



SPECIAL EDUCATION RESOURCES

Supported Decision-Making: Because Choices Matter

TABLE OF CONTENTS

[Introduction](#)

[About this Resource](#)

[Educator Perspective](#)

[Policy Makers and Advocates Perspective](#)

[Family Perspective](#)

[Self-Advocate Perspective](#)

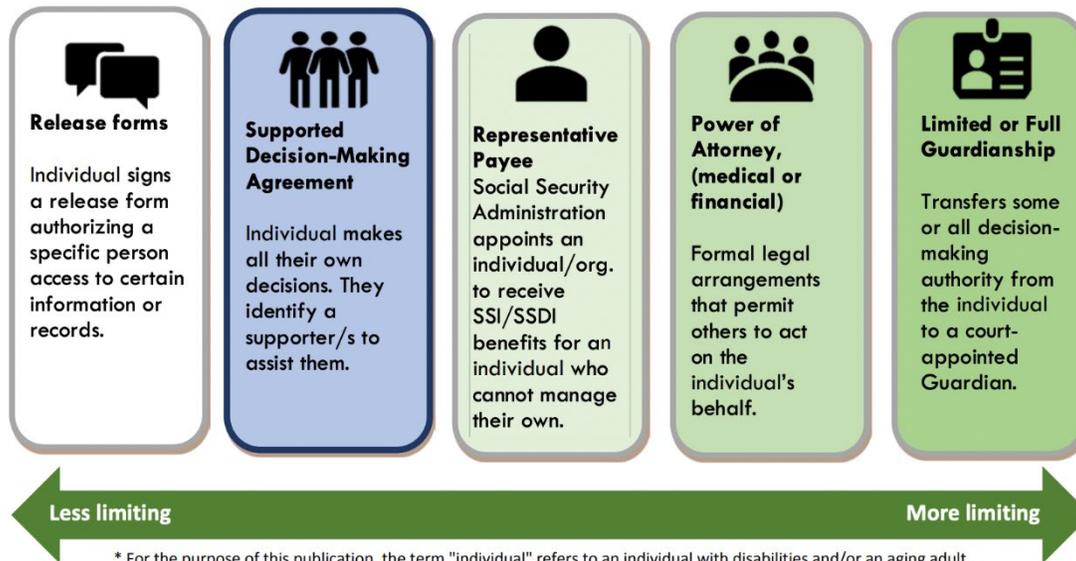
Introduction

In 2018, Supported Decision-Making Agreements was legally enacted in Wisconsin, greatly impacting the lives of individuals with disabilities. “Supported Decision-Making is a process of supporting and accommodating an adult with a functional impairment to enable the adult to make life decisions...without impeding the self-determination of the adult” ([Wis. Stats. §52.01\[6\]](#)). Many welcome Supported Decision-Making as an alternative to guardianship, breaking out of the long-held belief that guardianship is the best option for people with disabilities. As the [Wisconsin Board for People with Developmental Disabilities](#) states, Supported Decision-Making “empowers individuals with disabilities to make informed decisions about their life that protect their rights *and* ensure their safety and privacy.”

Both guardianship and Supported Decision-Making are options that people with disabilities can consider as they enter into adulthood, but these options have distinct differences. Guardianship is the legal process of appointing a substitute decision-maker and allows the court to make the ultimate decision about an individual’s rights and future. Under full guardianship, an individual will lose the right to vote, marry, make financial and medical decisions, and choose where and how they want to live, if specific exemptive steps are not taken. In guardianship, if the original guardian is no longer able to preside over decision making, the court can appoint a new guardian, which could be a complete

stranger. At times, the court may appoint a corporate guardian who may manage fifty or more other guardianship cases. On the other hand, Supported Decision-Making empowers the person with a disability to make decisions about their own life with the aid of one or more trusted supporters. Supported Decision-Making puts the individual with a disability at the center of conversation, allowing them the freedom to make mistakes but still recover and learn.

