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A POTENTIAL CIVIL DEATH: GUARDIANSHIP OF PERSONS WITH DISABILITIES IN UTAH

Sydney J. Sell*

I. INTRODUCTION

The dictionary defines guardianship as “care; responsibility; charge.”¹ Guardianship presents itself as a noble, sacrificing mechanism. While the idea of guardianship in general may be a socially accepted and oftentimes ignored instrument, many do not consider just how life-altering the appointment of a guardian can be. While the term “civil death” has traditionally been used to describe convicts stripped of all legal rights,² legal scholars have used the same term to describe guardianship proceedings.³ While appointing a guardian to a child likely will not alter the rights previously held by such a child, adults with disabilities are particularly vulnerable to being stripped of their legal rights. Society has greatly improved on how we treat adults with disabilities, but there are still several issues surrounding guardianship proceedings throughout the United States and, more specifically, in Utah.

This Note tracks guardianship and guardianship-related issues throughout time while discussing reformation efforts and mechanisms to mitigate the damages guardianship may impose upon a person, especially a person with a disability. Part

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¹ *Guardianship*, RANDOM HOUSE UNABRIDGED DICTIONARY (2d ed. 1987).

² See Gabriel J. Chin, *The New Civil Death: Rethinking Punishment in the Era of Mass Conviction*, 160 U. PA. L. REV. 1789, 1790 (2012) (“Civil death extinguished most civil rights of a person convicted of a crime . . .”). The first use of the term civil death was used by Sir William Blackstone, who “famously observed that upon marriage women suffer[] civil death in the sense that all of the dimensions of her legal personhood were transferred into the hands of her husband . . .” Gerald Quinn, Professor, Ctr. for Disability Law & Policy, Nat’l Univ. of Ir. Galway, Address at Tbilisi State University, Georgia: From Civil Death to Civil Life: Perspectives on Supported Decision-Making for Persons with Disabilities 3 (Dec. 20, 2015) (transcript available through the National University of Ireland Galway).

³ See CHAIRMAN OF SUBCOMM. ON HEALTH AND LONG-TERM CARE, H. COMM. ON AGING, 100TH CONG., ABUSES IN GUARDIANSHIP OF THE ELDERLY AND INFIRM: A NATIONAL DISGRACE 67 (Comm. Print 1987) (stating that guardianship “in many ways is the most severe form of civil deprivation. . . .”); see also Quinn, *supra* note 2, at 8 (“[Persons with disabilities] have suffered extensive civil death in law especially through the imposition of legal guardianship.”); Michael L. Perlin, “*Striking for the Guardians and Protectors of the Mind*”: *The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 PA. ST. L. REV. 1159, 1159 (2013) (stating that entry of guardianship orders in much of the world is a kind of “civil death”).

II of this Note outlines how guardianship in general has evolved throughout our history in tandem with evolving social norms and a more thorough scientific understanding of intellectual disabilities. Part III outlines recent reform in adult guardianship proceedings and discusses alternatives to guardianship, such as supported decision-making. Part IV introduces Utah's most recent guardianship bill, which removes the requirement of counsel in certain situations and describes the constitutional, legal, and social consequences both the State of Utah and people with disabilities may face. Part V describes Canada's supported decision-making legislation as model legislation and puts forth the view that guardianship should be seen as a last resort.

II. GUARDIANSHIP: IN GENERAL

A. *A Historical Look*

Guardianship⁴ traces its roots back to ancient times, when humans still attributed mental disabilities to the supernatural, the devil, or a curse.⁵ This perception changed with the studies of Hippocrates, a Greek physician, who introduced the notion that mental disabilities were natural.⁶ Although, this is not to claim that mental disabilities were understood or accepted per se.⁷ Guardianship was traditionally used to control the finances of incapacitated adults, but the medical, personal, and legal needs of those persons were either ignored or subjected to religious rituals.⁸ In other civilizations around the globe, guardianship mimicked the Greeks.⁹

Guardianship developed significantly in English common law when the idea of *parens patriae* caught hold.¹⁰ This was first announced in the Statute de Praerogativa Regis, reading:

⁴ There are many different names for guardianship, such as “guardianship of the person,” “guardianship of the estate,” and “conservatorship.” 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, 37–38 (1999). For purposes of simplicity, this Article will use “guardianship” as a general term.

⁵ *Id.* at 40.

⁶ *Id.* at 41.

⁷ *Id.*

⁸ *Id.*

⁹ *Id.* at 43–48.

¹⁰ Nicole M. Arsenault, *Start with a Presumption She Doesn't Want to be Dead: Fatal Flaws in Guardianship of Individuals with Intellectual Disability*, 35 *L. & INEQ.* 23, 26 (2017).

[A] king . . . as the political father and guardian of his kingdom, has the protection of all his subjects, and their lands and goods; and he is bound, in a more peculiar manner to take care of those who, by reason of their imbecility and want of understanding, are incapable of taking care of themselves.¹¹

The doctrine of *parens patriae* refers to the duty of the state to serve as a protector, or father, to those who do not have the capacity to care for themselves.¹² English common law separated said persons into two groups: “Idiots” and “Lunatics.”¹³ A person labeled an “idiot” was seen as naturally disabled, often born with a disability, and unable to perform simple daily tasks.¹⁴ These people were also labeled “innocents,” a likely euphemistic term used to both protect family members and to designate that these people did not pose danger to their communities.¹⁵ Lunatic, by contrast, was a term used to define a wide variety of conditions and ailments.¹⁶ These were often temporary conditions, and determinations of lunacy were often made based on a perceived threat of danger posed by the person.¹⁷ While the King could seize lands from both an idiot and lunatic, he could only administer the lands of a lunatic.¹⁸ In medieval England, the protection of the mentally disabled person, and not just their property, slowly developed and eventually became the new norm.¹⁹ This outlook was not based on compassion, but instead was meant “to prevent the mentally disabled from becoming a public burden or dissipating their assets to the detriment of their heirs.”²⁰

The doctrine of *parens patriae* caught hold in the United States, making its way overseas just as most of our legal doctrine has. While the doctrine was used in early colonial America,²¹ it wasn’t fully articulated by a court until 1890, when the Supreme Court decided *Late Corp. of The Church of Jesus Christ of Latter-Day Saints v. United States*.²² In *Late*, the Court allowed redistribution of property taken from the Church to other users, referencing the doctrine of *parens patriae* as part of

¹¹ NICHOLAS N. KITTRIE, *THE RIGHT TO BE DIFFERENT: DEVIANCE AND ENFORCED THERAPY* 59 (1971) (internal quotation marks omitted).

¹² *Parens Patriae*, BLACK’S LAW DICTIONARY (9th ed. 2006).

¹³ Arsenault, *supra* note 10, at 26.

¹⁴ Peter Rushton, *Lunatics and Idiots: Mental Disability, the Community, and the Poor Law in North-East England, 1600–1800*, 32 *MED. HIST.* 34, 37 (1988).

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ MARY F. RADFORD, *GEORGIA GUARDIANSHIP AND CONSERVATORSHIP* § 1.1 (2017–18 ed. 2017).

¹⁹ John Parry, *Incompetency, Guardianship, and Restoration*, in *THE MENTALLY DISABLED AND THE LAW* 369, 369 (3d ed. 1985).

²⁰ *Id.*

²¹ Johns, *supra* note 4, at 53.

