



Commonwealth of Massachusetts
Massachusetts Developmental Disabilities Council

*108 Myrtle Street, Suite 202
Quincy, Massachusetts, 02171*

*CHARLES D. BAKER
GOVERNOR*

*KARYN E. POLITO
LIEUTENANT GOVERNOR*

*HOLLY E. SIMIONE
CHAIRPERSON*

*DANIEL M. SHANNON
EXECUTIVE DIRECTOR*

October 4, 2021

The Honorable Senator Blumenthal
Chair
Subcommittee on The Constitution
Committee on the Judiciary
United States Senate
706 Hart Senate Office Bldg.
Washington, DC, 20510

The Honorable Senator Ted Cruz
Ranking Member
Subcommittee on The Constitution
Committee on the Judiciary
United States Senate
127A Russell Hart Senate Office Bldg.
Washington, DC 20510

Re: Testimony from Massachusetts Developmental Disabilities Council – Hearing on Toxic Conservatorships: The Need for Reform

Dear Mr. Chairman, Ranking Member, and Subcommittee Members:

The Massachusetts Developmental Disabilities Council welcomes the interest in guardianship and conservatorship reform from Subcommittee on The Constitution. We urge you to listen to the voices of those with lived experience with the guardianship and conservatorship system and to focus your efforts on practices that will prevent unnecessary guardianship, a pervasive issue for intellectually and developmentally disabled Americans. Below we offer insights and resources from our advocacy work and share the experience of one of our Council members and her adult son who avoided guardianship and instead use guardianship alternatives including a method called supported decision-making. For meaningful systemic change to our country's flawed guardianship systems, guardianship alternatives must be supported and promoted on both a federal and state level.

Our work at the Massachusetts Developmental Disabilities Council. The Council is mandated by the Developmental Disabilities Assistance and Bill of Rights Act to empower



(617) 770-7676 (Voice)
(617) 770-1987 (Facsimile)
www.mass.gov/mddc

intellectually and developmentally disabled people and their families to help shape policies that impact them. Our work includes advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. A central aspect of this work is educating policymakers about issues that impact the disability community. For many years, the Council and its Members have been involved in advocacy across Massachusetts to promote guardianship alternatives including supported decision-making. We are active members of various guardianship alternatives coalitions that we lead or co-lead and have funded initiatives to promote guardianship alternatives at organizations including Massachusetts Advocates Standing Strong and the Center for Public Representation.

THE PROBLEM:

Guardianship and conservatorship systems are overused in part because of a lack of focus on guardianship alternatives and inadequate due process protections

When Britney Spears spoke out about her conservatorship, she brought unprecedented national attention to a problem we have long been focused on: fixing our flawed guardianship systems. This year’s media coverage of the guardianship and conservatorship systems made many members of the American public aware for the first time about the loss of rights resulting from a guardianship, the problems of guardians who neglect or abuse their authority, the detrimental impact this can have on disabled Americans and older adults, and the difficulty of restoring a person’s rights after a guardianship has been imposed. Many Americans did not realize until recently that these procedures existed, or that they were misused. Just as the disability community has long known, many Americans now see the need for guardianship as we know it to change.¹

In our advocacy, we hear repeatedly from developmentally and intellectually disabled advocates and their family members about the problems and issues with the guardianship system. As the Subcommittee has learned, this complex system of state laws is ripe for misuse, and unfortunately there are far too many cases where guardians either neglect their duties or act beyond the scope of their authority to the detriment of the people under guardianship.² In addition to the extreme cases of guardianship abuse that have rightfully been the focus of much

¹ In July 2021, sixty-nine percent of individuals of likely voters polled said that the guardianship and conservatorship system needs reform. Data for Progress, at 1.

https://www.filesforprogress.org/datasets/2021/7/dfp_21_7_conservatorship_toplines.pdf.

