

## National Resource Center for Supported Decision-Making Annual Report – 2016 Wisconsin

In 2015, there were 33,835 people in Wisconsin under guardianship; their respective guardians managed approximately \$569,367,589.98 in guardianship property and finances.<sup>1</sup> Frequently, the only oversight of guardians occurs during the yearly review of the condition of the ward and annual accounting of the ward's estate. The fear is that cases of abuse will be hidden within these large numbers. Worse yet, the number of guardianship cases are projected to increase as the population in our state ages.

In an effort to decrease the incidents of unnecessary guardianships and promote autonomy of people with disabilities, The Board for People with Developmental Disabilities (BPDD) applied for a National Resource Center on Supported Decision-Making grant. When BPDD was awarded this grant, it partnered with the Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR) to ensure both aging and disability populations were targeted under this grant. Additionally, GWAAR houses the Wisconsin Guardianship Support Center, a statewide resource that provides legal information and case consultation on guardianship, powers of attorney, and advance directives to social workers, attorneys, guardians, and family members. Staff working at GWAAR perform significant outreach to consumers and professionals related to guardianship and powers of attorney. This expertise in Wisconsin guardianship and powers of attorney law made GWAAR the perfect complement for this grant.

Deputy Director of BPDD, Fil Clissa, worked in conjunction with Jayne Mullins and Attorney Kate Schilling from GWAAR to facilitate meetings, identify obstacles, create publications, perform outreach, and connect people to resources which promote supported decision-making in Wisconsin. Over the course of a year, Wisconsin has taken a giant leap towards supported decision-making.

In November 2015, Attorney Grace Knutson represented the state of Wisconsin at the national symposium on supported decision-making in Washington D.C. Jonathan Martinis led the group to ensure that teams could share ideas, accomplishments, and practice tips. This enabled us to learn about the progress occurring in other states and apply that knowledge as we bring about change in Wisconsin.

---

<sup>1</sup> [Wisconsin Court System Circuit Court Access]. (n.d.). Unpublished raw data of guardianship records extracted using Consolidated Court Automation Program (CCAP). Retrieved July 07, 2015, from <https://wcca.wicourts.gov/index.xsl>.

In the fall of 2015, we began our efforts by identifying a core group of approximately 20 people from diverse backgrounds to engage in monthly meetings, discussions, and sharing of ideas. This stakeholder's group is made up of a diverse team of both professional and consumer stakeholders with a wide range of experience. The credentials of the group include a volunteer guardian, several attorneys, parents of children with developmental disabilities, consumers, professionals familiar with guardianship, a self-directed services coordinator for the county, staff from the Department of Public Instruction, a school transition coordinator, and staff from related non-profit advocacy groups.

Our stakeholders group identified goals, obstacles, and resources available on supported decision-making. While we have made considerable progress towards meeting our objectives, there is still significant work to be done in Wisconsin.

#### Identified barriers and challenges to supported decision-making

- Inherent paternalism and a desire to protect people with disabilities, rather than to empower them to make their own decisions due to the risk that mistakes will be made.<sup>2</sup>
- Fear that if people are not under a guardianship, that potentially vulnerable people may be taken advantage of or abused. The assumption appears to be that somehow a guardianship protects the person.
- We need to normalize the fact that all people seek help with making and implementing decisions
- Lack of reliable and responsible circles of support for some people
- Wisconsin's legal non-recognition of an educational power of attorney document.
- A Division of Vocational Rehabilitation (DVR) policy that requires a newly signed release of information for each subsequent communication, rather than allowing for an annually signed release.
- Lack of awareness of options in legal decision making. Guardianship should not be the default; it should only be pursued when all other options have been exhausted.

---

<sup>2</sup> Frank Johns, A. (2012). Person-Centered Planning in Guardianship: A Little Hope for the Future. *Utah Law Review*, Vol. 2012, No. 3, 1560.

