



Center for Public
Representation

**Congressional Testimony of the Center for Public Representation
Submitted by Cathy Costanzo, Executive Director
October 4, 2021**

My name is Cathy Costanzo and I am the executive director of the Center for Public Representation (CPR). CPR is a nationally recognized legal advocacy center committed to protecting and advancing the rights of people with disabilities and all others who are devalued in today's society. CPR uses legal strategies, systemic reform initiatives, and policy advocacy to enforce civil rights, expand opportunities for inclusion and full community participation, and empower people with disabilities to exercise choice in all aspects of their lives. CPR utilizes systemic reform initiatives to promote the integration and full community participation of people with disabilities. Working on state, national and international levels, CPR is committed to equality, diversity and social justice in all its activities.

CPR has long worked to promote guardianship reform and since 2014 has primarily focused its efforts to promote meaningful alternatives to guardianship. We have come to understand that retaining the right to exercise choice is perhaps the most fundamental right we have as human beings and among the most precious human rights. As such, CPR has been a national leader in promoting Supported Decision-Making (SDM) as a meaningful and superior alternative to guardianship.

Our society operates on two important assumptions: (1) all of us are able to make decisions and (2) in all but the most exceptional circumstances, our choices will be respected. Our laws and customs mostly reflect and enforce these critical cultural assumptions.

However, when a person is thought not to have the ability to make decisions, someone else may be empowered by some action of law to make decisions for him or her as a substitute decision-maker. The

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most common and most extreme form of substituted decision-making is guardianship, and in most places it is overused and often abused .Despite media exposes, state and federal inquiries, and major revisions to guardianship laws over the last three decades, the guardianship system in the United States continues to strip autonomy and dignity from the very people it is designed to protect and places them at risk of abuse, neglect, and exploitation.

In November 2018, the US Senate Special Committee on Aging issued a report that pleaded for cohesive data collection to inform and improve the nation’s guardianship system which serves at least 1.3 million seniors and people with disabilities nationwide. Three years later, there is still no cohesive system of data collection. That same committee report stridently urged judges to rely more on guardianship alternatives, such as SDM, healthcare proxies, advanced directives, and durable powers of attorney. But despite these important policy recommendations, guardianship (also commonly referred to as conservatorship), continues to be the default nationwide.

In the disability community, turning 18 is often the trigger for initiating guardianship proceedings. Indeed, school systems not only fail to advise families of other options, but remain one of the major source of referrals for guardianship. Among aging people with disabilities, the guardianship trigger can be a hospitalization, a sudden illness, or a diagnosis of dementia. As their abilities are compromised or questioned, aging adults can find themselves up against the threat of guardianship – an all-too-commonplace construct in the disability world.

Under the SDM model, individuals can turn to a network of supporters – trusted family members, friends, colleagues – to help them make decisions regarding healthcare, finances, jobs, and personal matters. The principles and inherent values of SDM can be embraced by anyone, anywhere who needs assistance making decisions over the course of their lifespan. To paraphrase the Hon. Kristin Booth Glen, retired judge and dean emerita at CUNY Law School, an SDM agreement is just as important as a healthcare proxy¹; both documents belong in every adult’s folder of important records.

¹ National Resource Center for Supported Decision-Making Symposium, Washington, D.C., June 11, 2019.

Given the nation's demographics and escalating senior population, there is a critical need to introduce the aging community to SDM. By adopting SDM now, seniors can stave off later attempts to chip away their rights and independence, and thereby retain their self-determination through their lifespan.² Research studies correlate self-determination with being healthier, more independent, and better able to recognize and resist abuse.³ On the flip side, the National Core Indicators (NCI) project consistently has found people under guardianship are less likely to live in the community, less likely to work in integrated settings, and less likely to have friends or other social networks.⁴

Since launching the nation's first SDM pilot in 2014, the Center for Public Representation has overseen five other pilots, established an SDM virtual library and realized significant findings:

- Under the guise of offering protection, the institution of guardianship strips away individuals' basic right to make their own choices in life.
- There are other options that both respect people's rights and provide protection.
- SDM, sometimes in conjunction with healthcare proxies and durable powers of attorney, is a viable alternative that offers people customized decision-making assistance so they can retain their right to exercise self-determination throughout their lives.