Current Decision-Making Support Tools



Source: [BPDD Supported Decision-Making Toolkit, 2020](#)

About this Resource

This resource was developed as a companion to Information Update Bulletin 19.02: Supported Decision-Making Agreements and was developed as an internship project through the Wisconsin Student Diversity Internship Program. The project goal was to provide additional information on why Supported Decision-Making agreements may be a preferred option for people with disabilities. More specifically, this resource was developed to provide a variety of perspectives to further emphasize why information about Supported Decision-Making must be provided early on to families and youth receiving special education services through an Individualized Education Program (IEP) prior to youth turning 18 when the transfer of rights occurs. That is, this resource expands on the requirement of IEP teams to provide adult students and their parents with information on Supported Decision-Making agreements, other alternatives to guardianship, and strategies to remain engaged in the adult student's secondary education ([Wis. Stats. §115.807\(4\)](#)). Decisions about decision making during a student's transfer of rights, including options such as Supported Decision-Making Agreements or guardianship should be made with the person with a disability at the center as a full participant along

with that person’s family members. The role of school staff on the IEP team is to provide the student and family with all of the options available to them, and not to recommend one option over another, so that the student and family can make their own decision about what is the best long-term option for the student.

This resource can assist IEP teams with additional insight into “why” adult students and families should fully understand all the decision-making supports and tools available to them and includes interviews from many types of people that interact with Supported Decision-Making, including self-advocates, family members, educators, advocacy organizations, and policymakers. It is our hope that their testimonials can shed a light on Supported Decision-Making as an alternative to guardianship. Their words show that Supported Decision-Making can change lives.

Wisconsin DPI thanks Emily Janicik and Suseela Raj for their dedication and support in developing this resource for IEP teams.

Educator Perspective

Alicia Reinhard, DPI’s transition and graduation consultant, has been teaching since 2010, long before Supported Decision-Making was a formal option for people with disabilities. In addition to her consulting work, Alicia runs the Transition Improvement Grant (TIG), which focuses on improving postsecondary outcomes, and provides statewide inter-agency guidance and support to ensure students with IEPs graduate college, career, and community ready.



When asked about her experience supporting students transition from high school to adult life as a teacher, Alicia emphasized the differences between the options available in the past compared to present day. The conversation with parents focused on the “transfer of rights, and it was mainly about providing information about guardianship or limited guardianship.” Now, Alicia advocates for introducing a spectrum of decision-making options to decide what is best for the student, shifting away from the idea that guardianship is the only option for people with disabilities.

Alicia strongly promotes including students with IEPs in the decision-making process as much and as early as possible, and she states, “the foundation begins as soon as students can start making decisions and express interest and needs.” In speaking about one of her past students who did not have much of a voice as a teenager, Alicia commented “when she turned 18, it was really hard for her to speak up and voice what she wanted. [There was] lots of confusion when it came to her workplace in the summer.” Because decision making was not expected of the student in high school, it was difficult for this student to express her needs once she became an adult. Alicia explains a student's self-advocacy and decision-making skills can “snowball into a very major decision with major implications, such as health care, surgery, and more.” Without the ability to practice decision making, individuals can become reliant on others, who might not always be there to help. It is important to be able to express what you need as an adult to a supervisor, teacher, or

spouse. Alicia emphasizes that there can be “mental health implications [for people with disabilities] if they don’t know how to speak up, and suffer in silence instead.”

Alicia states that “a big fear for caregivers is their child is being taken advantage of--these fears drive people towards guardianship.” However, as big as these fears are, there are also terrible stories about people under guardianship who can’t speak up when they are abused or neglected. “We have to teach young people with disabilities how to speak up when abuse occurs, and we can start this way younger instead with all kids,” leading to safer outcomes for everyone.