²² 136 U.S. 1, 56–57 (1890).

their rationale.²³ The Court also expressly delegated this “fatherly” power to the legislature, instead of the President.²⁴

The doctrine of *parens patriae* is widely applicable in a variety of court proceedings and legislative bills, from juvenile detention proceedings to state tort claims.²⁵ The process of appointing a guardian has been one natural extension of the doctrine, as guardians are seen as enforcers of court orders.²⁶ Guardianship has evolved throughout the ages, in tandem with changing social norms, more readily available scientific information, and shifting legal principles.

B. Elements of a Guardianship

Guardianship is a state-specific legal field.²⁷ Today, each state has laws dealing with guardianship of individuals with mental disabilities.²⁸ In order to analyze guardianship as a whole, it is necessary to identify the common elements in each guardianship proceeding: the potential ward,²⁹ their potential guardian, notice, a determination of incapacity, a hearing, and an order. For each element, this Note will define generally what it entails and then specify how it fits in with Utah’s guardianship proceedings.

Wards are generally a child, an elderly individual, or a person with a disability.³⁰ As mentioned previously, this Note focuses specifically on guardianship for persons with disabilities. Guardians can range from parents, siblings, and other family members to state agencies. For example, both Pennsylvania and Arkansas have public agencies on their list of who may serve as a guardian,³¹ and South

²³ *Id.* at 58–59.

²⁴ *Id.* at 58 (“[I]t now resides in the legislative department, ready to be called into exercise whenever required for the purposes of justice and right . . .”).

²⁵ See, e.g., Benjamin E. Metz, Reconstitutionalizing *Parens Patriae*: How Federal *Parens Patriae* Doctrine Appropriately Permits State Damages Suits Aggregating Private Tort Claims (unpublished note) (on file with Columbia Law Review), <http://www.law.columbia.edu/sites/default/files/microsites/career-services/Reconstitutionalizing%20Parens%20Patriae.pdf> [<https://perma.cc/36YB-AS8R>] (elaborating on the *parens patriae* jurisprudence).

²⁶ See *Cruzan v. Harmon*, 760 S.W.2d 408, 425 (Mo. 1988) (“The guardian is the delegatee of the state’s *parens patriae* power.” (citations omitted)).

²⁷ Sally Balch Hurme, *Current Trends in Guardianship Reform*, 7 MD. J. CONTEMP. LEGAL ISSUES 143, 144 (1996).

²⁸ Meta S. David, *Legal Guardianship of Individuals Incapacitated by Mental Illness: Where Do We Draw the Line?* 45 SUFFOLK U. L. REV. 465, 468 (2012).

²⁹ States use different terminology in place of “ward.” In this Article, I will use “ward” to mean the respondent in a guardianship proceeding.

³⁰ See *Guardianships/Conservatorships*, JUSTIA, <https://www.justia.com/estate-planning/guardianships-conservatorships/> [<https://perma.cc/8PRU-A5R6>] (last visited July 30, 2018).

³¹ See 20 PA. CONS. STAT. § 5511(f) (2005); ARK. CODE ANN. § 28-65-203(i)(4) (2014)

Dakota allows the Department of Human Services to be appointed as guardian.³² It is the court's responsibility to determine that the potential guardian will not profit from appointment or harm the ward.³³ In Utah, any adult may request to become a guardian.³⁴ Furthermore, the Utah Legislature established a statewide program that allows the Office of Public Guardian to "serve as a guardian, conservator, or both for a ward upon appointment by a court when no other person is able and willing to do so and the office petitioned for or agreed in advance to the appointment."³⁵

Notice is a particularly vital part of a guardianship proceeding involving an individual with a disability. Courts and lawmakers make certain that the respondent learns of the proceeding in a method they will be able to understand. In New York, West Virginia, Rhode Island, and Pennsylvania, for example, notice must meet specific requirements to be acceptable.³⁶ These include large and bold letters, an explanation of the purpose of the notice, a list of the respondent's rights, and consequences of guardianship.³⁷ Some courts have invalidated guardianship proceedings on the basis of failure to give notice.³⁸ For example, a Kansas court found a guardianship order void when the respondent was not notified of an alteration to the existing guardianship order.³⁹

In Utah, notice of a guardianship hearing must be given to many people, including:

- (a) the ward or person alleged to be incapacitated and spouse, parents, and adult children of the ward or person; (b) any person who is serving as guardian or conservator or who has care and custody of the ward or person; . . . [and] (d) any guardian appointed by the will of a parent who died later or spouse of the incapacitated person⁴⁰

The notice must also "be in plain language and large type . . . indicate the time and place of the hearing, the possible adverse consequences of the person receiving

³² S.D. CODIFIED LAWS § 29A-5-110 (2017) (stating that the appointment of the Department of Human Services as guardian may be made "only . . . if there is no individual, nonprofit corporation, bank or trust company or other public agency that is qualified and willing to serve.").

³³ See ME. STAT. tit. 18-A, § 5-311(c) (2007); 33 R.I. GEN. LAWS § 33-15-6(a)-(b) (2015); VT. STAT. ANN. tit. 14, § 3072(b) (2010).

³⁴ *Procedure for Appointing a Guardian for an Adult*, UTAH COURTS, <https://www.utcourts.gov/howto/family/gc/guardianship/> [<https://perma.cc/WY4G-YV9L>] (last modified June 11, 2018); see also UTAH CODE ANN. § 75-5-303(1) (2018) ("[A]ny person interested in the incapacitated person's welfare may petition for a finding of incapacity and appointment of a guardian.").

³⁵ UTAH CODE ANN. § 62A-14-105 (2018).

³⁶ Hurme, *supra* note 27, at 147.

³⁷ *Id.*

³⁸ *Id.* at 148.

³⁹ *In re Guardianship & Conservatorship of Fogle*, 837 P.2d 842, 846 (Kan. Ct. App. 1992).

⁴⁰ UTAH CODE ANN. § 75-5-309(1)(a)-(d) (2018).

notice of rights, a list of rights, including the person's own or court appointed counsel, and a copy of the petition."⁴¹

After a petition is filed, the first step in all guardianship proceedings is to hold a hearing to make a determination of incapacity.⁴² Most courts base this determination on the functional characteristics of the respondent.⁴³ In Utah, a petitioner in a guardianship proceeding must prove, by clear and convincing evidence, that the respondent is incapacitated.⁴⁴ This is defined as "lack[ing] 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 decisions; or (c) provide for necessities such as food, shelter, clothing, health care, or safety."⁴⁵ Once a respondent is deemed incapacitated, the court may approve a petitioner's request to become a guardian, although the court may appoint someone other than the petitioner as guardian.⁴⁶ Typically, if the respondent (or potential ward) has not chosen a lawyer, the court is required to appoint one.⁴⁷

Hearings are typically quick, streamlined, and efficient. While many states require the person alleging incapacitation to be present at the hearing, evidence shows that this seldom occurs.⁴⁸ Oftentimes courts view these hearings as potentially traumatizing—another example of their paternalistic outlook—and waive the requirement.⁴⁹ In Utah, the allegedly incapacitated person is required to be present at the hearing.⁵⁰ The person seeking the guardianship may request this requirement

⁴¹ *Id.* § 75-5-309(2).

⁴² *See, e.g., id.* § 75-5-303(2)(a) (stating that after a petition has been filed, "the court shall set a date for hearing on the issues of incapacity.").

