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For a Hearing on

Toxic Conservatorships: The Need for Reform

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I. Introduction

Good afternoon, Senator Blumenthal, Senator Cruz, and the members of this Subcommittee. Thank you for inviting me to speak today on the topic of guardianship law and reform. I am a staff attorney at the ACLU's Disability Rights Program, where we believe that all people with disabilities deserve to live meaningful, autonomous, and self-directed lives. For over 100 years, the ACLU has protected the civil liberties and autonomy of all people. Our focus on disability advocacy began in the 1970's, fighting to free people with disabilities from institutions – to free people who had been physically removed from society – stripped of their rights as political, civil, and human actors out of sight, out of contact, and out of mind. Thus, for instance, the ACLU litigated on behalf of people with disabilities housed – and cruelly mistreated and neglected – in New York's infamous Willowbrook hospital.¹

But institutionalization in locked buildings is not the only way that people with disabilities lose their rights, their autonomy, and their legal personhood. Guardianship² does the same thing. When a person is placed under guardianship, they are subjected to a “civil death.”³ A court is stripping a person of their right to act as an autonomous adult in our society – taking away the person's right to choose how their life unfolds, from the most minor to the most significant decisions: where to live, where to work, how to spend or save their money, whether to marry, whether to have children, who they will see and who they will not see. As Congressman Claude Pepper stated more than 34 years ago, reporting to a U.S. House Select Committee on Aging:

The typical [person subject to guardianship] has fewer rights than the typical convicted felon ... By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.⁴

Britney Spears' extraordinarily high-profile battle against conservatorship has launched this issue into the public's attention. But while Britney Spears herself is unique – for her fame,

¹ Aryeh Neier, *Cleaning Up The Snake Pit* (Nov. 8, 2019), available at: <https://www.aclu.org/issues/disability-rights/cleaning-snake-pit>.

² Most states use the term “guardianship” to refer to the stripping of an adult's civil liberties imposed by a court. California refers to this process as “conservatorship.” I use the term “guardianship” here to refer to this system as a whole, recognizing that the terminology varies state by state. I use this term to refer solely to systems in which adults lose their rights and are appointed guardians – this testimony does not relate to or opine on systems governing guardianship of children or minors.

³ Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the U.N. Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, Hum. Rts. Brief, Winter 2012, at 9; National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination* (March 22, 2018), p. 17 n. 6, available at: https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

⁴ U.S. Congress, 1987, *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace: Hearings Before the Subcommittee on Health and Long-Term Care of the Select Committee on Aging*, 100th cong., 1st sess., 5-10, 8 (statement of Claude Pepper), <http://files.eric.ed.gov/fulltext/ED297241.pdf>.

her wealth, and her talent – her conservatorship case is not. Spears is one of an estimated 1.3 million adults in this country under guardianship or conservatorship.⁵ The most unusual element of her case is the attention it is garnered. Spears’ experience of getting into a guardianship in a period of crisis, then facing a Kafka-esque maze to try to get out, is, far from being unique, in fact astonishingly routine.

The disability rights community, the aging community, and many other advocates and families have long understood, and experienced firsthand, the problems of guardianship. But for far too long, the guardianship system continued to strip people of their core, essential liberties – often permanently – with little interest, oversight, or concern by the general public. Your interest, Senators, and this hearing, provides many of us with the hope that this overuse and abuse of guardianship can change.

At the ACLU, we are working to change our country’s overreliance on guardianship, to reduce the number of people in guardianship, and to expand the use and recognition of alternatives to guardianship, such as supported decision-making, plain language documents, and other systems that allow disabled people to retain their civil liberties and live autonomous, self-directed lives. We have developed a resource library of educational materials, tools, templates, and legal documents that can be used to avoid guardianship and to promote alternatives.⁶ We have supported and represented people trying to get out of guardianships. Earlier this year, we filed an *amicus* brief on behalf of more than 20 disability and civil rights organizations highlighting the disability rights implications in Britney Spears’ high-profile conservatorship battle.⁷

II. Philosophy and Vision of Change

The ACLU Disability Rights Program – like many disability rights and disability justice advocates – believes that disability is a natural, inevitable part of the human condition. We are working toward a world in which the full range of disabled and non-disabled human experience is recognized, supported, and celebrated. A key step in this work is dramatically reducing the number of people who are stripped of their rights simply because of their disabilities. That is to say, dramatically reducing the number of people in guardianship across the country.

Because although disability is natural and part of human life, guardianship is not. Our vision of the world is one in which there are *far* fewer people in guardianship. We strive for a world in which there is a widespread and diverse range of support systems that allow people with disabilities to live and direct their own lives, to learn and communicate and develop, without court intervention, guardianship, and the stripping of rights and autonomy.

⁵ *Beyond Guardianship*, *supra* n. 3, at 65.

⁶ American Civil Liberties Union, *Supported Decision-Making Resource Library*, available at: <https://www.aclu.org/supported-decision-making-resource-library>.

⁷ Brief of *Amici Curiae* Disability Rights Organizations, *In re the Conservatorship of the Person and Estate of Britney Jean Spears* (July 12, 2021), available at: <https://www.aclu.org/legal-document/amicus-brief-re-conservatorship-estate-and-person-britney-spears>.

There are two, interrelated parts to this vision, each of which I will discuss further below. *First*, we need to increase protections and due process rights within guardianship systems, to stem the one-way tide of people *into* guardianships and expand the rate of people *exiting* guardianships. We need to treat guardianship proceedings as the invasive, high-stakes hearings that they are, where a person is facing a major and often permanent loss of rights and autonomy. We need to implement safeguards and procedures, due process protections, and disability accommodations that reflect that seriousness. *Second*, we need to strengthen and expand the world outside of guardianship – that is, the options and structures and supports and recognition that can allow people with disabilities to live and thrive and be supported without ever coming near guardianship. Supported decision-making is a key aspect of this vision.

Although guardianships are governed by state law, and established and executed by state courts, they implicate key federal constitutional and statutory rights, including Fourteenth Amendment procedural due process rights, and rights under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. These federal rights, as well as Congress’s spending and grantmaking authority, provide numerous avenues through which Congress and federal agencies can and should take action to address the shortcomings addressed here.

III. Problems Within Guardianship

Guardianships are established and governed by state law – states use different terms (what California calls “conservatorship,” most other states call “guardianship”) and have different procedures, presumptions, and structures.⁸

But at a high level of generality, guardianship proceedings have plenty in common.⁹ In a guardianship, a person or entity petitions a court to remove some or all of the decision-making power of another adult. The petitioner can be a family member, a care provider, a nursing home or hospital, or a government entity. A court then considers this petition and either grants or denies the guardianship. If the court grants the guardianship (and courts often grant guardianship as a matter of course), the court determines which rights and powers the subject of the guardianship (sometimes called the “ward”) loses, and the court assigns a person or entity to hold and exercise those rights that it has stripped from the “ward.” Studies show that courts most often grant “plenary” guardianships that strip the person of *all* rights, instead of tailoring or limiting the loss of rights.¹⁰ The person or entity assigned to hold and exercise the rights on a day to day basis is the guardian. But the court retains jurisdiction over the guardianship. It may review the guardianship at set intervals. The court alone has the power to end the guardianship, change its terms, or change who the guardian is.