More work is needed to introduce people across the country to SDM, and to ascertain how many are under guardianship or under the threat of guardianship. Currently, it is unclear how many people with disabilities or aging adults are even informed about less restrictive alternatives.

Funding also is needed to support SDM pilots, especially in rural communities, and to support civil rights advocates representing individuals at risk of guardianship as well as those who are seeking to terminate guardianships and restore their rights. This work needs to be backed by the federal government:

² Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 *Fordham Urban L. J.* 495 (2016).

³ Jonathan Martinis and David Godfrey, *Supported Decision-Making in Late Life*, National Aging and Law Conference PowerPoint, HHS.2014.ACL-ADD-DM-0084, Slide 5, *citing* Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998.

⁴ Valerie Bradley, Dorothy Hiersteiner, Jane St. John, and Mary Lou Bourne, *What Do NCI Data Reveal About the Guardianship Status of People with IDD?* National Core Indicators Data Brief, April 2019, 6.

the Civil Rights Division with the Department of Justice should issue guidance recognizing SDM as a viable guardianship alternative.

As the Fourth National Guardianship Summit recommended last spring, the federal government should work with states and guardianship network organizations to educate stakeholders – courts, lawyers, guardians, school personnel, families – about SDM. The Summit further recommended that judges ensure that there is “clear and convincing evidence” that SDM is not feasible before considering guardianship. This requirement already is in place in states such as Texas. In addition, Summit participants called upon the Department of Justice to recognize SDM as a reasonable accommodation under the Americans with Disabilities Act to support individuals and enable them to retain their right to make informed decisions.

CPR supports these recommendations and believe that they can provide a foundation for meaningful change. However, we believe more is needed and consider the following

Congressional actions essential:

1. Direct the Secretary of Education to issue guidance on the use of alternatives to guardianship in transition planning and reinforcing that IDEA requires provision of transition planning services that maximize their opportunities for independence in adulthood.
2. Fund ACL to provide technical assistance and demonstration projects to help State Adult Protective Services (APS) programs use alternatives to guardianship when responding to welfare concerns.
3. Focus federal policy on advancing the systematic adoption, implementation, and sustainability of evidence-based alternatives to guardianship that are voluntary in nature—i.e., decision-making arrangements that are chosen and able to be cancelled or changed by the people with disabilities themselves.
4. Clarify that SDM is an accommodation under the ADA that allows a person to retain the right to make informed decisions about his or her own life.
5. Create a nationwide technical assistance to promote best practices in SDM and to address gaps in SDM implementation. The Administration for Community Living (ACL) has extensive expertise in addressing knowledge gaps through its Projects of National Significance (PNS) and other innovation grant programs.¹ ACL should reinvest in the creation of a new, long-term national technical assistance center to advance the practice of SDM.

6. Fund a national SDM initiative in each of the 50 States and territories to promote alternatives to guardianship. recently completed a five-year grant to create the National Resource Center for Supported Decision Making (NRC-SDM), which made important progress toward identifying best practicesⁱⁱ and provides critical technical assistance.ⁱⁱⁱ

In summary, Federal policy should focus on advancing the systematic adoption, implementation, and sustainability of evidence-based alternatives to guardianship that are voluntary in nature—i.e., decision-making arrangements that are chosen and able to be cancelled or changed by the people with disabilities themselves. To achieve this vision, federally-funded programs must prioritize alternatives to guardianship, ensure that investments are made to help States improve access to alternatives to guardianship; and ensure additional research and technical assistance on best practices for SDM is consistently funded over time.

CPR has prepared a position paper outlining detailed recommendations for federal legislation to reduce the reliance on guardianship over persons with disabilities and older adults through a federal focus on SDM and other alternatives. These recommendations are set forth below.

Respectfully submitted this 4th day of May, 2021.