⁴³ Hurme, *supra* note 27, at 157.

⁴⁴ *See* UTAH COURTS, *supra* note 34 ("Evidence of incapacity"); *see also* UTAH CODE ANN. § 75-1-201(22) (2018) ("'Incapacitated' or 'incapacity' is measured by functional limitations and means a judicial determination after proof 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."); UTAH CODE ANN. § 75-5-304 (2018) ("The court may appoint a guardian as requested if it is satisfied that the person for whom a guardian is sought is incapacitated and that the appointment is necessary or desirable as a means of providing continuing care and supervision of the incapacitated person.").

⁴⁵ UTAH CODE ANN. § 75-1-201(22) (2013).

⁴⁶ *See* UTAH CODE ANN. § 75-5-311 (2018).

⁴⁷ *Id.* § 75-5-303(2)(b) (stating that "[u]nless the allegedly incapacitated person has counsel of the person's own choice, the court shall appoint an attorney to represent the person . . .").

⁴⁸ *See* Catherine Stevenson & Elizabeth Capezuti, *Guardianship: Protection Versus Peril*, 12 GERIATRIC NURSING 11, 11 (1991) (finding only 10 percent of sample of incompetent persons attended guardianship hearing).

⁴⁹ Hurme, *supra* note 27, at 155.

⁵⁰ UTAH CODE ANN. § 75-5-303(5)(a) (2018).

be waived, but the court will appoint a court visitor to investigate.⁵¹ This investigation may also be waived, if clear and convincing evidence is presented that proves the person either has fourth stage Alzheimer's, is in a coma, or has an intellectual disability and an intelligence quotient score under 25.⁵²

Once the case has been decided, the judge will issue a guardianship order. These orders may be plenary, meaning the guardian has all decision-making power; or limited, meaning the court will designate which powers the guardian has and which the incapacitated individual will retain.⁵³ In Utah, the guardianship statute mandates that the "guardian's authority will be limited unless nothing less than a full guardianship is adequate."⁵⁴ For the past several decades, disability rights advocates have been calling for tailored guardianship.⁵⁵ Many states have provisions that either encourage or mandate limited orders over plenary orders.⁵⁶ Unfortunately, these mandates have not guaranteed that more limited orders are granted. Studies have shown that the number of limited orders being granted before and after reform demonstrate that statutory mandates have not changed much.⁵⁷

C. *The Current Standard: Surrogate Decision-Making and Best Interest Standard*

The current standards for adult guardianship are either surrogate decision-making, stemming from the government's duty to protect its citizens, or best interest decision-making.⁵⁸ Surrogate, or substitute, decision-making means the guardian uses their own judgement to make decisions in place of the incapacitated ward.⁵⁹ Best interest decision-making is a much less clear standard. The substituted decision-making standard is based upon the Uniform Guardianship and Protective Proceedings Act:

Except as otherwise limited by the court, a guardian shall make decisions regarding the ward's support, care, education, health, and welfare. A guardian shall exercise authority only as necessitated by the ward's limitations and, to the extent possible, shall encourage the ward to

⁵¹ *Id.*

⁵² *Id.* § 75-5-303(5)(b).

⁵³ See Mary Joy Quinn & Howard S. Krooks, *The Relationship Between the Guardian and the Court*, 2012 UTAH L. REV. 1611, 1620.

⁵⁴ UTAH COURTS, *supra* note 34.

⁵⁵ Hurme, *supra* note 27, at 161–62.

⁵⁶ *Id.* at 163–66.

⁵⁷ See Kris Bulcroft et al., *Elderly Wards and their Legal Guardians: Analysis of County Probate Records in Ohio and Washington*, 31 GERONTOLOGIST 156, 156–64 (1991) (stating that 100% of petitions were granted as orders, and only 7% were tailored).

⁵⁸ See generally Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491 (analyzing the two standards and how they work in reality).

⁵⁹ See Norman L. Cantor, *The Bane of Surrogate Decision-Making: Defining the Best Interests of Never-Competent Persons*, 26 J. LEGAL MED. 155, 155 (2005).

participate in decisions, act on the ward's own behalf, and develop or regain the capacity to manage the ward's personal affairs. A guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian. A guardian at all times shall act in the ward's best interest and exercise reasonable care, diligence, and prudence.⁶⁰

This seems to articulate the use of substitute decision-making along with the best interest standard. This tension was not resolved until the publishing of the more current Uniform Laws. In a revised comment, the Act stated:

Although the guardian only need consider the ward's desire and values to the extent known to the guardian, that phrase should not be read as an "out" for the guardian. Instead, the guardian must make an effort to learn the ward's personal values and ask the ward about the ward's desires before the guardian makes a decision. When the guardian is making decisions for the ward, the guardian, wherever possible, should use the substitute decision-making standard Only when a guardian is not able to ascertain information about the ward's preferences and desires should a guardian use a traditional best interest decision-making standard. In determining the best interest of the ward, the guardian should again consider the ward's personal values and expressed desires.⁶¹

In reality, guardians may not strictly adhere to their state's decision-making mandates. It is unlikely these issues would be litigated in court, and both standards overlap enough to make them nearly indistinguishable. Both standards demonstrate that even the most conscientious guardian will make decisions that derive from his or her own morals and values. This conclusion, along with a variety of other concerns, is what has driven reformers to suggest a completely new type of decision-making,⁶² which reduces the guardian's own input and instead allows the ward or incapacitated person to continue to exercise their autonomy.

⁶⁰ UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314(a) (NAT'L CONFERENCE OF COMM'RS ON UNIF. STATE LAWS 1997). A similar provision was codified in the Utah Code in 2018. *See* UTAH CODE ANN. § 75-5-312(7) (2018).

⁶¹ UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314 cmt. 8A (NAT'L CONFERENCE OF COMM'RS ON UNIF. STATE LAWS 2003).

⁶² *See* Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PA. ST. L. REV. 1111, 1115–21 (2013) (describing various concerns that have led to the push for supported decision-making).

III. RECENT REFORM AND SUPPORTED DECISION-MAKING

A. Reform Efforts in the Past 3 Decades

While twentieth-century guardianship proceedings mirrored this country's mass institutionalization of people with disabilities, guardianship reform has made stable progress since.⁶³ The first guardianship reform was dedicated to protecting wards from abuse and neglect.⁶⁴ This included creating a stricter guardianship procedure to ensure that potential guardians would not pose a risk to their wards.⁶⁵ Over the past few decades, reform has instead focused on "the segregating nature of guardianship" and pushed for less restrictive alternatives and created limited, or tailored, guardianships.⁶⁶ Several states have responded by enacting both procedural and substantive guardianship laws to mitigate both the segregating nature of guardianship and risk of abuse.⁶⁷ Now, each state has embedded into its guardianship law a requirement that courts must examine less restrictive alternatives to guardianship, such as joint bank accounts and health care directives.⁶⁸ There has also been a shift in how courts will determine incompetency, from a medical outlook (i.e., based on a medical diagnosis) to a functional ability approach.⁶⁹ Furthermore, many states have heightened their burden of proof in proceedings devoted to determining incompetency.⁷⁰

Critics of guardianship have also pushed for granting limited guardianships. While guardianship traditionally has been an "all or nothing proposition," limited guardianship confers specific powers to the guardian, and reserves all others for the incapacitated individual.⁷¹ Although this option is available to nearly all courts, it is reluctantly chosen.⁷² One explanation for this may be impracticability. For individuals deemed incapacitated, "it is rare to have the ability to make sound

⁶³ 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, 876–80 (2016).

