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Thank you, Chairman Casey, Ranking Member Braun, and Members of the Committee, for the opportunity to testify on the importance of alternatives to guardianship for people with disabilities, including people with intellectual and developmental disabilities and older adults.

My name is Karrie Shogren. I am the Director of the Kansas University Center on Developmental Disabilities (KUCDD), part of the national network of 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) funded by the Administration for Community Living. I am also the Ross and Marianna Beach Distinguished Professor of Special Education and a Senior Scientist at the Schiefelbusch Institute for Life Span Studies at the University of Kansas. In addition, I serve as the President of the Board of Directors of the American Association on Intellectual and Developmental Disabilities. In all of my roles, I seek to advance research-based solutions that enable the self-determination and inclusion of people with disabilities across the life course. My training and background in education, psychology, and research methodology have enabled me to be a part of efforts to create solutions that promote self-determination and engage people with disabilities, their families, their supporters, and their communities in making decisions about their lives.

My research over the past 20 years is rooted in the principle that people with disabilities have the right to make decisions about their lives and that there is clear evidence we can build systems of supports that enable this right. This work is necessary as people with disabilities have not always been afforded the right to self-determine their lives, a right people without disabilities often take for granted.

While I am the one speaking today, I want to emphasize that the ideas I am sharing have emerged from the disability community and been shaped by researchers, legal scholars, practitioners, and advocates across this country and the world. I also want to note the impact of my lived experiences as a friend, colleague, and supporter of people with intellectual and developmental disabilities who are under guardianship arrangements as well as who use formal and informal supported decision-making arrangements. These experiences—supported by findings from research—have shown me that we can provide alternatives to guardianship that preserve rights, enhance outcomes, and support the intent of disability civil rights laws, such as the Americans with Disabilities Act, which states in its Findings that:

physical and mental disabilities in no way diminish a person’s right to fully participate in all aspects of society, but that people with physical or mental disabilities are

frequently precluded from doing so because of prejudice, antiquated attitudes, or the failure to remove societal and institutional barriers.¹

In my testimony today, I seek to make three basic points:

- Adults with disabilities and older adults have the right to make decisions about their lives.
- We can create decision-making supports that do not result in the removal of decision-making rights.
- Supported decision-making has the potential to lead to better outcomes.

The Right to Make Decisions

Adults with disabilities and older adults, as all adults, have the right to make decisions about their lives. However, it is frequently cited that approximately 1.3 million adults with disabilities and older adults are under guardianship arrangements that limit their legal capacity to make decisions about their lives.² The terminology used to describe guardianships, procedures for seeking guardianship, and options for people seeking or seeking to change guardianship arrangements varies widely across states. This limits a full picture of the circumstances that lead to guardianship arrangements, outcomes of guardianship arrangements, and the use of alternatives to guardianship arrangements. However, there is little doubt that issues and considerations related to guardianship and alternatives to guardianship are a part of the day-to-day lives of many people with disabilities and their families, particularly people with intellectual and developmental disabilities and older adults.³

Guardianship arrangements are legal arrangements under which an adult's decision-making authority is granted to another person (a guardian) based on a determination of impaired decision-making capacity.⁴

Being under a guardianship arrangement can take away rights to:

- Make legal decisions,
- Make relationship decisions (e.g., marriage),
- Make reproductive decisions,
- Make financial decisions,
- Make health and medical decisions,
- Make educational decisions,
- Make decisions about where to live,
- Make employment decisions,
- Vote and be involved in civic life,
- Travel freely,
- And, be involved in other daily life decisions.

Increased attention has been directed to the need for protection and empowerment in the context of guardianship arrangements.⁵ The National Guardianship Association holds that guardianship should "only be considered after alternatives to guardianship have proven ineffective or are unavailable."⁶

However, in practice, there is a general consensus that guardianship remains a “default” for many people with disabilities who need supports with decision making. There remains limited access to and understanding of less restrictive alternatives across education, disability, legal, health, and community systems.^{3,7} This limits the right of people with disabilities and older adults to be involved in decisions about their lives, despite the fact that most people view exercising their right to make decisions as essential to their lives.