² See, e.g., National Center on Law and Elder Rights, *When the Guardian is An Abuser*

<https://ncler.acl.gov/getattachment/Legal-Training/When-the-Guardian-is-an-Abuser-Ch-Summary.pdf.aspx?lang=en-US>

(citing U.S. Senate Special Committee on Aging, Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans, November 2018, p. 5 ([W]hile data is lacking, “unscrupulous guardians acting with little oversight have used guardianship proceedings to . . . obtain control of vulnerable individuals and . . . to liquidate assets and savings for their own personal benefit”); U.S. Government Accountability Office, Elder Abuse: The Extent of Abuse by Guardians is Unknown, but Some Measures Exist to Help Protect Older Adults, GAO-17-33 (2016) <https://www.gao.gov/assets/gao-17-33.pdf>).

media and public attention,³ the other overwhelming, contributing problem is that **guardianship is overused**.

Like every other state, data in Massachusetts on guardianship is limited and incomplete,⁴ but we do know that typically 11,000 guardianships and 3,000 conservatorships are filed every year, for a total of over 43,000 over four years.⁵ Though comprehensive data is lacking, our advocacy has shown us that, consistent with national trends, guardianship is often presented as the default choice,⁶ resulting in unnecessary guardianship. The consequences are significant. Overuse of the guardianship system with unnecessary guardianships mean fewer resources are available for monitoring and oversight. Further, because family members frequently pursue a guardianship without fully understanding what a guardianship order will do, whether it is truly necessary, or what it will mean for their loved one's legal status, they are often surprised by the breadth and scope of its effect. In fact, a guardianship has a far-reaching, long-lasting impact on people's lives and fundamental rights, often beyond what a well-intentioned petitioner might ever imagine. Research shows that people under guardianship are less likely to live independently, to access preventative health care, or work in a paid job in the community.⁷ And research also shows racial disparities: Black people under guardianship less likely to have a family member as a guardian.⁸ For these reasons, families can find themselves unknowingly opening the wrong door and then learning too late that the door is hard to walk back through.

Our experience in Massachusetts mirrors that across the country: guardianship is presented to many families with intellectually and developmentally disabled children as the default option as they approach age eighteen. Families report to us feeling pressured to pursue guardianship by schools and other systems with which they interact. This phenomenon is

³ See, e.g., Heidi Blake & Katie J.M. Baker, *Beyond Britney: Abuse, Exploitation, and Death in America's Guardianship Industry*, BuzzFeed News (Sept. 17, 2021)

<https://www.buzzfeednews.com/article/heidiblake/conservatorship-investigation-free-britney-spears>; New Yorker, *How the Elderly Lose Their Rights* <https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>; KTNV Las Vegas, *Disgraced former Nevada guardian sentenced to serve up to 40 years* (Jan. 04, 2019) <https://www.ktnv.com/news/investigations/disgraced-former-nevada-guardian-sentenced-to-serve-up-to-40-years>

⁴ 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), at 41

https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf [hereinafter: Nat'l Council on Disability, *Rights into Reality*]; National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, 65-70 (Mar. 22, 2018)

https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf [hereinafter Nat'l Council Dis., *Beyond Guardianship*]. See also Letter from Sen. Elizabeth Warren & Sen. Robert P. Casey, Jr. to Hon. Xavier Becerra, Sec'y, Dep't of Health & Hum. Serv. & Hon. Merrick Garland, Att'y Gen., Dept. of Just. (July 1, 2021) <https://www.warren.senate.gov/imo/media/doc/2021.07.01%20Letter%20to%20DOJ%20and%20HHS%20re%20Conservatorship.pdf> (requesting detailed agency data on guardianships to inform policy work).

⁵ In Massachusetts Probate and Family courts, 9,317 guardianship petitions were filed in fiscal year 2020. In previous fiscal years there were about 11,000 a year. See *Probate and Family Court Department, Filings By Fiscal Year and Case Type*, <https://www.mass.gov/doc/probate-family-court-summary-of-cases-by-fiscal-year/download>. Under Massachusetts law, a conservatorship is when someone is appointed by a court to make financial decisions about a person's property and financial matters. MASS. GEN. LAWS ch. 190B, § 5-419.