⁶⁴ *Id.* at 878.

⁶⁵ *Id.*

⁶⁶ *Id.*

⁶⁷ 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, 171 (2010).

⁶⁸ Burke, *supra* note 63, at 878.

⁶⁹ Salzman, *supra* note 67, at 171.

⁷⁰ *Id.* at 171–72.

⁷¹ Nancy J. Knauer, *Defining Capacity: Balancing the Competing Interest of Autonomy and Need*, 12 TEMP. POL. & C.R. L. REV. 321, 336–37 (2003).

⁷² *Id.* at 337; see Leslie Salzman, *Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 279, 294–96 (2011); see also UTAH CODE ANN. § 75-5-304(2)(a) (2018) ("The court shall prefer a limited guardianship and may only grant a full guardianship if no other alternative exists. If the court does not grant a limited guardianship, a specific finding shall be made that nothing less than a full guardianship is adequate.").

decisions in one area of life and be incompetent in another.”⁷³ Limited guardianships may reserve decision-making power to the ward, but in reality, the ward’s wishes may not be considered by the guardian with the ward’s only recourse being a motion to remove or replace the guardian.⁷⁴

While these reforms signal a positive change in the way our nation views and treats people with disabilities, they have not dealt with the underlying issues of guardianship, which include taking away an individual’s autonomy and ability to make decisions, and giving that power to another person.

A. Supported Decision-Making

In recent years, disability advocates and critics of guardianship have put forth a new mechanism designed to replace guardianship for assisting individuals with disabilities, titled supported decision-making.⁷⁵ This stemmed from the 2006 General Assembly of the United Nations’ adoption of the Convention on the Rights of Persons with Disabilities,⁷⁶ which “signaled an international shift in the focus and attention for persons with disabilities.”⁷⁷ Supported decision-making is the process by which an individual with a disability obtains a team of people to assist him or her in making decisions, whether it be medical, personal, or financial.⁷⁸

The goal of supported decision-making is to give people with disabilities the tools to make decisions for themselves, an important part of being a human being.⁷⁹ As one legal commentator puts it, “[t]he concept of supported decision making [sic] is predicated on the basic principle that all people are autonomous beings who develop and maintain capacity as they engage in the process of their own decision making, even if some level of support is needed to do so.”⁸⁰ There is also some evidence that the ability to make one’s own decisions relates directly to the health and well-being of that individual.⁸¹ When a person with a disability is given the

⁷³ Burke, *supra* note 63, at 879.

⁷⁴ Salzman, *supra* note 67, at 175–76.

⁷⁵ See, e.g., AM. BAR ASS’N, COMM’N ON DISABILITY RIGHTS, REPORT TO THE HOUSE OF DELEGATES (2017), https://www.americanbar.org/content/dam/aba/administrative/SDM%20Resolution_RevisedFinal%20113.authcheckdam.pdf [https://perma.cc/6494-ADVA] (“[T]he [ABA] urges . . . 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 . . .”).

⁷⁶ Convention on the Rights of Persons with Disabilities and Optional Protocol, Dec. 13, 2006, 2515 U.N.T.S. 3.

⁷⁷ Burke, *supra* note 63, at 880.

⁷⁸ CTR. FOR PUBL. REP., *Supported Decision-Making*, <http://supporteddecisions.org/> [https://perma.cc/F54V-564B].

⁷⁹ See Kohn et al., *supra* note 62, at 1128.

⁸⁰ Salzman, *supra* note 67, at 180 (citation omitted).

⁸¹ See Nina A. Kohn, *Elder Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1, 27–30 (2006) (stating that psychological literature demonstrates that a sense of self control may positively impact an individual’s physical and psychological health).

power to determine their own future, they demonstrate “increased and enhanced independence, employment, community integration, and safety.”⁸²

While supported decision-making has made a large push into the world of guardianship, it is slow to catch hold in legislation. In response to the standards announced in the 2006 General Assembly, many international jurisdictions have created decision-making mechanisms as alternatives to standard guardianship proceedings.⁸³ The “pioneering legislation on this front”⁸⁴ has been the adoption of Canada’s Representation Agreement Act,⁸⁵ discussed further in Part V. In the United States, progress has been sluggish. Texas adopted supported decision-making alternatives to guardianship in 2015,⁸⁶ making it the first state to formally recognize supported decision-making.⁸⁷ Delaware, Maine, Missouri, New Mexico, Wisconsin, and the District of Columbia have been the only jurisdictions to follow suit thus far.⁸⁸

The concept of supported decision-making also has backings in the integration mandate of Title II of the Americans with Disabilities Act of 1990 (the “ADA”).⁸⁹ The integration mandate was born in 1999, when the Supreme Court decided the pivotal case of *Olmstead v. L.C.*⁹⁰ The case involved two women with disabilities living in a state-run psychiatric institution.⁹¹ After undergoing clinical assessments, employees recommended that both women be treated in a community-based setting; the state ignored these recommendations.⁹² Both women sued, and the Supreme Court held that “unjustified isolation” of an individual with a disability constitutes discrimination under Title II of the ADA.⁹³ While this holding was specific to unjustified institutionalization, the Court articulated principals that can be used to criticize the isolating features of adult guardianship. For example, the Court elaborated on the damage segregation can cause to both the individual and society,

⁸² Jonathan G. Martinis, *Supported Decision-Making: Protecting Rights, Ensuring Choices*, 36 BIFOCAL 107, 110 (2015) (citations omitted).

⁸³ Burke, *supra* note 63, at 881.

⁸⁴ *Id.* (citation omitted).

⁸⁵ Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.).

⁸⁶ TEX. EST. CODE ANN. §§ 1002.0015, 1357 (2015).

⁸⁷ Burke, *supra* note 63, at 881.

⁸⁸ See DEL. CODE ANN. tit. 16, § 9401A et seq. (2018); D.C. Code § 7-2131(11) (2018); ME. REV. STAT. ANN. tit. 18-C, § A-2 (2017); MO REV. STAT. XXXI, §475.010(13)(a) (2018); N.M. STAT. ANN. § 45-5-303(4)(a)-(d) (West 2018); WIS. STAT. §§ 52.01–52.32 (2017). Alaska has also codified supported decision-making, effective in December 2018. H.B. 336, 30th Leg., 2nd Reg. Sess. (Alaska 2017).

⁸⁹ Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213 (1990).

⁹⁰ 527 U.S. 581 (1999).

⁹¹ *Id.* at 593.

⁹² *Id.*

⁹³ *Id.* at 597.

including perpetuating stereotypes⁹⁴ and limiting the life activities of people with disabilities.⁹⁵

Like institutional confinement, guardianship oftentimes has the practical effect of isolating individuals with disabilities. Once an individual loses the ability to make his or her own decisions, he or she may also lose the chance to stay in contact with friends, stay in school or at a particular job, or live in a certain place. This has the effect of isolating the individual, and therefore the argument can be made that guardianship goes against the mandate announced in *Olmstead* by choosing to isolate an individual rather than support them in their decision-making.⁹⁶

Although it has been nearly twelve years since supported decision-making was first encouraged by the United Nations, there is relatively little empirical research on how it is implemented and how it impacts individuals with disabilities. As more states adopt supported decision-making as an alternative to guardianship, more evidence will demonstrate whether the mechanism works not just in theory, but in reality. The growth of support for alternative decision-making mechanisms signals that our country is continuing to improve and reform how we treat people with disabilities.

