

# Supported Decision-Making – An Alternative to Guardianship

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Volume 28, Issue 1, of the *South Dakota Report* contained an article discussing the transfer of parental rights at age of majority. 34 C.F.R. § 300.320(c) requires that at least one year prior to a child with a disability reaching age of majority under state law, the IEP must include a statement that the child has been informed of what rights will transfer. Since the age of majority is eighteen in South Dakota, the IEP must include such a statement prior to the child's seventeenth birthday. The article further discussed how, under 34 C.F.R. § 300.520, when a child reaches the age of majority, the school district must provide notice to the student and parents that all rights accorded parents under Part B of IDEA have transferred to the child (including children who are incarcerated), except when a child has a guardianship that takes effect at age of majority.

The emphasis of that article was the *content* of what students and parents are told. The State Department of Education's technical assistance guide to IEPs and its Parental Rights document emphasize the required timelines for notice (as set out above), but they provide little-to-no direction on the content of the discussion that must take place. The article discussed how the notice of transfer of rights can be made more meaningful for both students and parents based on the content of the discussion. The article closed with a section on whether guardianship is appropriate. This article picks-up where the first article left off, specifically discussing aspects of guardianship in more detail and emphasizing alternatives to consider prior to guardianship (Supported Decision-Making and Power of Attorney), how transition services can and should foster such alternatives, and closes with a discussion of the Jenny Hatch case.

For years, DRSD has heard concerns from several other States that schools inform parents they *must* obtain guardianship when their child turns age eighteen. In South Dakota, however, DRSD has often heard that parents are not informed *enough* about guardianship or alternatives from schools. DRSD has not promoted guardianship, but rather the emphasis has been on education - to make sure parents are aware of that option and to make sure parents who believe a guardianship is needed are informed of what they need to do if they want the guardianship in place when the child turns age eighteen. If parents in South Dakota believe they are not informed enough about guardianship, it is a safe bet they are also not sufficiently informed of alternatives to guardianship. Alternatives, such as Supported Decision-Making, can be part of a child with a disability's transition services.

## Supported Decision-Making

Supported Decision-Making (SDM) is the process of assisting persons with a disability to make their own decisions so they can develop and pursue their own goals, make choices about their life, and exercise some control over the things that are important to them. SDM is a process that can be used in both the educational context and for adults with disabilities. SDM provides for a team approach to decision-making. The person with a disability chooses who he or she wants on his or her SDM team and a written agreement is made on the type of decisions in which each team member will assist. The "team" may be one person or several, based on the needs and desires of the individual.

SDM is an important process for persons with disabilities because it allows for self-determination. In the United States, every person is born with unalienable rights – to life, liberty, and the pursuit of happiness. Having rights means having the ability to make choices and make decisions. Having the ability to make choices is called self-determination. Touting that one has rights is meaningless if one is not allowed to actually use them. When people are not allowed to make their own choices, they are stripped of self-determination. It stands to reason if one is stripped of the ability to make decisions about his or her life, that would certainly affect one's self-esteem. One would probably feel helpless, angry, or any number of negative emotions since one would no longer be able to make decisions about one's own life. That is what

guardianship does and why it is important to always identify and consider less-restrictive alternatives prior to commencement of guardianship proceedings.

SDM can help individuals with disabilities to understand information, issues, and choices so that they may weigh their options. It ensures decisions are based on the individual's own preferences. It helps individuals with disabilities to make informed choices. All forms of SDM preserve individuals' right to make choices because it allows persons to receive the amount of support needed without giving up the right to make choices. "Supported Decision-Making has the potential to increase self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased control, independence, employment, and community integration." (Blanck & Martinis, 2015).

The concept of Supported Decision-Making should not sound foreign because it is something the general public utilizes every day. At work, it is common to run something by a co-worker or supervisor before proceeding. At home, it is common for one spouse to get the opinion of the other before making purchases. In the community, it is common to take a friend shopping to get input prior to purchasing a new dress. It is certainly common to consult with professionals, such as an investment broker prior to purchasing investments, an attorney to help understand legal documents, and a doctor to diagnose and explain/treat medical conditions. The examples are endless in terms of how people informally utilize a form of Supported Decision-Making on a day-to-day basis. On the other hand, SDM is a foreign concept for many people with disabilities because most often people are making decisions for them.