⁸ For an overview of guardianship laws and systems nationwide, see American Bar Association Commission on Law and Aging, Resources & Research, *Guardianship and Supported Decision-Making*, available at: https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/.

⁹ *Beyond Guardianship*, *supra* n. 3, at 31-34; Jasmine Harris, *Processing Disability*, 64 Am. U. L. Rev. 457, 507-510 (2015).

¹⁰ See Matt J. Jameson, Tim Riesen, Shamby Polychronis, Barbara Trader, Susan Mizner, Jonathan Martinis, and Dohn Hoyle, *Guardianship and the Potential of Supported Decision Making With Individuals with Disabilities*, Research and Practice for Persons with Severe Disabilities, at 2-3 (2015).

As Senators Warren and Casey have recently highlighted, there is no reliable or complete data on guardianships or conservatorship in the country.¹¹ BuzzFeed recently estimated that 200,000 guardianship cases are filed every year.¹² The National Center for State Courts has estimated a decade ago that there were 1.3 million adults in guardianships nationwide, controlling roughly \$50 billion in assets.¹³ But these are estimates. We don't actually *know* how many people have lost their rights this way. We don't know how old they are. We don't know their race, their gender, their wealth. We know that racism plays a huge role in our society's conception of disability, but we don't have data about how that plays out in guardianship.¹⁴ We don't know who petitioned to take away their right. We don't know how long they have lived without their rights and liberties. We don't know if they had a lawyer. We don't know what they want.

But we know some things. We know that certain populations are at high risk of guardianship. Those include people with intellectual and developmental disabilities, many of whom are funneled into guardianship immediately upon turning 18, through the "school-to-guardianship pipeline."¹⁵ They include people with psychiatric disabilities and mental illnesses. And they include older adults who age into disabilities like dementia and Alzheimer's disease.¹⁶ We know that these are all categories of people with disabilities – which is why guardianship is inherently a disability rights issue.¹⁷ *Only* people with disabilities – or perceived to have disabilities – risk guardianship. We know the guardianship system is deeply troubled. We know that many people in guardianship want to – and should – get out.

¹¹ Letter from Senators Elizabeth Warren and Robert P. Casey, Jr. to Hon. Xavier Becerra, Secretary, Dep't of Health and Human Services, and Hon. Merrick Garland, Attorney General, Department of Justice (July 1, 2021) available at:

<https://www.warren.senate.gov/imo/media/doc/2021.07.01%20Letter%20to%20DOJ%20and%20HHS%20re%20Conservatorship.pdf>; see also Sally Hurme and Erica Wood, "Introduction," 2012 Utah L. Rev. 1157, 1162 (2012); GAO Report: *Elder Abuse: The Extent of Abuse by Guardians is Unknown, but Some Measures Exist to Help Protect Older Adults* (November 2016), available at: <https://www.gao.gov/assets/gao-17-33.pdf>.

¹² Heidi Blake and Katie J.M. Baker, *Beyond Britney: Abuse, Exploitation, and Death Inside America's Guardianship Industry* (September 17, 2021), available at:

<https://www.buzzfeednews.com/article/heidiblake/conservatorship-investigation-free-britney-spears>.

¹³ Brenda Uekert and Richard Van Duizend, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform* (2011); *Beyond Guardianship*, *supra* n. 3, at 65.

¹⁴ See Talila A. Lewis, *Longmore Lecture: Context, Clarity & Grounding* (March 2019), available at:

<https://www.talilalewis.com/blog/longmore-lecture-context-clarity-grounding>; Talila A. Lewis, *January 2021 Working Definition of Ableism*, (2021), available at: <https://www.talilalewis.com/blog/january-2021-working-definition-of-ableism>.

¹⁵ National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (June 10, 2019), 29-37, available at: https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf; see also *Guardianship and the Potential of Supported Decision-Making*, *supra* n. 10, at 36-51.

¹⁶ See Kristin Booth Glen, *What Judges Need to Know About Supported Decision-Making, and Why*, Judges' J., Winter 2019, at 26, 27; Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 Fordham Urb. L.J. 495, 501 (2016).

¹⁷ Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157 (2010).

A. Due Process Problems in Guardianship Proceedings

A guardianship petition puts a person at serious risk of wide-ranging and long-term deprivation of their rights and liberties. But the foundational due process requirements that should accompany such a major deprivation of rights are very often absent in guardianship proceedings. Instead, guardianships are often imposed through essentially *pro forma* processes, in spite of the serious ramifications of the imposition. The Utah State Courts Ad Hoc Committee on Probate Law and Procedure memorably reported in 2009 that, “[t]he appointment of a guardian or conservator removes from a person a large part of what it means to be an adult: the ability to make decisions for oneself. . . . We terminate this fundamental and basic right with all the procedural rigor of processing a traffic ticket.”¹⁸

1. Due Process Problems in Establishing Guardianship

Guardianships are major invasions of a person’s civil liberties and trigger due process protections, including the rights to notice, to be heard, and – in light of the physical liberty restrictions of guardianships *and* as a reasonable accommodation under disability rights laws – right to counsel.¹⁹ However, these fundamental process protections are too often absent or inadequate.

Notice: As an initial matter, notice is often deficient in guardianship proceedings. In at least one state, notice of a petition can be sent by mail – not even requiring service on the person who faces the guardianship.²⁰ Even if a person does physically receive notice, notices of petitions are complex, legal documents that are inaccessible for many people. Many people reports that they have lost their rights through guardianship without having any understanding of what was happening, including the risks, alternatives, and rights to challenge the proceeding. Notices often use technical legal jargon and require a high level of literacy. They are often complicated forms that with boxes to check and cross-references. They typically fail to plainly highlight the key information for meaningful notice of a guardianship. They rarely include such clear declarative sentences as:

- You may lose your right to make choices.
- A judge will decide this on [date, time, location]. You can go to the courthouse to talk about this with the judge.
- Call this phone number if you have questions or want help.
- Here is what to do if you want to keep your rights.

Hearing: Another core element of due process is the opportunity to be heard. But in some states, people can be placed under guardianship without a hearing taking place at all, allowing the judge to strip a person of their rights, impose the guardianship, and appoint a

¹⁸ Utah State Courts Ad Hoc Committee on Probate Law and Procedure, *Final Report to the Judicial Council*, preface (February 23, 2009) available at: <https://www.utcourts.gov/committees/adhocprobate/Guardian.Conservator.Report.pdf>; see also *Beyond Guardianship*, *supra* n. 3, at 86.