- Some parents believe that an adult guardianship action is just an extension of their role as a parent, not a taking away of a person's due process rights.

A potential hurdle that has been raised is that supported decision-making is not specifically mentioned within the Wisconsin statutes or in any Wisconsin case law. Therefore, some members of the public may question its legality and whether it is a viable option. However, the principles of supported decision-making are inherent within Chapter 54 of the Wisconsin statutes:

#### Guardian of estate

shall "provide a ward with the greatest amount of independence and self-determination with respect to property management in light of ward's functional level, understanding. . . personal wishes and preferences. . ." Wis. stat §54.19, see also §54.20

#### Guardian of person shall

"place the least possible restriction on the individual's personal liberty and exercise of statutory rights, and promote the greatest possible integration of the individual into his or her community." Wis. stat. §54.25 (2)(d) 3.b

#### Guardian of person shall

"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." Wis. stat. §54.25 (2)(d) 3.b

#### Guardian of person

"In making a decision to act to the contrary to 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." Wis. stat. §54.25 (2)

Finally, but most importantly, the Wisconsin statutes state that a guardianship is inappropriate when other, lesser-restrictive means are available for decision making. (Wis. stat. § 54.10 (3)(c)(4)) This provision provides the legal foundation for supported decision-making in Wisconsin.

## Outreach & Outcomes

Members of the stakeholders group performed the following outreach events where supported decision-making was discussed and promoted.

- ❖ Keynote and presentations: Board for People with Developmental Disabilities Conference, November 2015
- ❖ Presentation: Autism Society Conference, April 2016
- ❖ Presentation: Circles of Life conference, April 2016
- ❖ WINGS Summit on May 25<sup>th</sup>, 2016.
- ❖ Fil Clissa is working with People First Wisconsin's Executive Board (all self-advocate) on developing presentation materials targeted for self-advocates. The presentation will be centered around a series of questions: "How is your relationship with your guardian? How do you handle conflict? And how can you reshape that relationship to be more supportive or be included in more decisions by using more Supported Decision-Making in your life?"
- ❖ May 12, 2016, State Bar of WI, Annual Guardian ad Litem Training for attorneys (Attorney Mitch Hagopian)
- ❖ June 2016—Kate Schilling introduced the concept of supported decision-making to nearly all of the elder benefit specialists (90) and some disability benefit specialists (approximately 25) statewide.
- ❖ July 2016—Kate Schilling introduced the concept of supported decision-making to nearly all of the Aging & Disability Resource Center directors within the state.
- ❖ FOCUS conference on November 18, 2016 (Attorney Kate Schilling and Attorney Grace Knutson will present to professionals who work in nursing homes, assisted living facilities, community-based residential facilities, and staff from the Division of Quality Assurance which oversees licensure of facilities.)
- ❖ Annual Judicial Conference in November 2016 (through WINGS)
- ❖ Adult Protective Services conference in October 2017 (to target social workers)
- ❖ Wisconsin Self-Directed Conference in November 2016
- ❖ Meeting with DPI on incorporating SDM into benchmarks and Planning tools.
- ❖ Developing a website on SDM
- ❖ WINGS group will be presenting at a judicial conference in Nov. 2016
- ❖ Tools and materials are in the process of being created
- ❖ Developing draft legislation to shop to legislators this upcoming session.

Additionally, the Wisconsin Guardianship Support Center at GWAAR now incorporates a discussion of supported decision-making into nearly all outreach presentations on

powers of attorney or guardianship. The following are presentations in 2015-2016 which specifically included (or will include) a discussion on supported decision-making:

- Judicare (Legal Services Corp.) attorney training
- Presentation to tribal benefit specialists on guardianship
- Presentation to the Assisted Living Coalition
- Disability Rights WI—FamilyCare & IRIS Medicaid Waiver Ombudsman training
- Transition Academy presentation
- Board On Aging and Long-Term Care Ombudsman training
- FOCUS conference presentation

In addition to the outreach efforts of our stakeholders, the Wisconsin Department of Health Services is embracing the promotion of supported decision-making. In February 2016, it released a technical assistance memo to the Aging and Disability Resource Centers regarding signatures and the authority for signing Medicaid applications. The memo included a discussion on supported decision-making as an option in legal decision making. Additionally, supported decision-making has been incorporated into the curriculum for all newly-hired Adult Protective Services staff statewide.