Policy Makers and Advocates Perspective

Lisa Pugh is the director of The Arc Wisconsin, an advocacy group for intellectual and developmental disabilities, and has a strong record of fighting for the rights of people with disabilities. When asked what she wants people to know about Supported Decision-Making, Lisa said that it is an important “self-determination measure; when people have authority to make choices for themselves, they are safer, and able to protect themselves from abuse and neglect.” Educating all people that interact in this process, whether it is self-advocates, parents, or professionals, can help others understand Supported Decision-Making more, and embed this practice into daily life for everyone.

Fil Clissa, the Community Inclusion organizer at the Wisconsin Board for People with Developmental Disabilities (BPDD), also has helped Supported Decision-Making become a broad practice in Wisconsin. She emphasized that everyone has, “bias we need to dispel, and dispel myths about people with disabilities. [Some people] automatically assume that someone with a disability is unable to make decisions for themselves. But, none of us make decisions in a vacuum, we consult friends and trusted allies; people with disabilities are no different.”

Both Lisa and Fil highlight that Supported Decision-Making can have many benefits in the long run compared to guardianship. Everybody makes mistakes when they turn 18, but people with disabilities are not always given that same grace. In an effort to learn and grow from these experiences, Lisa says “Supported Decision-Making puts a framework of decision making that allows people to make decisions and mistakes without all of the bad consequences or to be more informed of consequences.” In addition, “someone doesn’t turn into a decision-making person overnight, it needs to be practiced at a young age and on.” In a similar vein, Fil states, “the more opportunity you have to make decisions, the more likely you will make better decisions in your life in the future. Practice makes perfect, we will always make mistakes.” People learn and grow from their mistakes, which Supported Decision-Making affords them the chance to do. And because Supported Decision-Making allows such a flexible framework, people with these plans can grow out of the option to have supporters and make choices independently.

While data on Supported Decision-Making in Wisconsin is scarce, Lisa and Fil have reported that guardianship petitions have decreased in the last several years. It is hard to track how many people use Supported Decision-Making framework because there is no paperwork to file, but Lisa says that “anecdotally from schools and parents, we think

guardianship has slowed.” Furthermore, Fil reports that the number of petitions in court has decreased over the last ten years, which is a hopeful sign. One of the biggest goals of Supported Decision-Making is to provide a broader array of least restrictive options for the transfer of rights as well as provide more appropriate options for students where a supported decision-making agreement is the most appropriate first step in selecting a decision-making tool when other more restrictive options may be considered at a later time for those who need it.

George Zaske is an attorney at Zaske Law Office in Hudson, WI, as well as the parent of a child with a disability. George is a strong advocate for Supported Decision-Making from both his experiences as an attorney and as a parent. Guardianship differs from Supported Decision-Making in the fact that with guardianship, someone is being appointed as a substitute decision-maker, instead of the individual making the decision themselves. George points out that under guardianship, “[you] lose the right to marry, choose where you live, [the right to decide about] medical procedures, finances, and it’s difficult to have independent quality of life.” While Supported Decision-Making allows for flexibility in how the self-advocate is being aided, guardianship is oftentimes a full transfer of rights, which can be devastating for the individual’s freedom.



Most parents begin to hear about guardianship through the school system and parent network, which may include accurate or inaccurate information. When beginning the process, the parents will fill out a petition for guardianship, which can be done easily without a lawyer. To prove how simple it is, George filled out the paperwork during a conference in front of a crowd; the whole process took seven minutes, a very small amount of time that is equivalent to “someone losing all of their civil rights.” After this process, the parents and child with a disability will have a court hearing that can last from 15 to 30 minutes. During this hearing, the judge generally listens to the parents, even though “not a lot of in-depth evidence is taken...[the process is] systematic [where] the parent comes in, alleges the child has a disability, and there is not a lot of push back.” In legal terms, the individual with a disability is called a ward, and although they have the right to advocate for themselves, it is not always taken seriously.