⁶ Nat'l Council on Disability, *Rights into Reality*, at 29.

⁷ See *What Do NCI Data Reveal About the Guardianship Status of People With IDD?* at 5 https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf

⁸ *Id.* at 4.

so common and universal in the U.S. that it has been termed the “**school-to-guardianship pipeline**.”⁹ Families report being told by schools, service providers, health care providers, and others that guardianship is the only way they can continue to participate in Individualized Education Plan meetings, attend medical appointments, or help with managing money. As a result, many families obtain a guardianship without exploring or even considering other alternatives that might meet the needs of their family member. Of course, this does not discount the fact that many families may still choose to petition for guardianship regardless of the information they receive, but every disabled person and their family members deserve to have access to accurate, complete information about their options. Most important, schools and federally funded government agencies including vocational rehabilitation agencies should not be pressuring families to pursue a legal option that may not achieve the families’ goals, is expensive, is difficult to reverse,¹⁰ and will restrict the disabled person’s legal rights for their entire life. This is more troubling when guardianship is presented in a vacuum where the wide range of alternatives that might meet the needs of the disabled young adult are absent.

As an example, in the educational context, voluntary shared decision-making is one way to ensure family members can remain involved in their child’s education after the child turns eighteen. The Massachusetts Department of Elementary and Secondary Education has issued an advisory making explicit that an adult student not under guardianship can voluntarily share decision-making authority with an adult or choose to delegate decision-making authority.¹¹ For many families, shared educational decision-making for education after the child turns eighteen could address one of the major reasons schools encourage families to obtain guardianship.

A lack of due process protections further contributes to the overuse of the guardianship system.¹² From our advocacy work we see a few central issues, which are consistent with national trends: guardianship hearings can be too brief and many times the respondent does not even appear before the court,¹³ respondents are not automatically appointed counsel in all guardianship proceedings (and laws vary widely by state),¹⁴ and restoration of rights is rare and difficult to obtain.¹⁵ In Massachusetts, like many states, respondents in a guardianship proceeding are automatically appointed an attorney in some *but not all* circumstances. For instance, with some exceptions, even at the outset of a guardianship proceeding the respondent is not automatically appointed counsel.¹⁶ As a result, unless the court chooses to appoint counsel, the burden is on the respondent to understand the proceedings adequately enough in order to know to request counsel. Frequently the respondent does not have

⁹ Nat’l Council on Disability, *Rights into Reality*, at 21-36.

¹⁰ See 110-117.

¹¹ See Mass. Dept. Elementary and Secondary Education, Administrative Advisory SPED 2011-1, (Sept. 20, 2010) https://www.doe.mass.edu/sped/advisories/11_1.html.

¹² Nat’l Council Dis., *Beyond Guardianship*, at 85-89

¹³ *Id.* at 85-87.

¹⁴ See generally American Bar Association, Commission on Law and Aging, *Representation and Investigation in Guardianship Proceedings*, https://www.americanbar.org/content/dam/aba/administrative/law_aging/chartrepresentationandinvestigation.authcheckdam.pdf

¹⁵ See American Bar Association, *Restoration of Rights in Adult Guardianship: Research & Recommendations* (2017), https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf. [hereinafter ABA, *Restoration*]

¹⁶ Mass. Gen. Laws Ann. ch. 190B, § 5-106 (West).

enough information to understand their legal rights, including their right to request counsel in a guardianship proceeding, or information about these options is not presented in a way that is accessible to the respondent.¹⁷

Finally, we also know that rights restoration cases are rare,¹⁸ and even more rare for young adults.¹⁹ Low rates of rights restoration cases are especially concerning because many young adults are placed under conservatorship before they reach age twenty-six, and widely accepted neuroscience research shows us that the brain is not fully developed until this age.²⁰ Therefore, adequate due process protections, and in particular a right to counsel and access to zealous representation by lawyers trained to work with the disability community, are essential in restoration cases. While data is again lacking, there is evidence that representation at these hearings may make the guardianship more likely to be terminated.²¹ Currently, laws requiring right to counsel in rights restoration proceedings vary by state.²²