¹⁹ *Mathews v. Eldridge*, 424 U.S. 319, 331 (1976); *Lassiter v. Dep’t of Soc. Servs.*, 452 U.S. 18 (1981); see also John Pollock & Megan Rusciano, *Right to Counsel in Restoration of Rights Cases*, 42 BIFOCAL 75, 78 (2021); Salzman, *Rethinking Guardianship (Again)*, *supra* n. 17.

²⁰ See, e.g., Ind. Code Tit. 29, § 29-3-6-1.

guardian solely based on the written pleadings, which can be devoid of any information about what the person losing their rights wants.²¹ Even if there is a guardianship hearing, the person at risk of guardianship is often not present.²² There is a clear presumption in this system that the presence of the disabled person is not essential; and that their perspective and wishes are inconsequential.

Right to Counsel: Another key problem comes from the lack of legal counsel in guardianship proceedings. Most – but not all – states include *some* right to counsel in some guardianship situations.²³ But in many states access to counsel is inadequate. In some states the right to counsel is discretionary or dependent on the disabled person affirmatively requesting an attorney (which also, of course, requires that the person understand that they *can* request an attorney, and the failures of notice discussed above often foreclose this).²⁴ In other states, counsel may be appointed in a role akin to a *guardian ad litem*, whose role is not to advocate for the person’s *stated* wishes, but instead to advocate for (the *counsel’s perception of*) the person’s “best interests.”²⁵ This means that there are instances where, even if the person at risk of guardianship is represented, their lawyer may not actually be advocating for what they want. The paternalism in this model, in which an attorney can advocate for *either* what her client wants *or* what *the lawyer thinks* her client *should* want – is contrary to the lawyer’s role in virtually every other setting and undermines the procedural due process rights of representation.

The lack of zealous advocacy by counsel for a person’s stated wishes (and, in many cases, the lack of counsel at all), raises serious due process concerns. In guardianship proceedings, the core “claim” against a person is that they “lack capacity” – that they cannot live their own independent lives. In guardianship proceedings where there is no right to counsel, the court is taking the claim of “incompetence” seriously enough to consider stripping a person of their rights and liberties, but *not* taking that seriously enough to ensure that there is a professional in the room advocating for their wishes or mitigating the alleged “incompetence”.

The impact of these three elements: failures of notice, lack of opportunity to be heard, and lack of counsel, combine to mean that untold thousands of people with disabilities lose their rights and liberties either in *pro forma* proceedings where they are not part of the process at all, or in which they must try to participate in, or challenge, a complex system alone, without counsel, accessible information, or support.

²¹ See American Bar Association Commission on Law and Aging, *2014 Emergency Guardianship Statutes*, available at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/Emergency_Guardianship_Chart.pdf; Heidi Blake and Katie J.M. Baker, *They Both Fought to Break Free From Guardianship. Only One Escaped*. (September 19, 2021), available at: [They Both Fought To Break Free From Guardianship. Only One Escaped. \(buzzfeednews.com\)](https://www.buzzfeednews.com/article/they-both-fought-to-break-free-from-guardianship).

²² Harris, *Processing Disability*, *supra* n. 9, at 506.

²³ See American Bar Association Commission on Law & Aging, *Representation and Investigation in Guardianship Proceedings (Statutory revisions as of August 2020)*, available at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/chartrepresentationandinvestigation.pdf; National Coalition for a Civil Right to Counsel, *Status Map*, available at: <http://civilrighttocounsel.org/map/>.

²⁴ See, e.g., Ind. Code § 29-3-5-1(c); Neb. Stat. § 30-2619(b); Okl. Stat. tit. 30 § 30-3-107; Wyo. Stat. § 3-1-205(a)(iv), Pa. Cons. Stat. § 20-5511(a).

²⁵ See, e.g., Id. Code § 15-5-303(b), 315; N.D. Cent. Code § 30.1-28-03; Tex. Estate Code § 1054.001.

2. Due Process Problems in Ending Guardianship

Once a person is in a guardianship, it is both extremely hard and rare for to get out.²⁶ Some of the barriers are practical: guardians routinely control a person’s money, monitor their communication, track their location, limit their travel, and limit their access to the internet – any of which can stymie a person’s ability to begin to know how to try to change a guardianship. People under guardianship have often been stripped of their right to sign a contract, making it difficult or impossible to retain a lawyer or sign a guardianship dissolution petition.²⁷ There are many people who, *because* of the controls exercised by their guardian, would have virtually no way to challenge those very controls or the guardianship itself.

There are also evidentiary and procedural barriers to getting out of guardianships. In many states, there is *no* identified evidentiary standard for dissolving a guardianship.²⁸ In some states, the person under guardianship bears the burden of proving that they no longer need it. This is a heavy burden in any situation, but here, too, the practical limitations of the guardianship can make this burden virtually insurmountable. If a guardian controls a disabled person’s money, limits their communication, access to information, and holds the right to access the person’s health information, a person can become almost wholly foreclosed from establishing any evidence to prove that they don’t need the guardianship.

3. Presumptions that guardianships are necessary

The due process problems of guardianship are exacerbated by the lack of information – and outright misinformation – that leads many people to seek guardianships that are unnecessary. Many people face guardianship because a family member has been advised to petition for guardianship based on false or insufficient information.

The “school to guardianship pipeline” is a key example of this.²⁹ When young adults with intellectual and developmental disabilities approach 18, school districts across the country advise parents and family members to get guardianship as a matter of course. Many parents are (erroneously) told that if they do not get a guardianship, they can no longer participate in their child’s Individualized Education Plan meetings or help their child in medical or financial situations.³⁰ A 2015 study found that school personnel were the most common referral source to recommend guardianship.³¹

²⁶ See Jenica Cassidy, *Restoration of Rights in the Termination of Adult Guardianship*, 23 Elder L. J. 84, 95 (2015).

²⁷ Nina A. Kohn, Catheryn Koss, *Lawyers for Legal Ghosts: The Legality and Ethics of Representing Persons Subject to Guardianship*, 91 Wash. L. Rev. 581 (2016).

²⁸ Erica Wood, Pamela Teaster, Jenica Cassidy, American Bar Association Commission on Law and Aging with the Virginia Tech Center for Gerontology: *Restoration of Rights in Adult Guardianship: Research and Recommendations* (2017), available at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration-of-rights-in-adult-guardianship.pdf.

²⁹ Center for Public Representation, *Supported Decision-Making and Education*, available at: <https://supporteddecisions.org/getting-started-with-supported-decision-making/sdm-and-education/>; *Turning Rights Into Reality*, *supra* n. 15, at 29-37.

³⁰ *Id.*

³¹ Jameson et al., *Guardianship and the Potential of Supported Decision-Making*, *supra* n. 10, at 36–51.

This routine recommendation is both unnecessary and dangerous. Young adults with disabilities can have parents, family, and other trusted people participate in their education, medical, financial, and other planning and decision-making *voluntarily*, without a guardianship, even after they turn 18. They can use powers of attorney, simple authorizations to share educational or medical records.³² But very often, families do not know this. Instead, they are told the opposite: that they must get guardianship. They are *not* told of alternatives, or the risks and reality of guardianship.³³ Guardianships are sought as a matter of course in other contexts as well – after a health or financial scare with an aging family member experiencing dementia, or during or after a psychiatric crisis.