After guardianship is assigned, it is extremely difficult to remove. “A judge has determined that the individual is incompetent,” which is a broad determination, says George. “There are varying degrees of competency: what is required to vote versus what is required to sign a contract or make a decision on a complex medical procedure.” To reverse this, evidence has to be provided to prove that the ward is now able to make this decision; this can prove to be a tough task. In many cases, removing guardianship can be very difficult because “you might have to go against your parents, and [the ward will] need a lawyer, need to call witnesses, push forward motion, and need significant resources. Many individuals receiving long term care cannot have more than \$2,000 worth of assets.” All of this can be an uphill battle, especially for people that are not used to having their own autonomy. This emphasizes the need to wait on petitioning for guardianship.

One of George's son's classmates lost his right to vote after having a full guardianship enacted, even though politics was one of his favorite subjects and "he certainly had the capacity to vote." When his parents checked all of the boxes on the guardianship form, they didn't realize it included taking the right to vote. Once the family realized this, the young man was devastated, and the family filed a motion to get his right to vote restored, which included presenting evidence to the judge. The process took about six months; George had to work with the family and identify witnesses, including a tutor and a teacher, to testify that this young man had the intellectual wherewithal to vote. In addition, in a guardianship assessment conducted by a physician, the right to vote was not checked as a right that should be taken away, which helped when the court put up resistance to regaining that right. All of these measures helped the young man regain the right to vote, even though it was a lengthy and trying process. In the courtroom, when the judge asked the young man if he plans to vote in the next presidential election, he said, "Yes, I am judge."

George brings up the important point that "neuroscience tells us that an individual's brain isn't fully developed at 17.5, it is fully at 25. When someone is put under guardianship at such a young age, they lose the ability to make decisions and mistakes for themselves." Individuals under guardianship are not as aware of their autonomy, so there are fewer chances to become better at decision making. In his experience, George states that "parents go for guardianship because they are afraid of exploitation, but it is a better option to give time to allow the individual to mature and give them time to grow, then decide what is right [moving forward]."

Family Perspective

"I think when you do Supported Decision-Making as opposed to guardianship, there is more opportunity," George Zaske says. In addition to being an attorney, George is a father of a son with a disability, 23-year-old Franklin. When Franklin was 17.5, the age when the intimidating legality of adulthood looms over many children with disabilities and their families, George knew that he had to give Franklin more time to learn and grow instead of immediately locking him into the permanency that the option of guardianship offers, so he leaned into the concept of Supported Decision-Making, even though it was not yet legally enacted in the state of Wisconsin at the time. Lisa Pugh, also a proud parent of an individual with a disability, made the same decision with her daughter Erika, now 22 years old. Lisa knew that Supported Decision-Making would allow her daughter to become a strong, successful adult, telling people early on that "[Erika] is capable of making her own decisions, and this is how we are doing it together."



Lisa's advocating voice has been shaped by a world in which having a child with a disability is a complicated journey. In this world, any path that a child with a disability takes into adulthood, including Supported Decision-Making, has its own set of challenges. When Erika had just turned 18, a nurse from a local hospital called, stating that she needed to speak to Erika about an upcoming appointment. However, Erika is nonverbal, and such a

phone call does not accommodate her mode of communication. Lisa let the nurse know this and described Erika's Supported Decision-Making plan, but the nurse countered with, "Well, you need to be her guardian." Lisa responded by producing Erika's Supported Decision-Making form and subsequently worked to find a proper solution.

George Zaske had a similar experience when trying to open an ABLÉ Account at a bank with his son Franklin. However, he, too, was able to resolve it with patience and a mindset that put his child's autonomy and right to decision making first. George explains that, at times, "people...have built-in bias" and "systems have certain expectations." However, George says Supported Decision-Making is allowing him to foster Franklin's growth and resilience against such societal issues, "trying to instill in him his ability to respectfully challenge systems when he runs into them because they can be pretty big, and they can be pretty opposing and intimidating." Lisa agrees that bias and unjust expectations, along with the newness of Supported Decision-Making, can result in challenges. She explains, "I feel that the parents who are starting to use Supported Decision-Making now really are pioneers because they often know more about it than either the professionals they are interacting with or the community."