As an example, for people with intellectual and developmental disabilities, the National Council on Disability has described a “school-to-guardianship pipeline.”² When young people with disabilities receiving special education services under the Individuals with Disabilities Education Act reach the age of majority (18 in most states), educational rights transfer to students. In a national survey on guardianship from the perspective of people with disabilities and their families, respondents shared that full guardianship was commonly suggested by school personnel and others during conversations about changes in decision-making rights occurring at the age of majority.⁸ But, seeking guardianship at this juncture is not the only pathway. Alternatives, like supported decision-making, can center people with disabilities as the rights-holder, enable families to continue to support their adult children, and enable adults with disabilities to have better life outcomes; yet, families, educators, school systems as well as other disability support systems often reporting having limited awareness of alternatives to guardianship.⁹ The impact of this school-to-guardianship pipeline is reflected in national data suggesting a majority of adults with intellectual and developmental disabilities who receive publicly funded disability services aged 18 to 22 have a guardian.³

When guardianship is used as the default arrangement, it eliminates the opportunity for people with disabilities and older adults to access their right to make decisions, with needed supports. It also limits opportunities to grow in decision-making abilities, learn from mistakes, and engage in adult roles and responsibilities. Using guardianships in an overly broad way and without considering and testing alternatives before entering into guardianship arrangements, discounts decades of research as well as the lived experience of people with disabilities, families, and older adults that confirms that people with disabilities can and do make decisions when they have access to supports aligned with their needs, values, and preferences.¹⁰

This is why alternatives to guardianship have become a major focus of guardianship reform, with recommendations for alternatives to guardianship, such as supported decision-making, being made by multiple organizations.^{2,11-13} This is also why creating supports for decision making is a major focus of research and practice in disability supports and services.^{7,10,14} Defaulting to guardianship without considering alternatives sustains societal and institutional barriers rooted in prejudice and antiquated attitudes about the lack of decision-making capacities of people with disabilities that are not supported by research, advocacy, or lived experience.

A lack of access to alternatives creates negative outcomes for people with disabilities and older adults and their families. Family members have shared statements like the following:¹⁵

I didn't feel like we had any options. But I now feel guilt about it every day, because he can make decisions, with supports.

It was the hardest decision I think I've ever made. To have somebody label him as incapacitated, it was devastating. He was crying. We don't say these things around him. We don't talk about him in that way. We don't talk about what things he can't do. We talk about how he can do it ... It was not an easy decision. Especially when we really work hard to help him make his own decisions. What happens now?

Supported Decision-Making: Preserving Rights

What can happen now, to change the experiences of people with disabilities, older adults, and their families? Alternatives to guardianship that preserve rights afforded to all adults can become the default, a first option for people who need supports for decision making.

Supported decision-making, as an alternative to guardianship, assumes that people with disabilities and older adults have decision-making capacities and should have access to decision-making supports that enable them to retain decision-making rights. Supported decision-making is rooted in what we know about how people make decisions, what we have learned about how to understand and address support needs for decision making, and effective practices that empower people to engage with the supports they need so that they retain self-determination over their lives, which leads to enhanced outcomes.⁷

Supported decision-making can be understood as:

- The process whereby a person with a disability is enabled to make and communicate decisions with respect to personal, financial, and legal matters, on an equal basis with others without disabilities.

Supported decision-making:

- Does not remove decision-making rights,
- Focuses on aligning provided supports with support needs and the choices and preferences of the person,
- Integrates a range of supports (e.g., people, technology, other decisional aids) that can change over time based on the person's support and decision-making needs,
- Allows for the growth and development of decision-making abilities and supports.

Supported decision-making “mirrors what happens for most adults when they make decisions... they seek advice, input and information from friends, family or professionals who are knowledgeable about those issues, so they can make their own well-informed choices.”¹⁶

Unlike guardianship, supported decision-making recognizes that different supports may be needed in different situations, for different decisions, across the life course. The focus is on creating a network of resources and supporters that enable the person to access information to make decisions and the supports they need to communicate their decisions in ways that provide the same opportunities and supports all adults have to make decisions.

Establishing supported decision-making arrangements involves:

- Establishing the areas where a person needs decision making supports (e.g., health, financial, living arrangements, relationships),

- Identifying what supports (e.g., people, technology, other resources) will be provided,
- Confirming that the person with a disability or older adult will be the ultimate decision maker,
- Creating a plan for reevaluating and changing the supports, as needed, over time.

There are existing research-based tools and programs to support people with disabilities, their families and communities, and the systems that support them (e.g., medical, education, legal, financial) to identify decision-making support needs and operationalize access to these supports through formal (i.e., legal) and informal supported decision-making arrangements.^{7,10,17-22}

Following are descriptions by people with disabilities and older adults about their use of supporters—the people that help them gather and weigh information in making decisions—in supported decision-making¹⁵:

I have people by my side to give me the right prompts and explain a little more about what might happen or won't happen.

I like people that know me, I go with people who I trust, who are going to listen to me and help me make my decision. People who know me and a bit of my history.

These are your decisions, and the people who support you are there to give you guidance, but the final decision is up to you.

As families of adults with disabilities and older adults learn about supported decision-making, they often highlight how it addresses what is important to them, as illustrated in the following descriptions¹⁵:

We need to allow our adult children with disabilities to make mistakes and learn from them because we are not always going to be around to protect them.

Unlike guardianships, SDM can be tailored to my family member. It is what we all do and it makes us more effective.