## **SDM in the School Setting**

Jonathan Martinis, Senior Director for Law and Policy at Burton Blatte Institute, Syracuse University, describes the IEP as a "laboratory for Supported Decision-Making." One need not look any further than the "purposes" of IDEA to begin understanding what he meant. One of the purposes is "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs *and prepare them for further education, employment, and independent living.*" 34 C.F.R. §300.1 (emphasis added). It is the school's job to prepare students with disabilities for further education, employment, and independent living. Self-determination is the ultimate goal of education. In other words, the purpose of the school system is to teach and prepare all students for the next part of their lives, whether that be further education, employment, enlistment, living independent living, etc., and being able to weigh and make those choices. Clearly, being able to live independently involves much more than learning how to run appliances, pay bills, and drive or take public transportation. To be able to live independently, students need to be taught how to exercise their right to make decisions. They need to be taught self-determination.

Transition planning and services are the most important part of the IEP process. Students with disabilities are eligible to attend school through the year in which they turn age twenty-one in South Dakota, unless they have graduated with a signed diploma. Appropriate transition services are vital because they are supposed to provide students with the skills they will need to navigate life for the next 50+ years! It is the school's job to help students acquire the skills they need to live each day once they leave the school system. Transition services are required to be contained in the IEP that is in place when students turn age sixteen (or younger if appropriate). It is vital that transition services begin when required. Over the years, it was common for DRSD to hear from parents or school personnel that a school district does not provide actual transition services until the student's last year of school. School districts have been required to provide transition services beginning at age 16 (or younger) for 28 years (since 1990), yet just last month DRSD heard again of a district that fails to provide *any* transition services until students are nearing their eighteenth birthday and the services the district eventually provides do little to prepare the students for adult life. Districts that fail to prepare students for further education, employment, and independent living through transition services are failing to meet the purpose of IDEA and violating the law.

Transition services are a coordinated set of activities designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child to facilitate the child's movement from school to post-school activities. It includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and if appropriate, acquisition of daily living skills and provision of a functional vocational evaluation. 34 C.F.R.

§ 300.43(a). Daily living skills certainly includes the skills needed for self-determination. For any student at or approaching transition age, it is important that parents ask the school what it has for a self-determination curriculum. How is the district teaching the student to live independently and how is self-determination part of that instruction? If self-determination is not part of the curriculum, the school is probably not properly preparing the student for adult life and thus not meeting the purpose of IDEA.

Schools should be helping students in their ability to set goals, solve problems, make decisions, and advocate for themselves. Schools should also provide students the opportunity to utilize these skills as part of their transition services. If a school says at age eighteen that a student is unable to make decisions, it would be fair to ask what special education and related services have been provided for the past two years to help the student acquire the daily living skill of decision-making? When IDEA's parental rights transfer to students at age eighteen, students become responsible for making informed decisions regarding all aspects of their educational programming. That is why it is vital that students with disabilities be taught self-determination in the years prior to turning age eighteen.

Going back to Mr. Martinis' statement about IEPs being a "laboratory for Supported Decision-Making," there is a lot to that statement. The IEP process, probably more than any other, is set up to not only foster Supported Decision-Making, but *is* a form of Supported Decision-Making when students are allowed to lead the IEP Team meetings. Student-led IEP meetings was supposed to be a logical outcome of the addition of Transition Services to IDEA in 1990, but its use is not widespread. For students with disabilities, success in life can often be associated with the ability to self-advocate and make decisions (self-determination). Preparing students to lead IEP meetings provides a perfect opportunity to learn and practice these critical life skills. Conversely, if students attend IEP meetings, but have little involvement, the student learns only that his or her voice does not matter and all the adults will make decisions *for* the student.

Student-led IEP meetings fit squarely into the SDM process. Transition services require taking into account "the child's strengths, preferences, and interests." The IEP process comes with a team of professionals who can provide students the information needed to make informed decisions. If students are provided the training and supports needed to lead the IEP meeting, this would allow the student to identify goals, including goals/outcomes for post-school activities (such as those set out in the federal regulations - postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and/or community participation). It would assist and allow the student to identify the services the student needs to achieve those goals and outcomes. Combined with a self-determination curriculum, the IEP process should achieve helping students to set goals, solve problems, make decisions, and advocate for themselves, and provide students the opportunity to utilize these skills at the student-led IEP meetings – a laboratory for Supported Decision-Making indeed! As a bonus, the student will already be familiar with SDM as the student leaves the public school, should it be needed in other settings. There is plenty of material available on how to teach and prepare students to lead their IEP meetings, as well as studies on the benefits of student-led IEP meetings.