In many cases, then, guardianship is sought as a “first resort” – as a matter of course or a first response to a challenge, or a crisis, or simply as a first response to the fact of a disabled person reaching adulthood. The majority of states have laws that lay out the reverse – requiring that guardianship be sought only as a *last* resort, when other, less restrictive, options have been tried and failed.³⁴ The premise of guardianship as a last resort is critical, but even in states where it is in the law, it is rarely taken seriously.

This means that there are *many* guardianship proceedings where neither the person seeking guardianship, or the person at risk of guardianship, has anything approaching a full understanding of the consequences, pros and cons, and alternatives, to the system that is about to be put in place. There are *many* guardianships imposed where everyone in the room – the person seeking the guardianship, the person at risk of guardianship, the court, and the lawyers (if there are any), erroneously see and understand the proceeding as a routine, *pro forma* matter to create a benevolent, inevitable, and fundamentally harmless arrangement.³⁵

B. Harms of Guardianship

The near-uniform pressure and presumption that guardianship is inevitable and routine stands in stark contrast to the significant inherent risks and harms of guardianship itself. While the word “guardianship” invokes the benevolent ideal of a guardian angel, guardianships are far from benevolent or angelic. Because guardianships allow one person to have near-absolute power over another person, with virtually no safeguards or monitoring, guardianship as an institution is ripe for abuse.

³² See ACLU, *You Can Do it Without a Conservatorship!*, available at: https://www.aclu.org/sites/default/files/field_document/authorizations_to_share_medical_and_educational_records_based_on_california_law.pdf.

³³ *Beyond Guardianship*, *supra* n. 3 at 92; see also C. E. Rood, A. Kanter, and J. Causton, *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*, Research and Practice for Persons with Severe Disabilities 39, no. 4 (2014): 319–328; *Turning Rights Into Reality*, *supra* n. 15, at 31-32.

³⁴ American Bar Association Commission on Law and Aging, *Least Restrictive Alternative References in State Guardianship Statutes*, (2018) available at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/06-23-2018-lra-chart-final.pdf.

³⁵ Nina A. Kohn et. al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 Penn St. L. Rev. 1111 (2013).

There are *many* people in guardianships in this country who are honest, supportive, and caring, and who fulfill their roles with utmost integrity and good faith. There are many people who have guardianships but in fact do not substitute their views for those of the person under guardianship. There are many people who have guardianships for a range of legitimate and complex and nuanced reasons. There are many people who had no access to information about what they were agreeing to when they sought guardianship.

The harms and risks I lay out here are not accusations against individual guardians or families, or blanket statements of the reality of all guardianships. The harms I lay out are the systemic risks: that the structural distribution of power and lack of oversight sets up a system where abuse and neglect can, systemically, exist, undetected, all too often.

1. Abuse, Neglect, and Exploitation

High profile and well-documented cases have highlighted instances of abuse and neglect in guardianships – whether financial, sexual, physical, or emotional.³⁶ Guardianship, like institutionalization, is a system that inherently carries heightened risk of abuse and neglect: it creates a huge power differential, between the guardian, who holds rights, powers to communicate, and financial power, and the person under guardianship, who has lost these rights. And, as with institutions, this power differential is often exercised behind closed doors, in private, with little oversight or transparency. This is a recipe for abuse and neglect.³⁷ That guardianships make people vulnerable to abuse and neglect is both ironic and notable given that guardianships are often justified because the person is identified as being “vulnerable” to abuse or exploitation. The guardianship is justified as a way to protect them. But in many cases, guardianship *creates* the opportunity for exploitation, rather than helping the person identify ways to protect themselves against it.

Guardianships can also become abusive or predatory when the court changes a guardianship arrangement. A common example is when a parent becomes a guardian over a young adult, and serves with integrity and love and support for many years. But if that parent becomes ill, or passes away, or is for any reason unable to serve as guardian, the guardianship does not end. Instead, the court will select a new guardian, and the guardianship will continue. The new guardian may be a stranger, who may not know or care what the person’s preferences or values are, who may exploit or neglect the person, or who may make choices that make the guardian’s job easier, rather than reflecting the wishes and values of the disabled person. Similarly, if divorced parents can’t agree who should be the guardian, or if adult siblings disagree about who should be the guardian for an aging parent, courts may also grant the petition for guardianship but select a guardian who is a stranger, or a professional guardian, or an agency.

³⁶ See Rachel Aviv, *How the Elderly Lose Their Rights*, New Yorker, October 2, 2017, available at: <https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>.

³⁷ See, e.g., Blake and Baker, *Beyond Britney*, *supra* n. 12; Blake and Baker, *They Both Fought To Break Free From Guardianship. Only One Escaped*, *supra* n. 21; G.A.O. Report, *Elder Abuse*, *supra* n. 11; U.S. G.A.O. Report, *Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors* (September 2010), available at: <https://www.gao.gov/assets/gao-10-1046.pdf>; Kristin Booth Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, 3 Inclusion 1, 3-4 (2015).

2. Limiting development and self-fulfilling realities

But there are other risks and harms in guardianships, too, even when everyone is acting with the best intent and utmost honesty. One of these is the risk of a self-perpetuating or self-fulfilling reality, sometimes referred to as “stereotype threat.”³⁸ We are all aware of the role that expectations have in determining our futures, and the impact of stereotypes, based on gender, race, strengths, and weaknesses, on those expectations and realities. If a child is told he can go to college, or play soccer, or become a doctor, that goes a long way to helping that child realize and claim that future. Conversely, if a person is told, by their family, by their school, by their doctors, by a judge acting on behalf of the state, that they are not competent, and that they cannot be trusted to make their own choices, and cannot learn to make their own choices, that can easily become true or remain true even if it wouldn’t otherwise be or stay true.³⁹ Young adults who are told when they turn 18 that they are “incapable” may never have the opportunity – or develop the confidence – to *become* capable, to experience making and learning from their choices, mistakes, and getting help in this process.⁴⁰ It is a powerful message to be told that you are not capable, that you cannot be trusted, that your right to say “no” to something you don’t like is not your own.

People learn to make good choices by practicing making choices. None of us reached age 18 wholly “competent,” with our values and judgment and preferences and “good” decision-making skills fully formed and static. We learned, and continue to learn, to make choices that are consistent with our values and priorities by experiencing the consequences of choices that do and don’t feel right to us. People who get caught in the guardianship system are not given that opportunity – whether they are young adults who never had that opportunity because they moved directly into guardianship, or whether they face new health diagnoses or disabilities and lose the opportunity to explore and experience decision-making in that new reality.

IV. Supported Decision-Making and Other Alternatives to Guardianship

Disability is a natural, inevitable reality of the human condition. Guardianship is neither natural nor inevitable.