A handwritten signature in black ink, appearing to read "Cathy E. Costanzo". The signature is written in a cursive, flowing style.

Cathy E. Costanzo



Recommendations for Federal Legislation to Reduce the Reliance on Guardianship over Persons with Disabilities & Older Adults through a Federal Focus on Supported Decision-Making and other Alternatives

Introduction

Guardianship is the process through which an adult is found by a court to be legally incapable of making decisions for him or herself and another adult is appointed to make decisions on behalf of that individual. Guardianship laws assume that some people do not have the capacity to make legally binding decisions and put in place a substituted decision-maker. In contrast, Supported Decision-Making (SDM), an alternative to guardianship, includes persons with disabilities and older adults in the decisions that affect them (e.g., important decision about healthcare, property, and legal issues). It recognizes the autonomy, identity, and abilities of every person.

Individuals with ID/DD, serious mental illness, or cognitive disabilities because of aging are at greater risk of being subject to guardianship than other adults because of widely-held stereotypes about their ability to make decisions and function independently.

Growing concerns about the overuse and abuse resulting from guardianship has propelled a national dialogue about the need for federal regulatory and legislative action. The following document offers data, key principles, and policy recommendations for consideration among Congressional leaders who are currently developing federal legislation aimed at enhancing the rights of individuals subjected to guardianship, reducing the reliance on guardianship in the future, and promoting alternatives to guardianship like SDM.

Background Information (Key Findings & Data Points)

- According to the U.S. Department of Justice, there are approximately 1.3 million adults with guardians who control about \$50 billion in assets.^{iv} But the national data understates the enormity of system as well as its problems.
- In a [2010 report](#), the U.S. Government Accountability Office (GAO) found hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010. Guardians also stole \$5.4 million in assets from their wards in that period, the GAO said. (The GAO is currently working on an updated report.)
- Two reports published by the National Council on Disability in [2018](#) and [2019](#), respectively, found that people with ID/DD currently are at higher risk for guardianship because of the school-to-guardianship pipeline;

- A minority of states have guardianship provisions that are applicable solely to people with ID/DD, as opposed to other alleged disabilities. While some statutes incorporate additional procedural safeguards, these statutes do not always advance the procedural due process rights of people with disabilities.
- Despite the existence of restoration of rights procedures in the majority state laws, many people with disabilities and their families are unaware of those options, nor of the broad array of less-restrictive alternatives to guardianship.
- There is a dearth of reliable data on the number of adult abuse, neglect or exploitation cases in which the perpetrator is the court-appointed guardian of the victim.

Key Principles

As Congress contemplates the development of federal legislation to modernize the legal foundations of guardianship or conservatorship over parts or whole aspects of the lives of impacted individuals with disabilities, it is imperative that the focus of any legislation promote the following principles:

- All persons with disabilities are full citizens who have the right to make free and informed decisions.
- Persons with disabilities should control their own affairs and any measures that take away a person’s decision-making abilities must be closely monitored and reviewed.
- While guardianship should be reformed to enhance the rights of and protect the due process of individuals currently under guardianship, federal policy reforms should be focused on transitioning people into voluntary alternatives to guardianship, including significantly restricting the use of new guardianship applications.
- Because guardianship is a significant or total deprivation of a person’s liberty and/or property rights, less restrictive alternatives should always be considered before guardianship can be imposed, and relevant state agencies should make information about SDM available, including in plain language.
- Alternatives to guardianship should be defined in easily understandable and non-exclusive terms.
- SDM is an accommodation under the ADA that allows a person to retain the right to make informed decisions about his or her own life.
- Everyone should be able to choose SDM as an alternative to guardianship, and there should be no negative consequences for doing so. No one should be prevented from choosing SDM based on traditional definitions of “capacity” that discriminate against persons with disabilities.
- A person’s use of SDM should be considered by courts as evidence of a “less restrictive alternative” to guardianship regardless of their disability and whether their SDMA is one which requires legislative recognition for decisions made pursuant to it.