### **Next steps**

Through the outreach of our stakeholders, we have learned that the language we use is very important. When we promote supported decision-making, we need to say that it is “one of several options in legal decision making”, rather than label it “an alternative to guardianship.” If we do the latter, it sounds as though guardianship is the standard, and it normalizes the process of bringing a guardianship. We also need to be sure that our messaging is consistent across the entire state.

Education also needs to be framed around the concept of dignity of risk. There needs to be recognition that people with and without disabilities make mistakes, and the right to make decisions is not contingent on the quality of decisions made or whether another person would make that same decision. Rather, understanding and negotiating risk is an essential component of learning how to make decisions. And people learn how to make decisions through experience<sup>3</sup>.

The practice and utilization of supported decision-making is flexible and should be tailored to the individual person and his or her circumstances. However, since this is a newer concept, some people are confused by the perception of ambiguity. The newly

---

<sup>3</sup> Martinis, Jonathan, presentation May 10, 2016, *Supported Decision-Making: From Justice for Jenny to Justice for All!*. See also Blanck, P., and Martinis, J., “*The Right to Make Choices: The National Center for Supported Decision-Making*, 2015, Vol. 3 (p. 24-33).

created *ABA Practical Toolkit: Steps in Supported Decision-Making* will prove vital to the promotion and implementation of supported decision-making around the state.

## **Furtherance of supported decision-making in Wisconsin**

Our stakeholder group or “Community of Practice” continues to meet on a regular basis to exchange ideas and propel supported decision-making forward in Wisconsin.

While the momentum under this grant has brought an incredible amount of attention to supported decision-making in Wisconsin, we realize that there is additional work yet to be done in order to thoroughly embed this concept into the aging and disability networks within the state.

In June 2016, GWAAR applied for an Elder Justice Innovations Grant through ACL directed at reducing abuses in guardianship through the use of supported decision-making. With a successful grant proposal, GWAAR intends to hire two full-time staff to work within GWAAR’s Elder Law & Advocacy Center to promote, educate, and train both professionals and consumers across the state on how to facilitate supported decision-making models and integrate it into current procedures. GWAAR will focus its outreach and training efforts on the legal community (judges, attorneys, and guardians ad litem), medical community (doctors, nurses, assistants, and administrative staff), and aging-related social service agencies. The BPDD has agreed to partner with GWAAR to ensure outreach directed at youth and families, the school districts, transition related advocates, and the Department of Public Instruction.

This would be a two-year grant, funded at approximately \$420,000 each year. The ACL should announce the grant award recipients any day now.

## **Personal stories related to supported decision-making in Wisconsin**

### ***Story 1***

Attorney Kate Schilling has a very large extended family, including an uncle “Mike,” age 64 and diagnosed with alcohol-induced dementia. Mike was placed under guardianship at the age of 60 due to extreme short-term memory loss and disorientation as to present events (the president, seasons, year, etc.). A year after Mike stopped drinking, some of his memory and cognitive functions slowly returned. Over the course of the next two years, Mike’s family worked extensively with him on issues such as safety, money management, and social activities to increase his confidence and skill level in these

areas. In July 2015, the family petitioned the court to have Mike's guardianship scaled back under the premise of Supported Decision-Making. Mike had demonstrated that he was able to manage his own money, pay his bills with limited assistance, and make his own decisions with regards to his health and living situation. Mike's doctor was fully supportive of limiting the authority of the guardianship and, in light of Mike's improvements, suggested that Mike be re-tested for a driver's license. Based on the doctor's statements, the approval of the Department of Motor Vehicles following a successful road test, and statements from Mike and his family, the judge agreed to scale back the guardianship to a limited guardianship. The judge also agreed to revisit the appropriateness of even the limited guardianship in the upcoming years. This was a huge victory for Mike. Nearly a year later, Mike is now petitioning the court to have his guardianship terminated altogether. A hearing will be held shortly, and we are optimistic that the judge will agree that a guardianship is unnecessary. This case demonstrates that Wisconsin residents can benefit from Supported Decision-Making when they know that it is available and courts are educated about it as an option.