Although Supported Decision-Making has its challenges, neither Lisa nor George would want anything else for their child. "It's not a magical process," says Lisa, "but I definitely see [Erika] being respected as an adult who is part of her decisions." George concurs, stating, "I have not run into a situation where I feel like a guardianship would have been a better option." George says that when his son Franklin was 17.5, like a lot of teenagers, he "didn't have [many] interests besides watching sports and playing video games." However, through the framework of Supported Decision-Making, which has allowed George's son to learn and grow with independence and autonomy, Franklin has attended a local technical college, gained an enjoyable and valuable job, and is now thinking about moving out of his family's home and living on his own with the proper support system in place. Currently, George only provides Franklin with transportation to many appointments and meetings, as Franklin has learned how to independently navigate numerous formal decisions. And, like many young adults, Franklin enjoys going out with friends independently, too; he can often be found at Buffalo Wild Wings watching sports with a friend.

Lisa has also watched her 22-year-old daughter blossom into a successful, independent adult in the last few years through Supported Decision-Making. Lisa says, "because she doesn't talk, people often assume that [Erika] is not capable of making decisions." However, Supported Decision-Making has allowed Erika to show everyone that this could not be further from the truth. Erika uses modified sign language to communicate and a stamp to sign her name on documents. In the past year, Erika became a business owner when she purchased AdamCan Recycling, a business previously owned by a different individual with a disability which picks up, processes, and recycles cans throughout Dane County. Erika met with the previous owner, and with the business contract in front of her, "she used her stamp and signed on the line," Lisa recalls fondly. Erika is a member of the chamber of commerce now, and her decision to purchase



the business, a decision made possible through Supported Decision-Making, allows her to be an active member of the community.

Both George and Lisa have empowered their children to become independent, successful, and confident young adults through Supported Decision-Making. So, what advice might they have for others regarding Supported Decision-Making? Lisa highlights the importance of working towards “understanding those fears [regarding adulthood], where people’s ideas around guardianship come from, and tackling them one at a time.” And, she reminds supporters of individuals utilizing Supported Decision-Making to “hold firm that this is a process they can and should be using.” George has a similar message. “For a long time, as a parent, you’re kind of in front of your child, either in their birth-to-three program or working with the doctor. Then, you get into the public school system, and...you go to IEPs,” he says, “You tend to look for ways to...overcome barriers and smooth their path. And then I think as they get to be at least 16 [or] 17, [parents begin] taking more of a walk alongside them as opposed to being in front of them.”



The transition that happens next is frightening and difficult, but when George reflects on where he is currently positioned as Franklin’s father, a few years after this transition, he explains, “And, now, the way I look at it, [Franklin] is out there front and center facing the world, going where he wants to, trying to build a life for himself. I am behind him now, and I will stay behind him until he looks back and gives me a nod that he wants me to come up and help him.” That is the power of Supported Decision-Making.

Self-Advocate Perspective

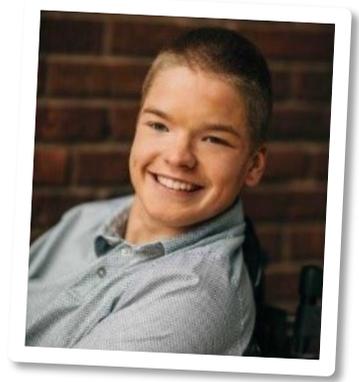
Ashley Mathy is a vibrant young woman who loves dancing, horseback riding, shopping, and participating in the Special Olympics. Additionally, she has a deep and inspiring passion for helping other individuals with disabilities. Ashley works at Headwaters, Inc., a non-profit agency that serves people with disabilities in northern Wisconsin, in addition to working as an advocate, a mentor, and a board member of the Board for People with Developmental Disabilities (BPDD). Ashley is also one of the thousands of adults with disabilities under guardianship in Wisconsin. Although Ashley is a bright, successful young person, when she considers the impact of guardianship on her life, she recalls some limitations and negative feelings. “I wish that I could, you know, be able to go wherever I want, or...have the same opportunities to be able to make mistakes like everyone else,” she reflects. She also states, “the impact of guardianship [can be] so, so draining.” However, Ashley says this is not any one person’s fault. “Parents only care about their kids, it’s not like they’re coming from a bad place,” she says, “So, we just have to educate them and teach them more about Supported Decision-Making so more people don’t go under guardianship like I did.”