- Supported Decision-Making Agreements (SDMAs) should be the result of a process of facilitation or education designed to ensure that the Decision-Maker understands what goes into deciding and obtaining support, and that Supporters understand their roles and how those roles may differ from their pre-existing relationships with the Decision-Maker.

Emphasis on Alternatives to Guardianship

Federal policy should focus on advancing the systematic adoption, implementation, and sustainability of evidence-based alternatives to guardianship that are voluntary in nature—i.e., decision-making arrangements that are chosen and able to be cancelled or changed by the people with disabilities themselves. Voluntary alternatives to guardianship include tools such as SDM, where people with disabilities use friends, family members, and others they trust to help them understand the everyday situations and choices they face, so that they can make their own decisions without the need for a guardian.

To achieve this vision, efforts should be undertaken to ensure that federally-funded programs prioritize alternatives to guardianship, that investments are made to help States improve access to alternatives to guardianship; and that additional research and technical assistance on best practices for SDM is consistently funded over time. The following recommendations outline key steps Congress can take to support these objectives.

Reduce the overreliance of guardianship through existing federally-funded programs, such as IDEA and adult protective services

Congress must address disturbing trends in key federally-funded programs where youth with disabilities and older adults are most prone to being pushed into guardianship arrangements, specifically by:

- Directing the Secretary of Education to issue guidance on the use of alternatives to guardianship in transition planning and reinforcing that IDEA requires provision of transition planning services that maximize their opportunities for independence in adulthood.
- Funding ACL to provide technical assistance and demonstration projects to help State Adult Protective Services (APS) programs use alternatives to guardianship when responding to welfare concerns.

Grants to States to Implement Supported Decision-Making (SDM)

Congress should establish grants to support States in adopting SDM and educating educate attorneys, judges, service providers, and the public; identifying and addressing barriers to SDM; establishing technical assistance programs and resources; and developing programs to provide decision-making support for people who lack pre-existing natural supports. States applying for grants would be required to confirm that SDM is recognized, either through statute or case law, as a legal alternative to guardianship, and be focused on special populations. These grants should be designed to establish, replicate, and scale up promising or best practices for sustainable SDM practices and models.

Funding Research and Technical Assistance on Best Practices for SDM

In addition to addressing state-specific barriers to accessing SDM and other alternatives to guardianship, States would benefit from nationwide technical assistance to address gaps in SDM implementation. The Administration for Community Living (ACL) has extensive expertise in addressing knowledge gaps through its Projects of National Significance (PNS) and other innovation grant programs.^v ACL recently completed a five-year grant to create the National Resource Center for Supported Decision Making (NRC-SDM), which made important progress toward identifying best practices^{vi} and provides critical technical assistance.^{vii} ACL has subsequently funded additional projects regarding supported decision-making, none are equally comprehensive as the NRC-SDM. Further funding could support the development of standards, competencies, and training necessary to build a robust field of professionals capable of supporting people in pursuing alternatives to guardianship, including but not limited to SDM.

We also support additional ACL funding through the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to support research on and dissemination of best practices in SDM, designed with a specific focus on addressing issues of racial inequity in seeking/accessing alternatives to guardianship; developing best practices for people with significant communication, memory, mental health, and cognitive support needs; and developing best practices in specific domains such as health care and financial planning.

Legislative Strategies for Limiting Guardianship/Conservatorship and Discouraging Reliance on Guardianship in Supporting People with Disabilities and Older Adults

Require States to Adopt/Implement the Uniform Act

States should adopt and implement the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (Uniform Act), including the provisions mandating representation by a lawyer of all adult respondents.^{viii} Guardianship laws need to ensure better avenues, stronger protections, and greater independence for individuals being considered for guardianship, and persons seeking to terminate or modify guardianship orders. Key provisions of the Uniform Act include:

- prohibiting guardianships where less restrictive alternatives would meet an adult's functional needs;
- requiring specific court findings before certain critical rights (e.g., to marry, vote, choose visitors) are abridged;
- requiring petitioners to state whether less restrictive alternatives have been attempted and justify any failure to do so;
- creating mechanisms that adults subject to guardianship and others can use to trigger modification or termination of an order;
- clarifying that a lawyer for a respondent, or adults subject to guardianship, must represent the adult's wishes; and

- enabling protective orders (or single transaction orders) instead of guardianship, thus expanding alternatives to guardianship.