There is an urgent need for thoughtful reforms driven by the experiences of people under guardianship or at risk of guardianship. We believe any reforms to the guardianship systems should focus on promoting use of alternatives to guardianship. There has been a growing national movement to promote the use of a guardianship alternative called **supported decision-making**.²³ Supported decision-making is a way for a disabled person or an adult with a cognitive impairment to make and communicate decisions with assistance from people they trust.²⁴ With supported decision-making the disabled person, or “decision-maker,” chooses a group of trusted supporters to assist with helping making decisions about issues like their health care, finances, services, or other matters that are important to the decision-maker. The

¹⁷ This also raises an important point about reasonable accommodations in courts. An innovative international model that has been replicated in Vermont provides disabled people with intermediaries called Communication Support Specialists in court proceedings. Disability Rights Vermont, Vermont Communication Support Project, <https://disabilityrightsvt.org/about/vermont-communication-support-project/>. The Communication Support Specialists in the Vermont program are independent and appointed by the court to assist the disabled individual with communication. The support is provided as an accommodation to overcome barriers to effective communications. Communication Support Specialist is in addition to legal representation and not a replacement for counsel. In addition, the Fourth National Guardianship summit recommended supported decision-making be considered an accommodation under the Americans with Disabilities Act. Fourth National Guardianship Summit, *Recommendations Adopted by Summit Delegates*, (May 2021) Adopted recommendation 2.4, http://law.syr.edu/uploads/docs/academics/Fourth_National_Guardianship_Summit_-_Adopted_Recommendations_%28May_2021%29.pdf [hereinafter *Guardianship Summit Recommendations*]. Guidance from the U.S. Department of Justice consistent with this recommendation would be a clear directive to courts to allow people to use supported decision-making as an accommodation to understand their legal rights and options in court proceedings, including guardianships.

¹⁸ ABA, *Restoration*, at 21.

¹⁹ The limited available data indicates that rights restoration is uncommon overall, and more common for older adults than for younger adults. ABA, *Restoration*, at 7.

²⁰ Mariam Arain et al., *Maturation of the adolescent brain*, 9 *Neuropsychiatric Disease & Treatment* 449, 449 (2013) available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3621648/>.

²¹ ABA, *Restoration*, at 46-47.

²² John Pollock & Megan Rusciano, *Right to Counsel in Restoration of Rights Cases*, 42:4 *BiFocal* 75 (Mar. 11, 2021) https://www.americanbar.org/content/dam/aba/administrative/law_aging/bifocal-vol42-issue4.pdf. See also American Bar Association, *Restoration*, at 13.

²³ See generally Center for Public Representation, *Supported Decision-Making*, <https://supporteddecisions.org/>; National Resource Center on Supported Decision-Making, <http://www.supporteddecisionmaking.org/>.

²⁴ Nat'l Council on Disability, *Beyond Guardianship*, at 130.

arrangement is often memorialized in a simple written agreement. Supported decision-making is typically coupled with other guardianship alternatives such as a health care proxy or power of attorney. It is through this combination of supports that the decision-maker can exercise their will and preferences and communicate their decisions.

Supported decision-making has been the subject of pilots²⁵ and is obtaining increased acceptance in courts,²⁶ in the law,²⁷ by key organizations and stakeholders, and the federal government.²⁸ In Massachusetts, as in many other states, there is currently legislation pending that would formally recognize supported decision-making and establish roles, responsibilities, limitations, and safeguards for the practice.²⁹ More widespread information about guardianship alternatives like supported decision-making is an essential step in avoiding unnecessary guardianship, which the Administration for Community Living has recognized through its funding of a number of national and state-level initiatives focused on supported decision-making and guardianship alternatives.³⁰

A STORY FROM MASSACHUSETTS:

How and why supported decision-making and guardianship alternatives work.