IV. A STEP IN THE WRONG DIRECTION?

A. Utah House Bill 101

In March of 2016, the Utah Senate passed House Bill 101, sponsored by Representative Fred Cox, which made a significant change to guardianship proceedings.⁹⁷ The bill provides that counsel for the alleged incapacitated individual is not required if the person is the child of petitioner, the person's estate does not exceed \$20,000, the person appears in court with the petitioner, the person is given the chance to communicate, if possible, their acceptance of the appointment, and the court is satisfied that counsel is not needed.⁹⁸

While this bill seems drastic, Utah is not the first state to implement such an exception. Six other states, including Massachusetts, Mississippi, Nebraska,

⁹⁴ *Id.* at 600 (“[I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”).

⁹⁵ *Id.* at 601 (“[C]onfinement 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.”).

⁹⁶ See Salzman, *supra* note 67, at 161 (“[T]he *Olmstead* integration mandate provides a basis to oppose the imposition of guardianship as a form of unlawful segregation.”).

⁹⁷ Marjorie Cortez, *Legislature Eliminates Legal Counsel Requirement for Disabled Adults If Parents Seek Guardianships*, DESERET NEWS (March 10, 2016), <https://www.deseretnews.com/article/865649823/Legislature-eliminates-legal-counsel-requirement-for-disabled-adults-if-parents-seek-guardianships.html> [https://perma.cc/66S3-HTEE].

⁹⁸ H.B. 101, 2016 Gen. Session (Utah 2016).

Pennsylvania, Wisconsin, and Wyoming, have adopted guardianship statutes that do not guarantee the appointment of counsel.⁹⁹ Nebraska's statute states that a court may appoint an attorney if the person indicates a desire for one.¹⁰⁰ Similarly, the Massachusetts statute states that the court shall appoint counsel if it is either requested or the court determines the respondent is inadequately represented.¹⁰¹ Wisconsin's statute is similar, but while counsel is not guaranteed, a guardian ad litem is.¹⁰² A right to counsel in Wyoming exists if ordered by the court, but respondents have a right to a guardian ad litem.¹⁰³ Mississippi does not state that respondents have a right to counsel,¹⁰⁴ and Pennsylvania states that counsel shall be appointed in appropriate cases.¹⁰⁵

The bill has gained both praise and support from individuals and groups in the Utah community.¹⁰⁶ The rationale behind the bill, and the echo from supporters of the bill, centers around the expense families incur when petitioning for guardianship for a child they have raised their whole life, who turned eighteen, and subsequently became an adult.¹⁰⁷ The criticism has seemingly overpowered the support. Outcry has come from disability rights advocates, who argue that this bill violates both due process and the ADA.¹⁰⁸ Even supporters admit the bill could cause some issues in

⁹⁹ AM. BAR ASS'N COMM'N ON LAW AND AGING, REPRESENTATION AND INVESTIGATION IN GUARDIANSHIP PROCEEDINGS (2016), https://www.americanbar.org/content/dam/aba/administrative/law_aging/chartrepresentationandinvestigation.authcheckdam.pdf [<https://perma.cc/RDE3-YLQB>].

¹⁰⁰ NEB. REV. STAT. § 30-2619(b) (2016).

¹⁰¹ MASS. GEN. LAWS. ch. 190B § 5-106(a) (2018).

¹⁰² WIS. STAT. § 54.42(1)(c) (2018). A guardian ad litem is an adult who is legally responsible for advocating on behalf of a ward for the duration of a legal proceeding. *Guardian ad Litem*, MINN. JUDICIAL BRANCH, <http://www.mncourts.gov/Help-Topics/Guardian-Ad-Litem.aspx> [<https://perma.cc/8FUC-5EDH>].

¹⁰³ WYO. STAT. ANN. § 3-1-205(a)(iv) (West 2018).

¹⁰⁴ MISS. CODE ANN. § 93-13-255 (West 2018).

¹⁰⁵ 20 PA. CONS. STAT. § 5511(a) (2018).

¹⁰⁶ See *infra* notes 107 and 108.

¹⁰⁷ See, e.g., Marjorie Cortez, *Bill to Eliminate Requirement for Prospective Wards' Legal Counsel in Guardianship Cases Put On Hold*, KSL NEWS (Feb. 3, 2016, 8:16 PM) <https://www.ksl.com/?sid=38382688&nid=960> [<https://perma.cc/FL8V-C7ZP>] (describing Senator Cox's rationale as a way to "assist families who have adopted or raised a child with disabilities from birth and have the young adult's best interests in mind . . .").

¹⁰⁸ See, e.g., Letter from Thomas F. Coleman, Legal Dir., Spectrum Inst., to Governor Gary Herbert, State of Utah (March 14, 2016), <http://spectruminstitute.org/guardianship/utah-governor-letter.pdf> [<https://perma.cc/T8LK-YTXZ>] ("Without counsel, [persons with disabilities] do not have access to justice."); *ACLU of Utah Files Lawsuit over Right to Counsel for People with Disabilities*, UTAHPOLICY.COM (July 9, 2017), <http://utahpolicy.com/index.php/features/featured-articles/13712-aclu-of-utah-files-lawsuit-over-right-to-counsel-for-people-with-disabilities> [<https://perma.cc/7ESN-QXSH>] ("When facing the loss of the right to make deeply personal decisions for themselves for the rest of their lives, people with disabilities need to have unfettered access to legal assistance."); Cortez, *supra* note 107 ("We believe the right to counsel, especially in proceedings that have the potential to abridge a person's fundamental rights, are exactly where independent

guardianship proceedings.¹⁰⁹ This controversial bill has prompted at least one lawsuit to be filed¹¹⁰ and poses several potential constitutional, legal, and social consequences.

B. *Is it Constitutional?*

“A judicial finding of incapacity and the granting of a guardianship can result in a grave deprivation of individual liberty interests, legally precluding the right to make and carry out the most basic decision about how to live one’s life.”¹¹¹ While the right to counsel for a criminal defendant is a long-established¹¹² and expected right, the right to counsel in a guardianship case is a more fragile concept. Courts have established that the deprivation of rights that occurs with appointment of a guardian is oftentimes worse than those of a convicted murderer.¹¹³ While convicted felons may still have the right to choose even the simplest of things, such as when to exercise, sleep, or with whom to associate, wards are stripped of even the most basic of choices.¹¹⁴

Under the Fourteenth Amendment, no person shall be deprived of “life, liberty, or property, without due process of law”¹¹⁵ Courts have held that appointment of guardianship is considered a deprivation of liberty.¹¹⁶ Traditionally, guardianship

representation is most important.” (internal quotation marks omitted) (quoting Andrew Riggle, public policy advocate at the Disability Law Center)).

¹⁰⁹ See, e.g., Cortez, *supra* note 107 (“[Senator] Cox acknowledged that some petitioners may not have the child’s best interests at heart.”).

¹¹⁰ See generally Complaint, Disability Law Cent. v. Utah, No. 2:17-cv-00748-JNP (D. Utah July 6, 2017), <http://www.acluutah.org/images/2-Complaint.pdf> [<https://perma.cc/27SE-8W3Z>].

