July 5, 2018

Senate Special Committee on Aging
Sen. Susan Collins, Chair
413 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairwoman Collins and members of the committee:

Thank you for the opportunity to provide input to your committee's examination of best practices and model policies related to guardianship. Older adults are not the only population that is disproportionately impacted by unnecessary or overly-restrictive guardianships. People with disabilities--especially people with Intellectual and Developmental Disabilities (I/DD)--are affected by the same guardianship issues your committee has identified and to which you are requesting input.

The Wisconsin Board for People with Developmental Disabilities (BPDD) is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act) with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with intellectual and developmental disabilities (I/DD). The impact of unnecessary or overly restrictive guardianships on people with I/DD directly effects individual's ability to make decisions about their own lives and can prevent the goals of the DD Act from being realized.

The National Council on Disability's March 2018 report provides a comprehensive review of guardianship against the backdrop of the civil rights advancements of individuals with disabilities in the past several decades, an analysis of the current guardianship system in America, and recommendations on shifting towards less restrictive alternatives to guardianship[1]. Similarly, the American Bar Association Commission on Law and Aging's research and recommendations for improving adult guardianship[2] finds that people with disabilities and older adults face the same systemic issues when it comes to having their decision-making rights terminated or restored.

In Wisconsin, aging and disability advocates have been collaborating on policy and best practice changes to make systemic improvements that benefit all populations impacted by guardianships. Collectively, we hear surprisingly similar stories and concerns regarding guardians overstepping their authority, abusing their wards, and variability between jurisdictions on how guardianships are handled regardless of whether the person under guardianship is an older adult or a person with a disability.

There are additional concerns that disproportionately impact people with disabilities and especially those with I/DD. Frequently, guardianships are imposed upon these individuals at a young age (as early as 17 years, 9 months in Wisconsin) and are rarely revisited. Many people spend many decades—their entire lifespan—under guardianship.

[1] *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities.* National Council on Disability. March 2018. (https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf)
[2] *Research and Recommendations on Restoration of Rights in Adult Guardianship*. American Bar Association. 2017. (https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf)

When guardianship is imposed at a young age, the court is limited in its ability to project the maturation and capacity building that will occur over the course of an individual's lifetime. In many cases. restrictive guardianships can limit opportunities to make decisions, learn from mistakes, and impact individual's "dignity of risk." People with disabilities can acquire new skills and decision-making capacity throughout their lives, however once a guardianship is granted it is rarely changed and even more rarely reversed.

For many people with disabilities, the court appointed guardian is often also a family member, frequently a parent. As the population ages, people with disabilities live longer, and families have become smaller and more geographically dispersed, the challenge of aging guardians is becoming an emerging issue. Many families have not done future planning or find that their plans need to evolve as the decades pass and their situations change. Often it is not clear when an existing guardian is no longer able (or willing) to fulfill their guardianship responsibilities. In some cases, there is no individual that has been identified who is willing to become the ward's guardian. Even when the guardian has identified a stand-by or successor guardian, the court's must determine whether that individual is appropriate.

What do we hear about guardianship in Wisconsin?

Lack of Wisconsin data on guardianships

Like most states, basic data on guardianships in Wisconsin is limited. There is no statewide data collection on guardianships, each county courthouse keeps its own records. From an August 2015 analysis of data reported to Wisconsin's Consolidated Court Automation Programs (CCAP), there are almost 34,000 people under guardianship in Wisconsin[3], and more than $690,000,000 in assets under the supervision of a guardian[4]. Wisconsin State Court data does track the number of guardianship petitions filed each year[5], almost 6000 guardianship petitions were filed in 2016 alone; the median age at disposition was 40. The total number of guardianship petitions filed has been increasing steadily since 2011, and the low average ages of the wards indicate that many people placed under guardianship are not older adults.

There is no statewide data that easily tracks how many people are subject to guardianship; describes guardianships in terms of basic demographic information (such as whether a ward is a person with I/DD, physical disability, mental health condition, or older adult); the extent of the guardian's authority[6];