The previous section explained some of the reasons that guardianship is not benevolent, or even neutral, and how it in fact carries considerable risks and harms. This section lays out the concept and practice of alternatives to guardianship, focusing on supported decision-making. Alternatives to guardianship are tools and systems that allow people to use supports that *they* choose to help them understand, make, and communicate their *own* choices and direct their *own*

³⁸ Steele and Aronson, *Stereotype Threat and the Intellectual Test Performance of African Americans*, 69 J. Pers. Soc. Psychol., 797-811 (1995).

³⁹ Edward L. Deci, *Intrinsic Motivation* (1975), 208; B.J. Winick, *The Side-Effects of Incompetency Labeling and the Implications for Mental-Health Law*, 1 Psychology Pub. Pol. and Law 21 (1995); Jennifer L. Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 Int. J. of Law & Psychiatry 354 (2010); Michael Wehmeyer & Michelle Schwartz, *The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation*. Educ. and Training in Mental Retard. & Dev. Disab. (1998).

⁴⁰ See Harris, *Processing Disability*, *supra* n. 9, at 489-497; Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 St. Louis Univ. J. of Health Law & Policy 289, 293 (2011).

lives. They are ways that people can get support without being stripped of their autonomy, rights, and liberty. Many alternatives to guardianship are as simple as a power of attorney, a joint bank account, a simple authorization to share health records, or installing a reminder or alert app on your phone. Others, like supported decision-making, can be more comprehensive.

A. Supported Decision-Making

Supported decision-making is one of the most expansive and widely recognized alternatives to guardianship.⁴¹ Supported decision-making is defined in the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act as “assistance from one or more persons of an individual’s choosing in understanding the nature and consequences of potential personal and financial decisions, which enables the individual to make the decisions, and in communicating a decision once made if consistent with the individual’s wishes.”⁴² Eleven states and the District of Columbia expressly recognize supported decision-making in their legislatures.⁴³ At least 40 states and the District of Columbia have introduced one or more pieces of legislation or resolutions specifically referring to supported decision making.⁴⁴ In recent years, courts across the country have recognized supported decision-making as an

⁴¹ Jonathan Martinis & Jessalyn Gustin, *Supported Decision-Making As an Alternative to Overbroad and Undue Guardianship*, 60 Advocate 41 (2017); Peter Blanck and Jonathan G. Martinis, “*The Right to Make Choices*”: *The National Resource Center for Supported Decision-Making*, 3 Inclusion 24 (2015); Tina M. Campanella, *Supported Decision-Making in Practice*, 3 Inclusion 35 (2015); Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, *supra* n. 37; Kohn *et al.*, *Supported Decision-Making: A Viable Alternative to Guardianship?* *Supra* n. 35.

⁴² Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (2017) § 102(31); *see also* §§ 301(a)(1)(A); 310(a)(1)); Dinerstein, *Implementing Legal Capacity Under Article 12 of the U.N. Convention on the Rights of Persons with Disabilities*, *supra* n. 3, at 8, 10.

⁴³ Center for Public Representation Supported Decision-Making, *U.S. Supported Decision-Making Laws*, available at: <https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/>; *see also More States Pass Supported Decision-Making Agreement Laws* (2019), American Bar Ass’n, available at: https://www.americanbar.org/groups/law_aging/publications/bifocal/vol-41/volume-41-issue-1/where-states-stand-on-supported-decision-making/.

⁴⁴ See National Center for Supported Decision-Making, available at: www.supporteddecisionmaking.org/states (listing state legislation and statutes referencing supporting decision-making by state); *see also* Gabrielle Bechynne, *Supported Decision-Making Agreements in Texas*, 13 Est. Plan. & Community Prop. L.J. 311, 335 (2020); Eliana J. Therodorou, *Supported Decision-Making in the Lone-Star State*, 93 New York U. L. Rev. 973 (2018).

alternative to guardianship.⁴⁵ It has been embraced by the federal National Council on Disability,⁴⁶ the American Bar Association,⁴⁷ and the National Guardianship Association.⁴⁸

Supported decision-making is a tool that allows people with disabilities to choose supporters to help them understand, make, and communicate their own choices.⁴⁹ Supported decision-making recognizes that *all* people can and do rely on trusted advisors (family and friends) to understand, make, and communicate decisions, and recognizes that using supports is a *good* thing.⁵⁰ Too often, if people with disabilities ask for help, or want to bring a parent to a doctor's appointment, or seek other support, this request is used as evidence of incapacity. Supported decision-making recognizes that using supports is a strength, and that if people use supporters appropriately and when needed, that is a way to *enhance* their capacity, and should be treated as such.

B. The Fiction of “Capacity”

No one lives a truly “independent” life. We all – disabled and not – live interdependent lives. We rely on doctors and medical professionals to help us understand and take care of our bodies. We rely on apps and Outlook calendars to remind us of our appointments and meetings. We rely on friends and partners to help us think through complicated situations and dynamics. We rely on people we trust to help us inform our opinions about issues outside of our expertise. We rely on financial professionals to help us fill out our taxes and manage wealth (if we are lucky enough to have it). We rely on advocates, journalists, and politicians we trust to educate us about information we cannot gather first-hand.⁵¹ All of those kinds of interdependence are normalized in our society – we do not consider someone to have less “capacity” because they seek medical care for a broken limb. We do not think that a person is not fully “competent”

⁴⁵ See *Ross and Ross v. Hatch* (Cir. Ct. of Newport News, Aug. 2, 2013), Case No. CWF-120000-426 (Final Order); *In Re: Ryan Herbert King*, (D.C.Sup.Ct. (Probate), Oct. 6, 2016), Case No.: 2003 INT 249 (Final Order); *In Re: Tecora Mickel*, (D.C. Sup. Ct (Probate), 2015), Case No: 2015 INT 000291; *Matter of DD* (N.Y. Surr. Ct. Kings County, Oct. 28 2015), 50 NY Misc. 3d 666; *In Re: the Guardianship of Jamie Beck* (Cir. Ct. of Wayne County, Indiana, June 12, 2018), Case No: 89CO1-1011-GU-025 (Order to Terminate Guardianship); *In the Matter of the Guardianship of the Person and Estate of KH* (2d Jud. Dist. Ct., County of Washoe, Nev., Sept. 11, 2017), Case No PR03-00264; *In re C.B.* (Super. Ct of Vt, Orleans Unit, April 11, 2017) (Stipulation to Dismiss Guardianship); *Matter of Eli T.* (N.Y. Sur. Ct. Kings County 2018) 89 N.Y.S.3d 844, 849; *In re Guardianship of Michael Lincoln* (Fla. St. Lucie Ct., 19th Cir. Ct. Oct. 13, 2016) Case no. 56 2014 GA 000041PPXXXX, slip op. at 4; *In the Matter of John Francis McCarty* (Ga. Fulton County Prob. Ct. Sept 16, 2018), Est. No. 225013, slip op. at pp. 1-2; *In re Joshua Damian Strong* (Knox County Prob. Ct., Me., June 6, 2018) Docket No. 2002-0082, slip op. at p. 1.