¹¹¹ Eleanor M. Crosby & Rose Nathan, *Adult Guardianship in Georgia: Are the Rights of Proposed Wards Being Protected? Can We Tell?*, 16 QUINNIPIAC PROB. L.J. 249, 251 (2003).

¹¹² See, e.g., Gideon v. Wainwright, 372 U.S. 335 (1963) (establishing the constitutional right to a lawyer).

¹¹³ See CHAIRMAN OF SUBCOMM. ON HEALTH AND LONG-TERM CARE, H. COMM. ON AGING, 100TH CONG., ABUSES IN GUARDIANSHIP OF THE ELDERLY AND INFIRM: A NATIONAL DISGRACE 8 (Comm. Print 1987) (statement of Claude Pepper, Chairman of H. Select. Comm. On Aging) (“The typical ward has fewer rights than the typical convicted felon.”).

¹¹⁴ See Bobbe Nolan, *Functional Evaluation of the Elderly in Guardianship Proceedings*, 12 L. MED. & HEALTH CARE 210, 214 (1984) (“[A ward] may be deprived of control over his residence, his associations, his property, his diet, and his ability to go where he [or she] wishes.”).

¹¹⁵ U.S. CONST. amend. XIV, § 1.

¹¹⁶ See, e.g., *In re Guardianship of Reyes*, 731 P.2d 130, 131 (Ariz. Ct. App. 1986) (“The appointment of a guardian often involves significant loss of liberty similar to that present in an involuntary civil commitment”); *In re Guardianship of Hedin*, 528 N.W.2d 567, 575 (Iowa 1995) (“Guardianship involves such a significant loss of liberty that we now hold that the ward is entitled to the full panoply of procedural due process rights”).

proceedings were held in an “atmosphere of informality.”¹¹⁷ Since proceedings were non-adversarial, courts did not guarantee strict procedures and instead viewed their role as serving the individual’s best interest.¹¹⁸ Accordingly, neither the Fifth nor the Fourteenth Amendment was applied to guardianship proceedings, although there was “nothing in either the fifth or the fourteenth amendments which limit[ed] the applicability of the due process clause to criminal matters.”¹¹⁹

In order to determine what process is due in a specific proceeding, three factors must be considered: (1) the private interest at stake; (2) the risk of erroneous deprivation of such interest using the current procedures; and (3) the state’s interest in efficiency.¹²⁰ The private interest at stake in guardianship proceedings is, as stated before, hefty.¹²¹ The analogy of guardianship appointments to civil commitments demonstrates that a potential ward risks the loss of nearly all their forms of decision-making. In civil commitment cases, due process is vigorously applied.¹²² The risk of erroneous deprivation in guardianship proceedings is less clear. In one Supreme Court case where this test was used, the Court found that in some cases, “complexity of the proceeding” could be “enough to make the risk of deprivation” higher.¹²³ This possibility is instead a reality in adult guardianship proceedings. If an adult needs a guardian, it is because they are either advanced in age, mentally disabled, or otherwise incompetent to the point they cannot adequately make their own decisions. Therefore, it appears that a potential ward in an adult guardianship proceeding may always face erroneous deprivation without being able to represent themselves in court.

The state has several different interests in guardianship proceedings. First, their *parens patriae* interest means they are out to protect the individual. For example, the state’s interest includes “to protect the incapacitated or disabled person from self-neglect and dangerous decisions, or from others who would prey on him, but also to ensure that the state does not overreach by interfering in the private lives and choices of its citizens and unnecessarily taking away their constitutional rights.”¹²⁴ While states do have an interest to conserve financial resources, there are several

¹¹⁷ Neil B. Posner, *End of Parens Patriae in New York: Guardianship under the New Mental Hygiene Law Article 81*, 79 MARQ. L. REV. 603, 606 (1996).

¹¹⁸ *Id.*

¹¹⁹ Peter M. Horstman, *Protective Services for the Elderly: The Limits of Parens Patriae*, 40 MO. L. REV. 215, 236 (1975).

¹²⁰ *Matthews v. Eldridge*, 424 U.S. 319, 321 (1976).

¹²¹ 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, 752 (2017) (“[A]dults have the greatest possible private interest in making their own most person choices.”).

¹²² See Susan G. Haines & John J. Campbell, *Defects, Due Process, and Protective Proceedings: Are Our Probate Codes Unconstitutional?*, 14 QUINNIPIAC PROB. L.J. 57, 86 (1999).

¹²³ *Lassiter v. Dep’t of Soc. Servs.*, 452 U.S. 18, 31 (1981).

¹²⁴ Hensley, *supra* note 121, at 752–53.

programs available to poor respondents, especially in Utah.¹²⁵ When weighing these three factors, the scales tip in favor of applying more due process in adult guardianship proceedings.

It is helpful to continue the analogy of guardianship proceedings to civil commitment. One Michigan court analyzed a statute which outlined the procedures for involuntary civil commitment, holding that the statute violated due process and discussing the need for right to counsel in a civil commitment proceeding.¹²⁶ Similarly, right to counsel is needed in guardianship proceedings.¹²⁷ Many of the same rights are being taken away,¹²⁸ and the state's interests remain the same.

Since there are not any cases finding removal of a right to counsel in a guardianship proceeding unconstitutional, it is difficult to predict how a court would rule in this situation. It is telling that Utah is not the only state to enact guardianship laws that do not make appointment of counsel mandatory, and these statutes have not been found to be unconstitutional. Perhaps there haven't been adequate challenges to these laws.

C. Requirement of Counsel in the Americans with Disabilities Act

In 1990, Congress passed the ADA, designed to reduce discrimination against people with disabilities.¹²⁹ The ADA has five chapters: Employment, Public Services, Public Accommodations and Services Operated by Private Entities, Telecommunications, and Miscellaneous Provisions.¹³⁰ Title II, Public Services, presents a hurdle Utah may have to overcome when stripping the right of counsel from potential wards. Title II provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation or denied the benefits of the services, programs or activities of a public entity”¹³¹ Courts have found that Congress intended this provision to apply to a person's fundamental right of access to the courts.¹³² Furthermore, the U.S. Department of Justice has passed regulations requiring that a public entity “take appropriate steps to ensure that

¹²⁵ See, e.g., *Guardianship Signature Program*, UTAH COURTS, <https://www.utcourts.gov/howto/family/gc/signature/> [<https://perma.cc/67JZ-5DW7>] (last visited July 30, 2018).

¹²⁶ *Bell v. Wayne Cty. Gen. Hosp.*, 384 F. Supp. 1085, 1093–98 (E.D. Mich. 1974).

¹²⁷ Haines & Campbell, *supra* note 122, at 86. According to Haines & Campbell, “[t]he rationale in applying due process vigorously in civil commitment cases is also applicable to protective proceeding cases, because the same fundamental liberties are involved.” *Id.* “Arguably, the state's interest is less compelling in protective proceedings, for while civil commitment cases involve society's interest in protecting itself from dangerous individuals, protective proceedings involve people who are not dangerous to anyone but themselves.” *Id.* (citations omitted).

¹²⁸ See *In re Guardianship of Reyes*, 731 P.2d 130, 131 (1986) (“[Guardianship] often involves significant loss of liberty similar to that present in an involuntary civil commitment for treatment of mental illness . . .”).

¹²⁹ Americans with Disabilities Act, 42 U.S.C. §§ 12111–12213 (2009).

