual is not unnecessarily stripped of his or her most basic rights. Providing this information would also help to inform society and encourage a change in its current view of individuals with disabilities—shifting the focus towards the best ways to empower this population instead of solely viewing these individuals as vulnerable and needing protection.

It is situations like Jenny's that should motivate a change towards empowering this population within society. As Jenny herself explained, every single person—regardless of his or her ability or disability—needs help making decisions, and taking away the person's ability to make his or her own decisions cannot be justified by the fact that the individual may need some type of support. Consequently, an individual's disability should not limit his or her capability to exercise even the most basic rights. As the ADA specifically states, "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society."³⁴³

343. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(a)(1) (2012).