⁴⁶ *Turning Rights Into Reality*, *supra* n. 15, at 79-83 (listing key findings and recommendations including use of supported decision-making).

⁴⁷ American Bar Association House of Delegates Resolution (2017), available at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.pdf; see also *Guardianship and Supported Decision-Making*, ABA, available at: https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/.

⁴⁸ National Guardianship Association, *Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making* (2017), available at: <https://www.guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf>.

⁴⁹ Dinerstein, *Implementing Legal Capacity Under Article 12 of the U.N. Convention on the Rights of Persons with Disabilities*, *supra* n. 3, at 8, 10-12.

⁵⁰ Kristin Booth Glen, *Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 Albany Gov. L. Rev. 94, 97-98 (2020).

⁵¹ *Id.*

because they hire a lawyer to manage a divorce. We do not believe that hiring a babysitter reflects that a person is an unfit parent. To the contrary: we consider those kinds of support *smart* – these are the kinds of interdependence that we have normalized in our society.

Some people with disabilities have greater and different support needs, types of interdependence that we have *not* normalized, types of support needs that we too often associate with an overarching “incapacity” or “incompetence.” But these associations are not inevitable. They are socially constructed boundaries, deeply intertwined with our history of racism, eugenics, and misogyny, and they can, and must, change.⁵² The range and necessity of support needs varies across humans (and across each individual’s lifespan, as we are born needing virtually complete support and may age back into those support needs). Some people with disabilities have significant or complex support needs and live lives that are more interdependent than nondisabled people. But the import we place on certain support needs, the underlying presumption that needs that are more extensive are more stigmatized – is a construct, grounded in our pervasive history and reality of ableism, intertwined with racism, classism, and misogyny. We can and must change these assumptions, and recognize disability, and getting and receiving support, as natural, positive parts of the human experience.⁵³ Changing our guardianship systems – and radically reducing the number of people in the country who have lost their rights through guardianship – is an important step in that process.

Guardianship treats “capacity” as an all-or-nothing, static concept. It takes a rigid view that if one doesn’t have capacity for *everything*, then one doesn’t have capacity for *anything*. And this view is only imposed on people with disabilities – nondisabled people can get support in many areas without anyone questioning their global “capacity.” But many evaluations relied on in establishing guardianships measure – at best – how well a person performs certain abstract tasks, untethered to context or real life, while alone in a strange place with a stranger.⁵⁴ For example, a common test evaluators use in “capacity evaluations” is how accurately a person can count back from 100 by 7’s.⁵⁵ This is not a core life skill. How well we count backward from 100 by 7’s says nothing about how we live our lives, what we want and value and who we have helping and supporting us. It doesn’t take into account whether this is a task that we need to perform in our daily lives, or whether we would ask a friend, or a calculator, to help us if we ever *did* need to count backwards this way. Although counting backwards by 7 is not a measure for how we can or do live our lives, for people with disabilities, it is relied on as a proxy for just that.

⁵² See Lewis, *Working Definition of Ableism*, *supra* n. 14; Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, 39 *Cardozo L. Rev.* 495, 498 (2017).

⁵³ See, e.g., Rabia Belt, Doron Dorfman, *Reweighting Medical Civil Rights*, 72 *Stan. L. Rev. Online* 176 (2020); Margaret Isabel Hall, *Mental Capacity in the (Civil) Law: Capacity, Autonomy, and Vulnerability*, *McGill Law Review* 58, no. 1 (2012): 64; 8 Israel Doron and Ann M. Soden, *Beyond Elder Law: New Directions in Law and Aging* (2012) (capacity is “a [legal] fiction determined by prevailing values, knowledge, and even the economic and political spirit of the time.”); Kristin Booth Glen, *Introducing a “New” Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 *Columbia Human Rights Law R.* 1, 13-26 (2017).

⁵⁴ *Beyond Guardianship*, *supra* n. 3, at 78-81.

⁵⁵ *Id.*

C. Supported Decision-Making and Capacity

Supported decision-making allows us to recognize the nuance and reality that “capacity” is not a black and white concept. It recognizes the value of using supports to help people strengthen their capacity, and the reality that people have preferences, wishes, and values even if they also have significant disabilities. It recognizes that capacity exists in context and in community. Supported decision-making recognizes that people with disabilities may use and need more or different support than nondisabled people, but that they, like all people, have preferences, wishes, and values, which can and should be respected regardless of disability. People with disabilities can and do use supported decision-making without court involvement, without a finding of “incapacity” and without facing the risks and loss of liberty that guardianship carries with it.

Supported decision-making as a concept is not limited to people with disabilities, or people at risk of guardianship. It describes how most people make important or complex decisions. For instance, if a person is facing a medical diagnosis and deciding how to proceed – what treatment to receive, whether to take leave from work, how to deal with childcare – most of us would consult with others before making that choice. We might seek a second medical opinion. We might talk to friends or family members who had experience in this area. We might do online research or ask opinions in online support groups or forums. The person seeking the advice, doing the research – facing the diagnosis themselves – remains the person who will make the decisions. But they will rely on supporters who, because of expertise, or a trusting relationship, or their objectivity, or their consistent values, can *help* the person reach their *own* decision.

So it is with supported decision-making for people with disabilities. The types of support and the types of decisions may be different. But the premise is the same: the person is making their own decision, with reference to their own values and preferences, with the help of people they choose and trust. People with disabilities may use supporters to help them read and understand complex documents, to help them think through the pros and cons of decisions, to act as notetakers in medical appointments and to brainstorm question in advance and remind the person of the areas of concern or confusion.

D. Supported Decision-Making and Quality of Life

Although many people seek guardianships in an attempt to protect a person with disabilities, supported decision-making is, in fact, often a safer, more protective route. Studies show that the best way to learn how to interact safely in the world is with practice and experience, and supported decision-making fosters that autonomy and experience.⁵⁶ *Everyone* learns – albeit at different paces and in different ways – how to navigate life, how to connect

⁵⁶ See Hickson, L., Khemka, I., & Reynolds, G., (2005), *Evaluation of a Decision-Making Curriculum Designed to Empower Women With Mental Retardation to Resist Abuse*. *American Journal on Mental Retardation* 110, 193-204; Blanck, P., Kruse, D., & Schur, L., (2013). *People with Disabilities, Sidelined or Mainstreamed?* Cambridge University Press; Michael L. Wehmeyer, Susan B. Palmer, Martin Agran, Dennis E. Mithaug, and James E. Martin, *Promoting Casual Agency: The Self-Determined Learning Model of Instruction*, *Exceptional Children* 66, no. 4 (2000): 400. 332 Yves Lachapelle, et al., *The Relationship Between Quality of Life and Self-Determination: An International Study*, *Journal of Intellectual Disability Research* 49 (2005): 740–744.