We know that supported decision-making and guardianship alternatives work. Massachusetts Developmental Disabilities Council Member **Sandra Heller** of Marion, MA and

²⁵ See Cathy Costanzo, Hon. Kris Glen, & Anna Krieger, *Supported Decision-Making: Lessons from Pilot Projects* (April 2021), <http://law.syr.edu/uploads/docs/academics/constanzo-glen-krieger.pdf> (background paper prepared for the Fourth National Guardianship Summit).

²⁶ Nat'l Council on Disability, *Rights into Reality*, at 27 ("The first reported court decision terminating a guardianship specifically in favor of SDM occurred in 2012 in the state of New York and was followed by other cases in New York (2015, 2016, 2017), Virginia (2013), Massachusetts (2015), the District of Columbia (2016), Florida (2016), Vermont (2017), Kentucky (2017), Nevada (2017), Maine (2018), and Indiana (2018).")

²⁷ States and jurisdictions passing comprehensive supported decision-making statutes include: Tex. Est. Code Ann. §§ 1357.001 - 1357.102 (West 2019); Wis. Stat. Ann. §§ 52.01-52.32 (West 2018); Alaska Stat. Ann. §§ 13.56.010-13.56.195 (West 2018); Del. Code Ann. tit. 16, §§ 9401A-9410A (West 2016); D.C. Code Ann. §§ 7-2131 - 7-2134 (West 2018); Ind. Code Ann. §§ 29-3-14-1 - 29-3-14-13 (West 2019); N.D. Cent. Code Ann. §§ 30.1-36-01 - 30.1-36-08 (West 2019); 42 R.I. Gen. Laws Ann. §§ 42-66.13-1 - 42-66.13-10 (West 2020); Nev. Rev. Stat. Ann. §§ 162C.010 - 162C.330 (West 2020); Wash. Rev. Code Ann. §§ 11.130.700 et. seq. (West 2020) (effective Jan. 1 2022), 2020 Wash. Legis. Serv. Ch. 312 (S.S.B. 6287) Part VI § 601-612 (West 2020); La. Stat. Ann. § 13:4261.101- 13:4261.302 (West 2020); Sen. Bill No. 75, 73rd Gen. Assembly, 1st Reg. Sess. (Col. 2021); and N.H. Rev. Stat. § 464-D:1 (NH 2021).

²⁸ Among the many entities endorsing supported decision-making are the American Bar Association, National Guardianship Association, and the Administration for Community Living. See <https://supporteddecisions.org/about-supported-decision-making/organizations-advocating-for-supported-decision-making/>

²⁹ Sen. Bill 124, 192nd Gen. Court (Ma. 2021), <https://malegislature.gov/Bills/192/S124>; House Bill 272, 192nd Gen. Court, Reg. Sess. (Ma. 2021), <https://malegislature.gov/Bills/192/H272>. See also Fact Sheet on Mass. Legislation, <https://supporteddecisions.org/wp-content/uploads/2021/05/SDM-Bill-fact-sheet-S124-H272-4-16-2021.docx>.

³⁰ See Administration for Community Living, Supported Decision Making Program <https://acl.gov/programs/consumer-control/supported-decision-making-program> (describing funding of various national and local supported decision-making initiatives including National Resource Center on S); Administration for Community Living, "ACL Awards Alternatives to Guardianship Youth Resource Center," (Sept. 23, 2020) <https://acl.gov/news-and-events/announcements/acl-awards-alternatives-guardianship-youth-resource-center>.

her son **Craig Kinney** of Fairhaven, MA have a powerful story of their experience using guardianship alternatives so that Mr. Kinney could make his own choices with support and avoid guardianship.