Require Guardianship Diversion Programs to Facilitate Alternatives to Guardians

Every state should have a guardianship diversion program tasked with facilitating alternatives to guardianship, reducing the likelihood that guardianships will be granted where not necessary, and monitoring for the continued need for the guardianship. Such programs could be operated as a multi-disciplinary approach in collaboration with schools, adult protective services, healthcare, aging and disability service providers, the legal community, and other entities. Diversion should include education and facilitation about specific tools such as use of SDM, powers of attorney, and health care proxies. The diversion program should design and implement ongoing training and public information about alternatives to guardianship.

Require Alternatives to Guardianship to be Pursued prior to Guardianship being Imposed

Statutes, court rules, policies, and processes in every state should require courts to consider supported decision-making as one of the alternatives to guardianship at appointment and periodically thereafter by requiring that petitioners for guardianship plead affirmatively that SDM as one of the alternatives has been tried or why it was not feasible. Before guardianship is imposed, the court should have to find by clear and convincing evidence that SDM is not feasible. When this occurs, procedures should be in place to assure a periodic review of the need to continue guardianship and to revisit the feasibility of re-attempting SDM.

Training of Professionals who are Engaged in Guardianship Determinations to Build their Capacity and Commitment to Promoting Alternatives to Guardianship

States should provide accessible, practical, and tailored training to individuals and entities known to be pipelines to plenary guardianship (e.g., lawyers, judges, schools, nursing homes, health care providers, evaluators, investigators, adult protective services) on the following^{ix}:

- the impact of guardianship;
- legal and ethical obligations to exhaust alternatives to guardianship before pursuing it;
- alternatives to guardianship including SDM, formal and informal services and supports, advance directives, voluntary fiduciaries, other legal and non-legal interventions; and
- orders that are limited in scope and limited in time.

Proposed Reforms to Enhancing the Rights of Persons Subject to Guardianship

While CPR is adamantly opposed to the continued over-reliance of the legal system on guardianship of older adults and individuals with disabilities, we do believe it is necessary to institute federal reforms to strengthen existing legal processes and enhancing the rights of individuals under guardianship.

Guardianship Court Improvement Program

Establish a Guardianship Court Improvement Program modelled on the Child Welfare Court Improvement Program, and provide funding directly to the highest court in each participating state to enhance the rights and well-being of adults subject to, or potentially subject to, guardianship by:

- Effectuating consistent and meaningful data collection.
- Improving oversight and accountability.
- Avoiding unnecessary or overbroad guardianship.
- Enhancing collaboration and education among courts, agencies, and organizations that have an impact on adults subject to, or potentially subject to, guardianship.

Assuring Meaningful Due Process in All Judicial Proceedings for Individuals under Guardianship

Require States to ensure that all judicial proceedings which may impact any of an adult’s rights to legal capacity provide meaningful due process, which includes:^x

- the right to a qualified and compensated lawyer; reasonable notice provided in the adult's preferred language in an understandable and accessible format, served in a manner that ensures timely receipt;
- an impartial, valid, and reliable assessment by a compensated and qualified person conducting a capacity assessment who has knowledge and training about decision-making in the area(s) related to the proceedings, inclusive of the adult’s preferred reasonable accommodations and method of communication; and
- protection of the adult’s right to participate in the proceeding consistent with their preferences (including preferred communication accommodations) after the right to appear and the purpose of the proceeding have been explained to the adult through the means the adult understands.

Restoration of Rights for Individuals under Guardianship

States and courts must ensure full access to a full or partial restoration of rights as soon as possible after a right is legally restricted. The process to restore rights must include a clearly defined statute, regulation, court rule or policy which sets forth the procedures and the evidentiary burden and timelines and can be triggered by the individual through informal or formal means. Again, representation of the adult whose rights were legally restricted by a qualified and compensated lawyer, paid a reasonable fee with public funds if the adult is unable to pay, and appointed by the court should the adult not have a lawyer of their own choosing. meaningful periodic review by a court or other appropriate entity, inclusive of the perspective of the adult whose rights were restricted, of whether it is necessary to continue to restrict the adult’s rights.