with others, how to exercise boundaries, and when to ask for help. Part of being human is learning to make choices responsibly, with help and guidance where needed, and consistent with one's values. *Everyone* learns this over the course of a lifetime by trial and error, and in our own ways, and based on values, skills, and needs that change with time. People with disabilities, like people without disabilities, are safest and happiest when they learn these skills in the way that is meaningful for them, and when they have the support in the process.⁵⁷

Even people with high support needs, limited communication, or significant disabilities have and express preferences, and continue to learn and develop throughout their lives. Research consistently shows that people with disabilities have better subjective and objective life outcomes – including less risk of abuse – if they have greater self-determination.⁵⁸ For people with significant disabilities, establishing and expressing boundaries, preferences, and autonomy may progress differently than for nondisabled people. However, likes and dislikes, boundaries and desires are expressed (whether through words, actions, or facial expressions), practice and experience expressing those preferences – and having them respected, not ignored – is shown to protect most against exploitation. People get better at protecting themselves, at saying no, when they have practice doing just that. People with disabilities may learn in very different ways, or at different speeds, than nondisabled people. Encouraging families to be skeptical of guardianships does not mean disregarding a person's disability and support needs, which may be considerable. But many support needs can be met without guardianship, and that should be encouraged.

A major difference between supported decision-making and guardianships is that supported decision-making encourages individuals to widen their circles of support, and keeps the person with disabilities as the person making decisions, and retaining their civil liberties and legal personhood, with support as needed. A person under guardianship generally has one person – or one institution – with all of the power, and making all the decisions. With supported decision-making, one supporter may provide support around medical decisions, another with finding the best living situation, and a third with finances.⁵⁹ By widening the circle of engaged, involved supporters, supported decision-making arrangements have more built-in transparency,

⁵⁷ See *Beyond Guardianship*, *supra* n. 3 at 131 (and citations therein); Glen, *Supported Decision-Making From Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 Albany Gov. L. Rev. 94, 119-120 (2020).

⁵⁸ Wright, J.L., *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 Int'l J.L. & Psychiatry 350, 354 (2010); Salzman, *Guardianship for Persons with Mental Illness*, *supra* n. 39, at 291; Dalton, D., Drummond, D., Geenen, S., Powers, J., Powers, L., Swank, P., Summer, P. S., & Turner, A., *My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education*, 34 Child. & Youth Services Rev. 2179 (2012); Little, T. D., Palmer, S., Rifkenbark G. G., Shogren, K., & Wehmeyer, M., *Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities*, 4 J. Special Educ. 256 (February 2015); Baldwin, P., Evans, J., & McDougall, J., *The Importance of Self-Determination to Perceived Quality of Life for Youth and Young Adults with Chronic Conditions and Disabilities*, 31 Remedial & Special Education 252 (2010); Schwartz, M., & Wehmeyer, M., *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 Exceptional Child 245 (1997); Wehmeyer, S., & Palmer, S., *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination*, 38 Educ. & Training Developmental Disabilities 131 (2003).

⁵⁹ See, e.g., ACLU, Supported Decision-Making Resource Library, *Sample Supported Decision-Making Agreements*, available at: <https://www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library>; National Resource Center for Supported Decision-Making, *Supported Decision-Making Model Agreements*, available at: <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-model-agreements>.

checks and balances, and informal (or formal) oversight than a guardianship, where extraordinary control is vested in a single person whose power can be virtually unchecked. (In a number of supported decision-making models, if an individual needs support with finances, then a different person, a “monitor,” is also chosen to review the financial books once a month.)

E. Supported Decision-Making and Civil Liberties

Supported decision-making shares power, information, and transparency among many people, including the person with disabilities at the center of it. That person retains their civil liberties and also has the benefit of a wide and, ideally, collaborative circle of supporters. Most supported decision-making models also take pains to remind the supporters that their role is not to make decisions for the person they are supporting. Their role may be to help an individual understand what the choice is, to help discuss the pros and cons of specific choices, and, if necessary, to help communicate the individual’s choice. They may also provide support through reminders or logistics. It is not a coincidence that the model in which disabled people retain their civil liberties is *also* the model that has been proven to protect people and increase their quality of life – retaining your autonomy, rights, and self-determination is inherent to protection and quality of life. It is no different for disabled people.

Unlike guardianship, the court does not decide who the supporter is or how long the supporter serves. It is the individual with a disability, and the supporter together, who decide how long the support will continue, what it will encompass, and when it may be time to choose someone else to step into the role. This growth and development is built into supported decision-making, which can and should evolve over time. By contrast, it is time-consuming, costly, and sometimes functionally impossible to change a guardianship to reflect a person’s changing needs, skills, relationships, and preferences.

V. Recommendations

While guardianship is a matter of state law, Congress and federal agencies can and should take steps to address the harms and shortcomings of the guardianship system, to strengthen and expand alternative systems of support, and to protect the rights and autonomy of people with disabilities.

Congress can act on this issue through numerous mechanisms and authority. Guardianship proceedings implicate procedural due process protections under the Fourteenth Amendment, requiring meaningful notice and opportunity to be heard.⁶⁰ Further, as guardianship carries with it a restriction on physical liberty, whether through institutionalization or forcing a person to live in a certain place, the right to counsel is fairly conceived as part of the process necessary for “fundamental fairness” in a constitutional sense.⁶¹ Guardianship also implicates rights and obligations under federal disability rights laws, including the Americans

⁶⁰ *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976). See also John Pollock & Megan Rusciano, *Right to Counsel in Restoration of Rights Cases*, 42 BIFOCAL 75, 78 (2021); Ally Seneczko, *Special Education, Guardianships, and Procedural Due Process*, 81 Montana L. Rev. 289, 300-313 (2020).

⁶¹ *Lassiter v. Dep’t of Soc. Servs. of Durham Cty., N. C.*, 452 U.S. 18, 24-25 (1981); See also John Pollock & Megan Rusciano, *Right to Counsel in Restoration of Rights Cases*, 42 BIFOCAL 75, 78 (2021).

with Disabilities Act and Section 504 of the Rehabilitation Act, which require state courts to make “reasonable modifications” and to ensure that their programs are accessible to people with disabilities.⁶² Using these federal powers, as well as Spending Clause and grant-making authority, and the power of persuasion over federal agencies, I urge Congress to take bold steps to undertake the following changes.⁶³

A. Changes In The Guardianship System

First, Congress should establish minimum due process safeguards, consistent with Constitutional rights and rights under federal disability rights laws. Key recommendations here include:

Recommendation One: Recognize and strengthening of due process rights and protections of people at risk of, or already under, guardianship, including the following:

Implementing this recommendation includes recognizing the following rights:

- a. **Right to an attorney** to represent the individual’s stated interests (not “best interests”) in proceedings to institute a guardianship and in proceedings to terminate a guardianship. The right to counsel is not only a matter of due process protections but is also a “reasonable modification” and a nondiscriminatory “method of administration” required under federal disability rights laws.
- b. **Right to notice** in plain, accessible language, and, where necessary, access to auxiliary aids and services to ensure that the notice is meaningfully communicated. This should inform the person at risk of guardianship of:
 - i. guardianship proceedings;
 - ii. the risks and consequences of a guardianship for the individual;
 - iii. the right to contest the guardianship, including by demonstrating the use of alternative supports that obviate the need for guardianship;
 - iv. the process to seek dissolution of guardianship; and
 - v. how to get help understanding and exercising these rights.
- c. **Right to hearing.** No guardianship should be imposed without providing the individual the right to meaningfully participate in guardianship proceedings, including the right to be present at hearings, and to meaningful opportunity – and attorney representation – to change or dissolve guardianship.