Mr. Kinney is a 34-year-old man who works, lives on his own, and loves to travel and eat at restaurants. Mr. Kinney has down syndrome and, since birth, his family has been told by system after system and person after person that he is not capable of doing certain things and making certain decisions. Ms. Heller never saw him this way. Instead, she fought for and alongside Mr. Kinney for him to have every opportunity to make his own decisions and live a life in the community. Though there was no formal term for it at the time, Mr. Kinney has used supported decision-making since he was a teenager. He made important decisions about his life with support of trusted people who would help him understand his options and understand how he communicates.



“What is most important to me is not to be told what to do but to give me choices and help me make decisions.”

- **Craig Kinney**, Decision-Maker

When Mr. Kinney approached eighteen, staff at his school district told Ms. Heller she should consider placing him under a guardianship. Ms. Heller and Mr. Kinney knew this was not an option for him. Instead, they continued using his supported decision-making arrangement so that he could make his own choices. When he turned eighteen, Mr. Kinney also executed a health care proxy in case of emergency and a power of attorney for financial matters.

Later, as supported decision-making became more widely recognized as a concept, Mr. Kinney chose to create a formal supported decision-making agreement as part of a pilot from the Center for Public Representation in partnership with Mass Families.³¹ Since that time Mr. Kinney has continued to use his supported decision-making agreement in all kinds of decisions.

Over the years, Mr. Kinney’s supported decision-making arrangement and health care proxy have worked even as he dealt with significant health issues related to his disabilities, including multiple surgeries and hospitalizations as the result of getting a tracheotomy. Even during periods when he was hospitalized, Mr. Kinney was able to make and communicate his own decisions with assistance from supporters, including during extended periods where he was not speaking due to his medical condition. For example, when Mr. Kinney had to decide whether to undergo a certain surgery, his supporters explained how he might feel after. His supporters also explained to him how the surgery was intended to benefit him. Sometimes a supporter would repeat the same thing the health care providers had said to Mr. Kinney using different language. At times, Mr. Kinney understands concepts better when he hears them in Ms. Heller’s voice and with her natural language with which he is familiar. Mr. Kinney is also hard

³¹ Craig’s Story, <https://supporteddecisions.org/stories-of-supported-decision-making/craigs-story/>.

of hearing and sometimes reads lips, which his supporters understand and adapt their communication styles to.

While at times the medical teams questioned how the arrangement worked, Mr. Kinney and his supporters were steadfast in their commitment to supporting Mr. Kinney to make his own choices. At times, Mr. Kinney and his supporters would model for his health care providers how he made his decisions. Ultimately, the health care teams he worked with were able to hear Mr. Kinney's voice and honor his decisions.

As Ms. Heller explains:

"Today, I am happy to say that Craig's Supported Decision-Making agreement works! He has chosen four people in his life that are family and caregivers to be his 'supporters' on things that every person should be given the opportunity to decide.

"From Craig's early childhood to today, he is given every opportunity to be a decision-maker. He is proud and respected for being a registered voter, deciding where he lives and with who, how he spends his own earned money from working, who he wants to spend time with and most importantly, he is given the information and respect to understand his own medical needs. As a teenager Craig endured and required life sustaining medical procedures and not one day went by that everyone around him from the doctors to his family did not inform, explain and help him through these difficult years.

"We all learn through our own life experiences and we all rely on others in our lives to help us with decision making, my son is no different."

In her work with other families considering guardianship and guardianship alternatives, Ms. Kinney has seen first-hand how little information many families are provided. Over the years, Ms. Kinney also estimates she has supported at least one hundred families who have decided to petition for guardianship and says, "Ninety-nine percent of the time, the individual with the disability is not even at the court hearing. How can you take a person's rights away without even meeting them?"



"We all learn through our own life experiences and we all rely on others in our lives to help us with decision making, my son Craig is no different."

- **Sandy Heller**, Supporter & Massachusetts Developmental Disabilities Council Member

RECOMMENDATIONS:

Guardianship reform efforts will only be effective if they center and address guardianship alternatives. Without a focus on diverting people from unnecessary guardianship, the pipeline to guardianship will continue in schools and elsewhere.