¹³⁰ *Id.*

¹³¹ *Id.* at § 12132.

¹³² *Tennessee v. Lane*, 541 U.S. 509, 529–33 (2004).

communications with the applicants, participants, members of the public, and companions with disabilities are as effective as communications with others.”¹³³ The public entity also may not make the disabled individual pay for the cost of an accommodation.¹³⁴

One Supreme Court case involved the question of whether Congress could require states to pay damages to individuals with disabilities who were unable to access the courthouse.¹³⁵ The plaintiffs, who were both in wheelchairs, argued that since they were physically unable to get into the courthouse, this effectively denied them access to the judicial system.¹³⁶ One plaintiff crawled up the stairs to attend a court hearing but refused to do so again upon returning for a subsequent hearing.¹³⁷ He was then arrested for failure to appear. The other plaintiff, a court reporter, argued that her inability to participate in the judicial process denied her employment.¹³⁸

Individuals with disabilities are allowed reasonable accommodations if a physical or mental impairment does not allow them adequate access to the court. The state services may only resist accommodations that constitute a fundamental alteration of the service.¹³⁹ For example, a hearing-impaired party to a lawsuit successfully sued under the ADA, the court finding that he was a “qualified individual with a disability” and the court’s refusal to provide appropriate transcription services potentially violated Title II of the ADA.¹⁴⁰

To demonstrate that this bill violates Title II of the ADA, one would need to show that denying counsel in a guardianship proceeding would exclude an individual with a disability from participation in the proceeding.¹⁴¹ Furthermore, right to counsel would need to be framed as an accommodation that would not fundamentally alter the nature of the guardianship proceeding.¹⁴² Success under the ADA would likely be very fact-specific, and therefore, a facial challenge to this bill may be unsuccessful.

¹³³ 28 C.F.R. § 35.160(a)(1) (2011).

¹³⁴ *Id.* § 35.130(f).

¹³⁵ *Lane*, 541 U.S. at 530–31.

¹³⁶ *Id.* at 513.

¹³⁷ *Id.* at 514.

¹³⁸ *Id.*

¹³⁹ 28 C.F.R. § 35.130(b)(7) (2011).

¹⁴⁰ *Duvall v. County of Kitsap*, 260 F.3d 1124, 1135–38 (9th Cir. 2001) (finding the plaintiff supplied “sufficient evidence to create a material issue of fact as to whether the refusal . . . prevented him from participating equally in the hearings at issue.”).

¹⁴¹ *See* Anne B. Thomas, *Beyond the Rehabilitation Act of 1973: Title II of the Americans with Disabilities Act*, 22 N.M. L. REV. 243, 248 (1992) (explaining that discrimination against a qualified individual in the setting of programs or services provided by state and local governments may constitute a violation of Title II of the ADA).

¹⁴² *See id.* (stating that public entities must provide access to all programs, “except where to do so would result in a fundamental alteration in the nature of the program or in undue financial and administrative burdens.”).

D. Potential Social Consequences

As discussed in prior sections of this Note, guardianship as a whole can pose significant psychological, social, and emotional threats to individuals with disabilities. Removing the requirement of counsel may exasperate this even further. It is worth noting that this section is predictive. There is little to no evidence regarding the effect a bill such as this one has on individuals with disabilities. Even with the little evidence available, it becomes clear that taking away a potential ward's right to counsel can be harmful in at least two specific ways. First, it sends a signal to individuals with disabilities that their personal liberties can be taken away. Second, it potentially subjects individuals with disabilities to threats, abuses, and coercion.

Many, if not most, American students are taught fundamental constitutional rights, presumably including right to counsel, at some point in their education.¹⁴³ When this right is taken away from an already vulnerable group of people, we risk signaling to them that they are somehow less important. This is particularly true with the nature of a guardianship hearing. Subjecting an individual with a disability to a proceeding that has the consequence of taking away nearly all their personal freedoms, while simultaneously informing them that they do not have a right to counsel, reinstates the notion that society treats disabled people as lesser.¹⁴⁴

Secondly, giving an exception to the right of counsel can subject individuals with disabilities to abuse. Individuals with disabilities a heightened risk of physical abuse compared to non-disabled individuals.¹⁴⁵ In the 2012 National Survey on Abuse of People with Disabilities, 70% of people with disabilities responded that they had been victims of abuse.¹⁴⁶ Furthermore, 90% of individuals with disabilities who were victims of abuse said that the abuse had happened on more than one occasion,¹⁴⁷ 57% reported it had occurred over twenty times, and 46% reported it

¹⁴³ See, e.g., Valerie Strauss, *Many Americans know nothing about their government. Here's a bold way schools can fix that.*, WASH. POST (Sept. 27, 2016), https://www.washingtonpost.com/news/answer-sheet/wp/2016/09/27/many-americans-know-nothing-about-their-government-heres-a-bold-way-schools-can-fix-that/?noredirect=on&utm_term=.40c342cc44b4 [https://perma.cc/EJ6H-FGKL] (“Congress created Constitution Day in 2004, requiring all schools that receive federal funding to offer some type of ‘educational program’ on the U.S. Constitution on or close to Sept. 17 every year.”).

¹⁴⁴ See, e.g., Cortez, *supra* note 107 (“This is a population that’s been minimized in many, many ways. To have those rights not available to them, I think, is one more way we minimize that population.” (internal quotation marks omitted) (quoting Kris Fawson, Chairwoman of the Utah Coalition for People with Disabilities)).

¹⁴⁵ *Violence Against Adults and Children with Disabilities*, WORLD HEALTH ORG., <http://www.who.int/disabilities/violence/en/> [https://perma.cc/4BS4-V5GT] (last visited July 30, 2018).

¹⁴⁶ NORA J. BALADERIAN ET AL., SPECTRUM INST., DISABILITY & ABUSE PROJECT, A REPORT ON THE 2012 NATIONAL SURVEY ON ABUSE OF PEOPLE WITH DISABILITIES 3 (2013), <http://disability-abuse.com/survey/survey-report.pdf> [https://perma.cc/SY8J-YHQZ].

¹⁴⁷ *Id.*

had happened “too many times for them to count.”¹⁴⁸ When faced with a pending guardianship proceeding, a potential ward may have nowhere to turn if the potential guardian is abusive or has shown signs of abuse. An attorney may be the abused individual’s only advocate, and mandatory representation guarantees that the individual will have an opportunity to stop the guardianship from occurring.

E. Utah House Bill 167

During the 2018 General Session, the Utah House of Representatives introduced a new bill that amended House Bill 101.¹⁴⁹ It added two more conditions that must be present to waive the counsel requirement. First, it added that “no attorney from the state court’s list of attorneys who have volunteered to represent respondents in guardianship proceedings is able to provide counsel to the person within 60 days of the date of the appointment”¹⁵⁰ It also required that the court must appoint a visitor.¹⁵¹ This amendment appears to be the legislature’s reaction to public criticism following the original enactment of the bill.

These additions may cure the potential constitutional and legal challenges the original bill faced, however, it is unclear how this bill will operate when put into practice. Furthermore, it does not cure the overall concern that incapacitated individuals may face a proceeding to severely limit their rights without the guarantee of counsel. More challenges are imminent, as disability advocates attempt to move Utah in the right direction.