### **Story 2**

"Our discussions about SDM have helped my think very carefully about alternatives. My Mom has Alzheimer's but so far I have been able to use alternatives effectively. There is so much to help with health and financial decisions that is not well known. It would be interesting to have a financial person from- for example- a bank talk with us about resources to manage finances and how financial institutions can help. This would be a very helpful fact sheet for all our groups. "

### **Story 3**

"When my husband and I adopted my brother at the age of 8, we made the decision to allow him to keep his last name. Although he spent much of his childhood getting bumped from his home to our home to our sister's home and several foster homes, he always knew who his parents were. Even back then we felt it was imperative that he retain his identity.

Thinking back, I believe this is also why we were hesitant to become his legal guardian when he turned 18. Maybe it was also because we were in denial or that we didn't have a clue. We entered the transition years without giving a minute of thought to the issue of guardianship. We certainly had never heard the words "supported decision making." What I realize now is that our actions embraced supported decision making while we waited to acquire this new vocabulary.

Guardianship is a very personal issue and I suspect this is why his high school didn't address it. When my brother was 17, I remember the special education teacher mentioning to me that we needed to figure out what to do about guardianship. Do? That implied action. What I didn't know was how to proceed and no one was too eager to provide any direction. So, we did the only thing we felt comfortable doing; nothing. We left the subject alone and went on with life.

Only, we discovered not doing anything wasn't the right decision either. Why? It wasn't the right decision because not talking about guardianship also meant not planning long term for his financial and overall health and wellbeing. Planning like we would do for our biological children who aren't diagnosed with a disability. We simply were avoiding the topic, while continuing to encourage him to make his own choices and praying nothing "bad" happened. Whatever "bad" was, we didn't know. We were torn between wanting to protect him as we always had, but felt it was wrong to make the decision about whether or not he could get married or vote. So, if it was an all or nothing choice: we chose the least restrictive option of nothing.

My brother will turn 22 soon. He is still "his own person." In the past four years my husband and I have expanded our knowledge about guardianship and supported decision making. We still have room to grow. Our fear that something "bad" will happen has not decreased. Recently, he started a new job and one of the first thoughts I had was, "what if someone at his new job takes advantage of him, what will we do?" "What if he gets pulled over driving to work and the police officer misinterprets his difficulty with communicating for something else, what will we do?" I know in my heart the answer is the same as it would be for my children without a diagnosed disability. We will be there to support my brother as we always have. We will help him to understand what happened as well as talk to him about how his actions may or may not have contributed to the event. We will help him understand how he can work towards a different solution should something "bad" happen again. Inevitably there will be additional challenges.

We believe life is about risk and embracing the wonderful things that can occur as a result. Many times in my life I fell down and someone helped me process and understand what I could do differently the next time. Sometimes I made the same mistake twice. Sometimes, I knew better and didn't care that I was biting off my nose despite my face. Always I was allowed the freedom to create my own path towards the future.

The words "Supported Decision Making" hold more meaning to my husband and I. Slowly, we are gaining courage towards greater acceptance that it's ok for my brother to

make mistakes in his life. It's ok for him to take risks no matter what disability he has. Like all of us, we believe he deserves the option to live his life the way he chooses. He also deserves the opportunity to believe someone will always be there to help him through life challenges and celebrate his successes. I believe with my heart and mind that it's what we all really want in this unpredictable world we live in."