[3] Analysis conducted in August 2015 for Wisconsin's Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) group, formed to improve the court system's ability to work with the elderly and other vulnerable groups in reducing abuse and improving guardianship practice.
[4] This does not include money in small estates under $50,000 where many counties do not require accountings to be filed; actual assets under supervision of a guardian would be greater than $700,000,000.
5 https://www.wicourts.gov/publications/statistics/circuit/circuitstats.htm. It is not clear if the totals include the sum of "guardianships," "temporary guardianships," and "protective placements with new guardianship."
[6] Wisconsin has a limited guardianship system. Under a limited guardianship the person retains their rights to make decisions in certain areas of their life and the court decides the extent to which the authority to make other decisions is transferred to a guardian. The court may also transfer all decision-making authority to a guardian under a full guardianship. Certain rights are never surrendered by the ward regardless of the breadth of the guardianship order (Wis. Stats. 54.25(2)); other rights may be taken away by the court but cannot be exercised by the guardian (Wis. Stats. 54.25(2)(c)(3). Even when a guardian has been granted authority to make some or all decisions for a ward, under Wisconsin law (Wis Stats. 54.25(2)(d)(3), when exercising authority a guardian must:

a) Place the least possible restriction on the individual's personal liberty and exercise of constitutional and statutory rights, and promote the greatest possible integration of the individual into his or her community.
b) Make diligent efforts to identify and honor the individual's preferences with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation. In making a decision to act contrary to the individual's expressed wishes, the guardian shall take into account the individual's understanding of the nature and consequences of the decision, the level of risk involved, the value of the opportunity for the individual to develop decision-making skills, and the need of the individual for wider experience.

whether the guardian is a professional, family, or volunteer guardian; the current age of the ward and the age of the ward at which a guardian was first appointed; the assets involved; and other basic questions. These data points would be helpful to courts if they were available at the statewide level to better understand the outcomes of the current system, differences between jurisdictions, and to inform statewide policy analysis.

Guardianships pursued as first option for people with I/DD

While state data does not delineate the proportion of guardianships that have been applied to people with I/DD, the experiences of people with I/DD and their families indicate that guardianship is used first and almost exclusively for people with I/DD when it should be used last and rarely.

Many families of children with disabilities are instructed to petition for guardianship by teachers, doctors, and other non-legal professionals. Parents routinely tell us that guardianship is presented as the only option and is portrayed as administrative process rather than a decision that has permanent legal ramifications for both the individual and families. Many families that pursue and obtain guardianships do not fully understand the what the role and responsibilities of a guardian are under Wisconsin law.

Parents and advocates for people with disabilities have described the courts role in obtaining guardianship as a formality rather than a deliberative evaluative process. Many families are directed to the appropriate circuit court forms, and fill them out without understanding the content of the form and what areas of decision-making they are potentially impacting. Many guardianship petitions take less than 15 minutes. In some counties, advocates have been told by judges that all guardianship petitions are granted as full guardianships, sometimes in contradiction to the petitioner's request. Once a guardianship is granted it is rarely modified or reversed, even when the request is coming from the guardian themselves.

Other systems—including health care, banking, and human service providers—have policies and practices in place that assume the presence of a disability necessitates or automatically means there is a guardian. BPDD has heard from many people with disabilities that professionals do not believe them when they state they do not have guardian and have described encounters where professionals refused to communicate with them about their health care options, opening a savings account, or getting assistance with other personal business etc. unless they could prove they did not have a guardian.

Families rarely receive information about alternatives to guardianships—including Powers of Attorney (POA), Supported Decision-Making (SDM) agreements—and other alternative decision-making support options. BPDD conducted focus groups on Supported Decision Making in the fall of 2016 and found that many parents were unaware of the role and responsibilities of a guardian, did not feel their children were legally incompetent, but also felt that guardianship was expected and were unaware of alternatives. The focus groups also found that if SDM was an option many families would have tried it first, and that it would have helped them evaluate whether a guardianship was needed.

Lack of understanding role of guardian, limits of guardian authority

Many legal professionals, service providers, and advocacy groups consistently hear about guardians that are overstepping the authority that has been assigned to them by the courts. Many guardians believe the document empowers them to restrict their wards activities or prevent "bad" choices and are

exercising authority as a guardian that they may not have and that is contrary to the spirit of Wisconsin's limited guardianship system[7].

Common restrictions that the Guardianship Support Center and advocates hear guardians impose that go beyond what the courts have authorized include: limiting the use of phones, who the ward can see, whether wards have access to their money and how they can spend their money, what the ward may or may not eat, etc. Currently, Wisconsin does not have any training requirements for family or volunteer guardians.

Other common misperceptions BPDD routinely hears about from people with I/DD, families, and service providers include:

- Assumption that guardianship gives the guardian power over all decisions connected to the ward, leading to the guardian overstepping the authority granted to them by the courts.
- Misperception on the part of health care, other professionals, and service agencies that the guardian makes all decisions (many are unaware that limited guardianships are an option).
- Assumptions by health care, professionals, and service agencies that facilitate and empower guardians to exceed their authority. Many are unaware that they can ask to see the letter of guardianship to confirm who the guardian is and what decision-making authority has been granted.
- Lack of understanding of long-term implications and consequences of guardianship, especially as it related to family future planning[8].
- Misperception by family guardians that the role of a guardian/ward is not distinct and different than role of parent/child.
- Uncertainty from service providers about what recourse is available when a guardian is overstepping their authority, abusing their position, or clearly not exercising their authority in a way that places the least possible restriction on their ward, maximizes community integration, and honors the ward's preferences.