Reflecting a growing recognition of the feasibility and impacts of supported decision-making, Courts across the United States have begun to deny or terminate guardianships because a person is able to use supported decision-making. One of the earliest cases involved Margaret “Jenny” Hatch, a woman with Down syndrome, who defeated, at trial, a petition for permanent, plenary guardianship because she used supported decision-making to make her own decisions. In summarizing the impacts of the case, it has been noted,²³

At her 2013 trial, Jenny presented evidence and testimony showing that she used SDM to make her own decisions and direct her life and, therefore, did not need a guardian to make decisions for her. Jenny demonstrated that she had friends and supporters whom she relied upon when needed, and these people helped her understand, make, and communicate life choices that reflected her values, interests, and preferences. Experts testifying at trial opined that Jenny’s use of supported decision-making enhanced her

independence and quality of life, and it was consistent with research, best practices, and existing law.

In communicating about her experiences under guardianship, Jenny highlighted the stark differences in her experiences under guardianship and under supported decision-making arrangements. She asked:

*How do we make sure that a person's rights are not taken away like my rights were? Who will make sure that no one has to go through what I went through? Who will make sure that people do the right thing? Just because a person has a disability does not mean they need a guardian. Many times they just need support and a little help.*²⁴

A recent analysis by the American Bar Association Commission on Law and Aging²⁵ suggests that states have been rising to Jenny Hatch's call and the calls of other people with disabilities, older adults, researchers, and advocates to remove societal and institutional barriers to guardianship alternatives. As of 2022, they reported 14 states have some form of supported decision-making as an alternative to guardianship in state statutes; however, the analysis highlighted the variability of statutory definitions of supported decision-making, definitions of supported decision-making agreements (or lack thereof), and guidance on statutory safeguards against coercion and abuse in supported decision-making arrangements.

This variability highlights the importance of standards and guidelines for supported decision-making to ensure that all people with disabilities and older adults have opportunities to access and benefit from supported decision-making arrangements. It further highlights the ongoing need for protections for people who are under guardianship, other protective arrangements, supported decision-making arrangements, and other less restrictive arrangements to ensure their civil rights and their right to make decisions are protected to the maximum extent possible.

Embracing supported decision-making will require systemic change, including education, training and outreach to the multiple people and systems that influence decision-making rights, such as schools, health care, disability and aging support systems, lawyers, courts, and families. Training will also be needed for supporters to ensure understanding of and accountability to supporting the person to make decisions, instead of making decisions for the person. Supported decision-making will also require practice-based strategies to support people with disabilities and older adults to grow in their decision-making abilities, evaluate their decision-making options, and build support networks in the community as they enter into formal and informal arrangements.⁷

Conclusion: Enhancing Outcomes through Supported Decision Making

Preserving people's decision-making rights is an important end, but supported decision-making arrangements can have additional impacts that are important to people with disabilities, older adults, families, and society. For example, research has shown that adults with disabilities who exercise greater self-determination, including having more opportunities to make decisions about their lives, have improved employment and community participation outcomes and are better able to resist and avoid abuse^{10,26}. National data suggests that people with intellectual and

developmental disabilities receiving publicly funded disability services who are not under a guardianship arrangement are significantly more likely to work in a paid community job and have employment as a goal on their service plan. They are also significantly more likely to access preventative care and to report having input into where and with whom to live.²⁷

And, importantly, growing information is emerging on formal and informal supported decision-making arrangements suggesting the feasibility of this approach as well as positive impacts on the engagement of people with disabilities and older adults in decision-making and advocating for their needs, as well as reductions in risk for abuse because of having a team of supporters.^{2,7,28,29}

Supported decision-making centers the person with a disability or the older adult in decision making about their lives. It is consistent with current policy and values in the disability and aging fields and offers an opportunity to tailor supports to specific areas of need. There is no better time to ensure societal and institutional supports are aligned with the right of all people, including people with disabilities and older adults, to be involved in decisions about their lives.

To advance protection and empowerment in guardianship and alternatives, the goal of today's hearing, I offer the following recommendations rooted in research and the voices of people with disabilities and older adults:

1. Establish a clear, consistent definition of supported decision-making and guidelines for its formal and informal use to preserve the decision-making rights of people with disabilities and older adults.
2. Advance education, training, and outreach on supported decision-making and alternatives to guardianship across multiple systems that impact the preservation of decision-making rights, such as legal, education, workforce, aging, disability, advocacy, and health care.
3. Adopt recommendations by the National Guardianship Association and other organizations that guardianship be the protective arrangement of last resort.
4. Ensure protections for the civil rights of people with disabilities and older adults who are being considered for or are under guardianship or alternative arrangements, such as supported decision-making.
5. Establish data collection systems that allow for a clear picture of the use and outcomes of guardianship, supported decision-making, and other protective arrangements and alternatives.

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