Thus, what might Ashley want parents and others who support individuals with disabilities to know? She insightfully states, “I think we all care about and love people, and then we helicopter over them...we don’t give them a chance to prosper...I have had instances like

that, and it sometimes leads me to major depression. And, this is why I really do think Supported Decision-Making is great at a young age, for [people] not to say to [individuals with disabilities] ‘you can’t do this’ or ‘you shouldn’t do this.’”

Jordan Anderson agrees with Ashley that people need to know more about the importance of Supported Decision-Making. The 18-year-old recent high school graduate was incredibly close to having a guardianship put into place, and he credits a conference hosted by BPDD for helping him realize that he wanted to halt this guardianship before it was established. A mere day before his court hearing to establish guardianship, Jordan, after a suggestion by his teacher, decided to attend the Wisconsin Self-Determination Conference, a conference he would not have normally attended but did because of its virtual format that year. At the conference, he learned about Supported Decision-Making, an option that neither he nor his parents had been aware of previously. He immediately began working with his parents to halt the guardianship process that would have been solidified less than 24 hours later, instead establishing a Supported Decision-Making arrangement before he entered adulthood. “I’m just so grateful for my parents that they listened to me and that they thought my concerns through,” he explains with a smile.



Ashley comments, “I think Supported Decision-Making is a very good thing for people with disabilities because choice matters...Are you able to make that choice?” At 18 and with a Supported Decision-Making arrangement, Jordan is able to make that choice, and by starting to make such choices, he also has realized just how much choice does matter. He describes, “If I have a surgery coming up, my parents can help me discuss the pros and cons to the surgery, and I can sign my own paperwork now.” Both Jordan and Ashley know that actions that may seem insignificant to some, like signing paperwork, make an incredible difference in the life of a person with a disability, a person whose human dignity and autonomy are all too often threatened by society. Ashley puts it best, saying, “It’s very important for people with disabilities to be able to do things like everybody else, to feel like a real human, and to feel like they have an impact on society like everyone else. Otherwise, your whole life without that is just kind of like you’re in a box.”

With the help of Supported Decision-Making, in addition to supportive parents and a tenacious, positive perspective on life, Jordan has been able to move away from this “box” and dream far outside of it. This year, he is excited to begin attending a unique school-to-work program at the Marshfield Clinic called Project SEARCH. When describing his ambitious dreams for the future, Jordan says, “I just want to be involved in my community, and, when I get older, I really want to run for political office.” Jordan also has a passion for sports, which he also hopes to integrate into his bright future. Ashley, with wise words informed by her impressive work involvement and her personal experiences with guardianship, is able to capture the importance of opportunities, autonomy, and big dreams like those Jordan holds, saying, “Having a meaningful life is having the friends you want, to date who you want to date, to go into society like everyone else, to have all these

options. And, if we're not allowed to do any of that, it's almost like we're...locked up into a box, and we're scared to say what we want to say...You don't feel like a human."

What does it look like if someone is able to have the options Ashley describes? That is when the person is able to stop having to fight for their immediate autonomy and start doing, start living, and start dreaming. Supported Decision-Making has helped Jordan do just that. When asked his feelings about Supported Decision-Making, Jordan happily answers, "How does it make me feel? It makes me feel really grateful that I can make my own decisions with my parents' help now and again."



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