- A guardian trained on the rights restoration process and the guardian’s obligations regarding the restoration of rights, the training to occur initially upon appointment and upon a change in the applicable law, regulation, rule, or policy.
- Courts and lawyers trained on the rights restoration process.
- A prohibition on guardian interference with the restoration of rights, and as appropriate guardian facilitation of the restoration of rights. Any party seeking to restore any right or rights of an adult whose rights have been legally restricted need only demonstrate the right to restoration by a preponderance of the evidence.

Improve Oversight by Creating a Guardianship Ombudsman Program

Under the auspices of the Administration for Community Living (and modeled off the LTC Ombudsman Program), establish a federally-funded ombudsman program on guardianship to provide oversight, monitoring, and ongoing evaluation and data collection on guardianship arrangements.

Creating National Data Collection System on Guardianship

Establish incentives to States to collect comprehensive data on guardianship, such as by making grant funds contingent on data collection. Data should include information on the total number of people under guardianship; key demographic information such as gender, race, age, and primary language; type of disability; the length of the guardianship; the type of guardian (i.e., family member, friend, professional private guardian, or public agency); and type of residence. In addition, states should be required to collect specific information on the use of professional guardians, including the ratio of professional guardians to people under professional guardianship. Data should be reported and captured into one national data collection system, through the auspices of either the U.S. Department of Health and Human Services or the U.S. Department of Justice.

ⁱ *Projects of National Significance*, Administration on Community Living, <https://acl.gov/programs/strengthening-aging-and-disability-networks/projects-national-significance> (last visited Aug. 25, 2021).

ⁱⁱ Administration of Community Living, “Supported Decision Making Program,” available at <https://acl.gov/programs/consumer-control/supported-decision-making-program>.

ⁱⁱⁱ National Resource Ctr. for Supported Decision Making, *Resource Library*, <http://www.supporteddecisionmaking.org/content/resource-library> (last visited Aug. 25, 2021).

^{iv} Farrell, C. (2020, August). We don’t know how many people are being held captive against their will— can we fix America’s broken conservatorship system? MSN Market Watch. Retrieved from <https://www.msn.com/en-us/news/other/we-don-t-know-how-many-people-are-being-held-captive-against-their-will-can-we-fix-america-s-broken-conservatorship-system/ar-AAMPXqH>

^v *Projects of National Significance*, Administration on Community Living, <https://acl.gov/programs/strengthening-aging-and-disability-networks/projects-national-significance> (last visited Aug. 25, 2021).

^{vi} Administration of Community Living, “Supported Decision Making Program,” available at <https://acl.gov/programs/consumer-control/supported-decision-making-program>.

^{vii} National Resource Ctr. for Supported Decision Making, *Resource Library*, <http://www.supporteddecisionmaking.org/content/resource-library> (last visited Aug. 25, 2021).

^{viii} As outlined under Recommendation 3.1 in the Fourth National Guardianship Summit’s Adopted Recommendations (May 2021). Retrieved from <https://www.guardianship.org/wp-content/uploads/Fourth-National-Guardianship-Summit-Adopted-Recommendations-May-2021-1.pdf>

^{ix} As further described under Recommendation 5.1 in the Fourth National Guardianship Summit’s Adopted Recommendations (May 2021). Retrieved from <https://www.guardianship.org/wp-content/uploads/Fourth-National-Guardianship-Summit-Adopted-Recommendations-May-2021-1.pdf>

^x As further described under Recommendation 1.2 in the Fourth National Guardianship Summit’s Adopted Recommendations (May 2021). Retrieved from <https://www.guardianship.org/wp-content/uploads/Fourth-National-Guardianship-Summit-Adopted-Recommendations-May-2021-1.pdf>