⁶² See, e.g., Salzman, *Guardianship for Persons with Mental Illness*, *supra* n. 40, at 281-82; Leslie Salzman, *Using Domestic Law to Move Toward a Recognition of Universal Legal Capacity for Persons with Disabilities*, 39 *Cardozo L. Rev.* 521 (2017).

⁶³ Many of the recommendations here are consistent with recommendations adopted by the multidisciplinary delegates of the Fourth National Guardianship Summit, organized by the National Guardianship Network in May 2021, of which I was a delegate. The Summit recommendations were drafted and adopted by delegates who included advocates, family guardians, judges, lawyers, scholars, and other stakeholders. Syracuse University College of Law, *The Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability* (May 2021), <http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability> (“Fourth National Guardianship Summit”).

- d. **Right to least restrictive option.** Guardianships should be imposed only as a last resort. As such, no court should impose guardianship unless and until other, less restrictive options, have been tried. Courts should refuse to impose guardianships if alternatives, such as supported decision-making, have not been tried. Exploring supported decision-making and other alternatives is a “reasonable modification” to avoid guardianship.⁶⁴

Each of the above recommendations (1(a)-1(d)) are based on Constitutional due process rights and federal disability rights laws.

Recommendation Two: Funding and support for programs to develop and expand “off-ramps” at every stage of the guardianship system.

Congress should fund and support the following programs:

- a. **Guardianship diversion programs**, to divert people away from guardianship and towards voluntary alternatives like supported decision-making.
- b. **Guardianship termination programs**, providing assistance and legal representation to help people terminate guardianships and identify and use self-directed supports instead of guardianship.
- c. **Voluntary support programs** to help people identify, use, and advocate for voluntary, self-directed supports.
- d. **Education** programs for judges and lawyers on alternatives to guardianship, their obligations under Constitutional and disability rights laws to consider alternatives, and practical information and tools to direct and support people to get and stay out of guardianships.

Each of the programs outlined above (Recommendations 2(a)-(d)) should incorporate peer support and education, which recognizes and strengthens support and advocacy from and with directly impacted, disabled people. Each of these programs should require accompanying data collection and reporting, with continued funding conditioned on demonstration that the programs are reducing the number of people in guardianship.⁶⁵

These programs can be established through Congress’ spending power grant programs, with funding conditioned on demonstration that the programs are reducing the number of guardianships. These programs may also be required as reasonable modifications to the guardianship system, and/or as an application of the Americans with Disabilities Act *Olmstead* integration mandate.

⁶⁴ See Fourth National Guardianship Summit, adopted recommendation 1.2; *Beyond Guardianship, supra* n. 3, Finding and Recommendation #3, at 163-64.

⁶⁵ See Fourth National Guardianship Summit, adopted recommendation 3.3; *Beyond Guardianship, supra* n. 3, Finding and Recommendation #6, 166-167.

Recommendation Three: Comprehensive nationwide data collection.

Congress should ensure that state court systems, and federal agencies, collect and publish data on adults under guardianships and conservatorships. This data should include information on:

- How many people are in guardianships and conservatorships each year;
- How many new guardianships are granted each year;
- Referral sources for new guardianships;
- How long existing guardianships have been in place;
- How many people seek to terminate guardianship each year;
- How many try to get out of guardianship;
- Who is serving as the guardians;
- Financial reports;
- Access to counsel in guardianship proceedings
- Demographic information of people under guardianship, including age, race, ethnicity, gender, and disability;
- Geographic distribution of guardianships; and
- Efforts to require use of less-restrictive alternatives and projects and structures underway to discourage guardianship and encourage alternatives ⁶⁶

B. Changes to Strengthen Programs Outside of Guardianship

Changes *within* the guardianship system are not enough. Congress should also act to expand education, programs, and support so that people with disabilities can live their own lives without approaching the guardianship system. We need widespread recognition of supported decision-making and voluntary supports through which people retain their civil liberties so that they are never faced with guardianship. This includes expanding, recognizing, and strengthening programs to help people identify supporters and use supported decision-making, including people who have come out of guardianship, and to help people avoid guardianship altogether. These programs are tied to protections under federal disability rights laws, constitutional protections and grantmaking authority.

Recommendation Four: Agency Recognition of Supported Decision-Making

Congress should urging the Department of Justice to issue guidance recognizing and clarifying that supported decision-making is a valid, recognized tool, and clarifying that supported decision-making is an example of a “reasonable modification” and a nondiscriminatory method of administration that public entities – including courts, schools, medical professionals, and others – must recognize and consider before recommending or instituting guardianship, in order to avoid disability discrimination.⁶⁷

⁶⁶ See Letter from Senators Warren and Casey, *supra* n. 11; Fourth National Guardianship Summit, adopted recommendation 4.1; *Beyond Guardianship*, *supra* n. 3, Finding and Recommendation #1, 161-162.

⁶⁷ See Fourth National Guardianship Summit, adopted recommendation 3.1; *Beyond Guardianship*, *supra* n. 3, Finding and Recommendation #2, at 162-163.

Recommendation Five: Funding Supported Decision-Making Programs

Congress should award grants to fund and expand supported decision-making programs, including new and existing pilot projects, research, and programs to help people with disabilities understand and use supported decision-making. It should ensure that programs are accessible to people with a wide range of disabilities, take place in communities overrepresented by guardianship, take into account intersectional identities, and include efforts to help people who do not currently have supporters identify and establish these supports. Congress should ensure that programs include involvement by, and build on the expertise of, disabled people who have been – or are still – directly impacted by guardianship.⁶⁸

Recommendation Six: Education About Alternatives to Guardianship

Congress should fund and expand education to school professionals, medical professionals, lawyers, judges, families, care providers, and other entities and populations about the importance of alternatives to guardianship, the harms and realities of guardianship, and the promise and practice of supported decision-making. This education should be tied to practical tools and direct resources so that people can implement models of support that allow disabled people to retain their rights. These programs should be tailored to specific audiences and include the voices of directly impacted people.⁶⁹

I urge you to take these considerations seriously, and to work closely with the disability community in making changes to protect the civil liberties, autonomy, and dignity of people with disabilities in our country. Thank you.

⁶⁸ See Fourth National Guardianship Summit, adopted recommendation 2.1, 2.2, 2.3.

⁶⁹ See Fourth National Guardianship Summit, adopted recommendation 3.4.