## **Power of Attorney**

Another alternative to guardianship is the Power of Attorney (POA). The POA originated out of necessity in the area of business. A business owner could not possibly meet with and sign contracts with all customers, so the owner gave authority to do so to other employees. The other employees were deemed to be acting on behalf of the owner. This became known as "agency law." In this example, the owner would be the "principal" and the employee would be the "agent" or "attorney-in-fact." The original type of POA would end if revoked by the principal or upon death or incapacity of the principal.

The concept of agency law spread outside of the employment realm and a new type, called a "Durable Power of Attorney," was established. The idea behind this type was to allow the agent/attorney-in-fact to be able to act on behalf of the principal even after the principal's incapacity. South Dakota first established the Durable POA in 1977. It must be in writing and contain specific language conveying intent that authority is exercisable despite the principal's incapacity. It may grant current authority that extends beyond the principal's incapacity - "This power of attorney shall not be affected by disability of the principal." It may also grant authority only upon the principal's incapacity, which is referred to as a springing authority - "This power of attorney shall become effective upon the disability of the principal."

The Durable POA allows for additional authorities beyond ability to contract. South Dakota law gives the principal the authority to nominate a guardian or conservator should proceedings concerning the principal take place. SDCL § 59-7-2.4. It may allow the attorney-in-fact to make health care decisions, including admission to and custodial care provided by a licensed health care facility. The Principal can also give authority to consent to, reject, or withdraw consent for medical procedures, treatment, or intervention (SDCL 59-7-2.1) and make health care decisions relating to nutrition and hydration (SDCL 59-2.5-2.7).

A Durable POA is an attractive alternative to guardianship because it does not require a court hearing or court involvement and because of the flexibility in the types of authority it authorizes. In an education setting, a student of age of majority with capacity to understand what he or she is signing could sign a Durable Power of Attorney giving a parent or other individual the authority to act on his or her behalf. The POA could, of course, extend beyond educational decisions to any or all other aspects of the student's life. The student could make the decisions the student chose to and defer others to the person(s) selected under the POA. A POA is a much less expensive alternative than guardianship since it does not require going to court. The principal retains authority to make decisions, so unlike a guardianship, there are no rights affected. Essentially, it provides for a substituted decision-maker should the principal become unable or unwilling to make decisions. A Durable POA can be used in conjunction with SDM. A POA is another alternative schools should discuss when providing the initial notice of transfer of parental rights.

## **Guardianship**

Guardianship should be considered *only* after lesser restrictive alternatives have been considered and preferably tried. When a guardianship is put in place, it should be limited to only those areas where the individual actually needs the assistance of a guardian. South Dakota statutes recognize that the need for a guardian should not be automatically assumed and promote considering less restrictive alternatives.

South Dakota's guardianship statutes require that lesser-restrictive alternatives be considered at two steps in the process. Prior to a guardianship hearing, there must be an evaluation. SDCL 29A-5-306 requires that "the evaluation report provides to the court an idea of whether the provision of additional services would avoid the necessity of an appointment." It requires that the evaluator provide an opinion if a guardian/conservator is needed and, if so, the type or scope. SDCL 29A-5-312 directs the courts' consideration of the case, stating, in part: "The determination as to whether a guardian or conservator will be appointed, the type thereof, and the specific areas of protection, management and assistance to be granted, shall be for the court alone to decide. In making that determination, the court shall consider the suitability of the proposed guardian or conservator, the limitations of the person alleged to need protection, the development of the person's maximum feasible self-reliance and independence, the availability of less restrictive alternatives, and the extent to which it is necessary to protect the person from neglect, exploitation, or abuse."

Clearly, South Dakota judges must consider less restrictive alternatives prior to taking away a person's rights. However, there have not been many options. Supported Decision-Making is gaining traction as a viable alternative to guardianship across the country. Two or three states have even passed SDM legislation, but it does not need to be in statute to be utilized, as described above. At guardianship hearings, the burden should be on the petitioner to prove a guardianship needed. The court *should* ask what else has been considered and/or tried prior to granting a guardianship.