- 1. Department of Education guidance or regulations that require all transition aged youth and their families receive accurate information about guardianship alternatives in school and in state vocational rehabilitation transition programs would have a significant impact on the school-to-guardianship pipeline.** Department of Education officials can also issue guidance or regulations that would establish a clear process for an educational representative or joint educational decision-making, consistent with state law.³²
- 2. Federal incentives to states to enact laws that establish robust due process protections in guardianship proceedings will help prevent unnecessary guardianship at the outset, promote restoration of rights, and facilitate meaningful oversight.**³³ Critical due process protections needed include: (1) automatic appointment of counsel in guardianship proceedings, including restoration proceedings; (2) access to zealous representation that is consistent with the disabled person or older adult's expressed interest; and (3) access to resources to explore and consider meaningfully less restrictive alternatives. To ensure the due process protections are meaningful, there must be adequate funding of procedures and programs ensure respondents understand their rights at all stages of a proceeding and a guardianship. Similarly, states must also have adequate funding to ensure appointed counsel understands how to work with and communicate with disabled people.
- 3. Federal funding of guardianship alternatives pilots, diversion programs, projects, and initiatives—particularly those led by or co-led by intellectually and developmentally disabled advocates, their families, and other people at risk of guardianship—will promote widespread adoption of guardianship alternatives and supported decision-making.** While the groundwork has been laid with pilots and projects designed to transform systems and demonstrate the viability of guardianship alternatives, widespread adoption of practices will require further investment of federal resources.³⁴ This should include funding of diversion programs that provide education on guardianship alternatives to key entities including courts, schools, and federally funded state agencies.
- 4. Federal funding of initiatives and projects that provide specialized communication accommodations in guardianship proceedings could have a significant impact on**

³² See Nat'l Council on Disability, *Rights into Reality*, at 80; *Guardianship Summit Recommendations*, adopted recommendation 3.3.

³³ Nat'l Council on Disability, *Beyond Guardianship*, at 164-165; *Guardianship Summit Recommendations*, adopted recommendation 1.3.

³⁴ *Guardianship Summit Recommendations*, adopted recommendations 2.1, 2.2, & 3.3.

court access for people with disability-related communication barriers.³⁵ The federal government is well-positioned to support expansion of initiatives like the Vermont Communication Support Project, the only court communication accommodation project of its kind in the United States. Such initiatives have the potential to be transformative in the guardianship context and meaningfully contribute to due process but funding for pilots, research, and other demonstrations is necessary.

- 5. Reliable data on guardianship is sorely lacking and the federal government has an opportunity to require data collection through relevant agencies and state incentives.**³⁶ Advocates for reform have long protested that the lack of data on guardianship has far-reaching implication for our most basic understanding of how the guardianship and conservatorship systems function in this country, including concerning abuse and neglect by guardians.³⁷ Further, because we lack foundational information about guardianships and conservatorships, we do not know what disproportionate impacts guardianship has on disabled people who are Black Indigenous and People of Color, LGBTQIA+, and/or come from ethically and culturally diverse communities. Any data collection reforms must apply an intersectional lens so that data collected captures impact of guardianships on populations where there are additional or unique barriers to embracing guardianship alternatives.

We welcome your attention to these issues of pressing importance to the disability community and remain ready to collaborate and contribute to the important efforts of transforming these systems.

Sincerely,

/s/

Anna Krieger
Director of Public Policy

³⁵ Vermont Communication Support Project, “Frequently Asked Questions,” <http://disabilityrightsvt.org/wp-content/uploads/2021/01/VCSP-FrequentlyAskedQuestions-2020.pdf>.

³⁶ See e.g., Nat’l Council on Disability, *Beyond Guardianship*, at 161; Nat’l Council on Disability, *Rights into Reality*, at 79

³⁷ Nat’l Council on Disability, *Rights into Reality*, at 83. *Guardianship Summit Recommendations*, adopted recommendation 4.1.