Recommendations

Wisconsin's current guardianship law has positive elements that can serve as models for other states including:

- Limited guardianship option

[7] Under Wisconsin's limited guardianship system, the ward retains certain rights, and the guardian of the person is required to 1) place the least possible restriction on the ward's personal liberty and exercise of constitutional and statutory rights, and promote the greatest possible integration of the ward into his or her community. 2) make diligent efforts to identify and honor the ward's preferences with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation. 3) takes into account the ward's understanding of the nature and consequences of the decision, the level of risk involved, the value of the opportunity of the ward to develop decision-making skills, and the need of the ward for wider experience.

[8] This includes 1) families not understanding that the Courts decide who will succeed the current guardian, 2) especially in families where the ward is a person with a disability and the guardianship may remain unchanged for decades, examining changes in family dynamics that change the support network for the individual 3) determining when a family guardian is no longer capable of performing as guardian, etc.

- Clear language requiring guardians to exercise their authority in a way that places the least possible restriction on the ward, maximizes community integration, and honors the ward's preferences (Wis. Stats. 54.25)

- Clear language specifying rights retained by wards

- Specifying a list of criteria judges must consider when weighing whether a guardianship is warranted and what authority should be granted to a guardian (Wis. Stats. 54.10 (2) and (3)(b)), including *"Whether any alternatives to guardianship, including supported decision-making under ch. 52, have been attempted, and, if applicable, the degree to which they have been attempted, the length of time they have been attempted, and whether they have been attempted in a manner sufficient to demonstrate that alternatives to guardianship are insufficient to enable the individual to adequately exercise the right or rights in question."*

In 2018, Wisconsin passed a strongly bi-partisan bill formally recognizing Supported Decision-Making agreements[9] as an alternative to guardianship that can be a model for other states. This law benefits people of any age experiencing functional impairments. Supported Decision-Making agreements are designed to help the Person interact and communicate their decisions with third parties. People with disabilities and older adults can use their network of trusted family members, friends and professionals and formally identify Supporter(s) in a Supported Decision-Making agreement to help them gather information, understand and evaluate options, and communicate their decisions to others. The Supporter has no authority to make the person's decisions (the Person makes all their own decisions).

Wisconsin disability and older adult advocates have identified additional improvements are working to advance proposals that will require training for guardians and enable a Time-Limited guardianship option in future legislative sessions.

Especially for young people with I/DD, there is a need for an additional option in Wisconsin guardianship law that gives young people the time needed for their brains to fully mature, gain life experience, and practice with decision-making, and offers an opportunity to re-assess competency. Several states have incorporated automatic court review to evaluate whether continuing an existing guardianship is needed into their statutes[10].

Advocates have also identified a need for required standardized training and continuing legal education for guardians with a formal infrastructure to support and monitor training. Training for guardians is important 1) prior to a guardian being appointed 2) for newly appointed guardians 3) continuing throughout over the course of the guardian's appointment. Advocates have identified the following topics as core training requirements for all guardians:

- Duties and required responsibilities of guardians under the law and limits of guardian's decision-making authority.

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[9] Wis. Stats. Ch 52. Presentation on Wisconsin's Supported Decision-Making Law (http://wi-bpdd.org/wp-content/uploads/2017/10/Training_WI_SDM_legislation_031518.pdf) and FAQ on the law (http://wi-bpdd.org/wp-content/uploads/2018/06/SDM_FAQ.pdf)

[10] Kentucky, North Dakota, Missouri, Connecticut, Michigan, New Mexico, and the District of Columbia all have guardianship review or expiration processes within their statutes.
https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf

- Rights retained by the ward[11].

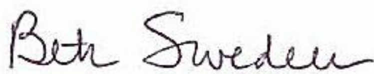
- Best practices for guardians to solicit and understand the wishes and preferences of the ward, involving the ward in decision-making, and taking ward's wishes/preferences into account in decisions made by the guardian.

- Restoration of ward's rights and removal of guardianship process

- Future planning and identification of potential stand-by or successor guardian(s)

BPDD's role under the federal Developmental Disabilities Assistance and Bill of Rights Act is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities. Improving the guardianship system directly correlates with improving the self-determination, independence, productivity, integration, and community inclusion of people with I/DD.

Thank you for your consideration,



Beth Swedeen, Executive Director
Wisconsin Board for People with Developmental Disabilities

[11] In Wisconsin, an existing section of the statutes itemizes a bill of rights wards have, but the consensus from experts in the field is that wards/guardians/providers are unaware of these rights.