V. CANADA’S REPRESENTATION AGREEMENT ACT AS A MODEL FOR STATE LEGISLATION

Implementing supported decision-making may be a large leap for state legislatures, especially with so little evidence showing the costs and benefits of this alternative. States should follow other jurisdictions’ leads when implementing alternative decision-making into their statutes. Canada boasts one example of legislation that should serve as a starting point for states. Canada was one of the first jurisdictions to pass legislation pertaining to supported decision-making.¹⁵²

In 1996, British Columbia passed the Representation Agreement Act.¹⁵³ This act guides both disabled adults and adults planning for their future to create contracts to designate people who will act as their supporters if they are or become incapacitated.¹⁵⁴ These contracts are called representation agreements.¹⁵⁵ When

¹⁴⁸ *Id.*

¹⁴⁹ *See* H.B. 167, 2018 Gen. Sess. (Utah 2018).

¹⁵⁰ *Id.*

¹⁵¹ *Id.* A court visitor is typically a volunteer of the court who interviews interested parties.

¹⁵² Burke, *supra* note 63, at 881.

¹⁵³ Representation Agreement Act, c. 405, R.S.B.C. 1996 (2010) (Can.).

¹⁵⁴ Burke, *supra* note 63, at 881.

¹⁵⁵ *Id.*

creating a representation agreement, an individual can authorize one or more persons to become his or her representative.¹⁵⁶ A representative is charged with managing the incapacitated adult's affairs, and potentially making decisions on his or her behalf.¹⁵⁷ The individual may also appoint a monitor, who acts as a "safeguard" and "ensures that the Representation Agreement is working"¹⁵⁸ In the contract, the individual can designate which responsibilities both the representative and monitor have.¹⁵⁹ It also gives the individual and supporting members a chance to talk about the individual's wishes in certain circumstances, which allows the representative to make decisions as the individual would.¹⁶⁰

Canada's supported decision-making act has been praised widely for its comprehensive, yet clear, alternative to guardianship. In particular, the change has been deemed to "shift the power dynamic within the relationship and craft a more thorough process that necessarily includes the person with disabilities in the decision."¹⁶¹ The Act also seems to be working. For example, a comprehensive study on the representation agreement proved the program accomplishes its goals.¹⁶² Out of the program participants surveyed, 45.8% of individuals reported that they spoke with their representative at least once a day.¹⁶³ The study also found that participants had discussed "their feelings and values about the types of situations that could arise and what impact that should have on how their representative made treatment decisions."¹⁶⁴ Furthermore, 89.6% of participants said that "completing a representation agreement made them feel like they had achieved a sense of control over their future."¹⁶⁵

If states began implementing supported decision-making statutes modeled after the Canadian Representation Agreement Act, they would enable people with disabilities to make their own decisions, reduce judicial expenditures by reducing the number of guardianship proceedings,¹⁶⁶ and set a new standard for treatment of people with disabilities.

¹⁵⁶ *Representation Agreement Overview*, NIDUS PERS. PLAN. RESOURCE CTR., http://www.nidus.ca/?page_id=50 [<https://perma.cc/7Q48-U6HE>] (last visited July 30, 2018).

¹⁵⁷ *Id.*

¹⁵⁸ *Id.*

¹⁵⁹ *Id.*

¹⁶⁰ *Id.*

¹⁶¹ Burke, *supra* note 63, at 881.

¹⁶² Wendy Harrison, *Representation Agreements in British Columbia: Who is Using Them and Why?* (Nov. 27, 2008) (unpublished M.A. thesis, Simon Fraser University) (on file with the Simon Fraser University Library, Simon Fraser University), <http://summit.sfu.ca/item/9236> [<https://perma.cc/KTP4-XHRP>].

¹⁶³ *Id.* at 71.

¹⁶⁴ *Id.* at 78.

¹⁶⁵ *Id.* at 40.

¹⁶⁶ *See About SDM, What Is Supported Decision-Making?*, SUPPORTED DECISION-MAKING, CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/about-sdm/> [<https://perma.cc/F54V-564B>] (last visited July 30, 2018) ("At least 1.5 million adults in the

VI. CONCLUSION

“There are few legal processes more restrictive of citizens in a free society than guardianship.”¹⁶⁷ The history of guardianship has been dark, from ancient times through the institutionalization seen in the twentieth century. Recent reform has begun to rethink the paternalistic idea that people with disabilities need to be protected, and instead has focused on the autonomy of people with disabilities and their decision-making abilities. This progress is important due to the sheer number of people with disabilities in the United States.¹⁶⁸ The progress is not linear, though, as evidenced by Utah’s guardianship amendments, which eliminate the right to counsel in certain situations. Although it is unclear at the time whether these amendments are legal under both the Constitution and the Americans with Disabilities Act, the effect they will have on people with disabilities is clearer. Removing the guarantee of counsel in guardianship proceedings subjects a potential ward to several issues, including access to the court, potentially abusive guardians, social stigma, and declining self-worth. It also reverses the last decade of empowering people with disabilities to participate in the community on an equal playing field as the rest of the population.

Current reforms focused on supported decision-making have begun to catch on around the United States. Disability rights advocates, individuals with disabilities, and critics of guardianship are advancing the view that guardianship should be seen as a last resort.¹⁶⁹ This is in part guided by the notion that individuals with disabilities are usually able to make their own decisions, sometimes with the support of others. This is also guided by the court’s opinion in *Olmstead*, which held that isolating individuals with disabilities from the community is a form of disability discrimination and goes against the mandate in Title II of the ADA.¹⁷⁰ Guardianship has the same isolating effect on people with disabilities, and supported decision-making is one solution to this problem.

United States are under guardianship, but the number could be as high as 3 million, given the remarkable dearth of data.”).

¹⁶⁷ OFFICE OF PUB. GUARDIAN, UTAH DEP’T OF HUMAN SERVS., A GUIDE TO GUARDIAN SERVICES IN UTAH 11 (2008), <http://digitallibrary.utah.gov/awweb/awarchive?type=file&item=17999> [<https://perma.cc/4NFS-7LAR>].

¹⁶⁸ See LEWIS KRAUS, REHAB. RESEARCH & TRAINING CTR. ON DISABILITY & DEMOGRAPHICS, 2016 DISABILITY STATISTICS ANNUAL REPORT 2 (2017) https://disabilitycompendium.org/sites/default/files/user-uploads/2016_AnnualReport.pdf [<https://perma.cc/AT2C-ZNPH>] (estimating the overall rate of people with disabilities in the United States in 2015 to be 12.6%).

¹⁶⁹ See, e.g., Philip Barnes, *Consider Alternatives to Guardianship for Students with Disabilities*, SPECIAL ED CONNECTION (Apr. 22, 2015), <http://www.drwilkesconsulting.com/Consider%20alternatives%20to%20guardianship.pdf> [<https://perma.cc/AZ6C-5CN7>] (stating that “full guardianship is the most restrictive option on a wide spectrum and should be viewed as a last resort . . .”).

¹⁷⁰ See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

Canada's Representation Agreement Act serves as a guideline for states when implementing supported decision-making alternatives to guardianship. The Act gives the incapacitated individual the power to contract with whomever he or she pleases to help with decision-making or to even take over decision-making when necessary.¹⁷¹ Statutes like these allow the individual to decide which things he or she needs help with and which decision-making powers he or she prefers to retain. Guardianship has come a long way, and the continued push for greater rights for people with disabilities will one day prevail.

¹⁷¹ *See supra* Part V.