Even when a guardian is appointed, South Dakota's guardianship laws are geared toward maximizing and developing a protected person's independence and self-determination, as set out at SDCL 29A-5-402, the responsibilities of the guardian:

- To be active and knowledgeable of the protected person.
- To maintain sufficient contact with the protected person to *know the person's capabilities, limitations, needs, and opportunities.*
- To make decisions regarding the protected person's support, care, health, habilitation, therapeutic treatment, and if not inconsistent with another order, determine residence.
- *To be guided in his/her activities only by the limitations of the protected person.*

- *To encourage, if feasible, the protected person to participate in **decision-making**, act on his/her own behalf, and develop or regain capacity to manage personal affairs.*
- *To consider the expressed desires and personal values of the protected person.*
- To always act in the protected person's best interests.

As set out above, a responsibility of a guardian is to build a protected person's ability. It is the guardian's job to maximize the protected person's self-determination and independence. The guardian should work to increase the person's capacity for self-determination through SDM or other means. For many, guardianship should be a way station, not the final destination, as a guardianship should be in place only so long as needed. If a lesser restrictive alternative, such as SDM, becomes a viable option, the guardianship should be terminated. Even when a guardian is appointed, its scope should be limited to the specific needs of the individual.

## **Supported Decision-Making for Adults with Disabilities**

Both during and after leaving public school, persons with disabilities may work with Vocational Rehabilitation (VR) to obtain a job, regain employment, or get a better job. The VR process also is set up to provide a form of SDM. The VR counselor works with the person, gives the person information to help the person identify and choose an employment goal, the job the person wants, and the services needed to get there based on informed choice. The VR process is also a form of SDM.

For persons receiving adult services, the ISP process is also one that would allow for SDM. Most people receiving adult services, however, already have guardians. While guardians should support and encourage use of SDM as discussed above, the question that must also be answered is whether SDM is an appropriate alternative to guardianship, and if so, whether the guardianship may be removed altogether or revised to a limited guardianship.

## **Barriers to Supported Decision-Making**

Barriers to wide-spread use of SDM are probably two-fold. One is fear of the unknown – fear of what will happen if a guardianship is removed or not put in place. The other barrier is simply that implementation of SDM would require a systemic change in how things have always been done.

### **Fear of the Unknown**

While most people have heard of guardianship, few have heard of SDM. Parents, especially, have fears about their children with disabilities and what will happen if the parents are not in control. This fear can take several forms.

Nationwide, schools are the number one source for recommending guardianship, as parents are told if they do not get guardianship by age of majority, all rights will transfer to the student and parents will no longer be allowed at IEP meetings. While it is true that all rights will transfer, students may continue to have their parents participate in meetings and assist them in making decisions. If SDM is working as it should in the transition services process, even in situations where parents are not participating for some reason, there will be a team to assist the student in making informed decisions.

As an aside, that schools are the number one source nationwide for recommending guardianship should be cause for concern. For the entirety of the students' education, schools stress providing services in the least restrictive environment. A purpose of IDEA is to prepare students for further education, employment, and independent living and districts are required to provide transition services to achieve that purpose. The goal of education is self-determination. For schools to promote and recommend guardianship as a student is about to reach age of majority, as opposed to lesser restrictive alternatives, seems to contradict everything the school and students are supposed to be working toward through the student's transition services.

Another fear is that the person with a disability will not be "safe" without a guardianship in place. "Safety" can mean several things. It could mean safety in crossing streets or not getting into strangers' cars. It could mean safety from physical or sexual abuse. The reality is, having a guardianship in place does not place an impenetrable safety shield around an individual. A guardian typically will not be with

the protected person daily, unless perhaps the person is living with the guardian. Having a guardianship in place will typically not have a direct bearing on the protected person's safety. A guardianship will not prevent a person from failing to look both ways before crossing a street. It will not prevent a person from getting into a stranger's car. It will not prevent abuse. Actually, utilizing SDM would have a much more direct effect on ensuring the person with a disability is making informed choices than simply having a guardian in place.

Another fear is that, even with SDM in place, the person still will not make decisions in his or her best interest. If the decision on whether a guardianship is needed is conditioned only on making choices in one's best interest, everyone would need a guardian. People without disabilities make choices that are not in their best interest every day. Perhaps they eat too much ice cream or drink too much beer. Perhaps they bought exercise equipment they have never used. Perhaps they were talked into doing something by a friend or telemarketer that they later regretted. Self-determination means having the right to make choices, not the ability to always act in one's best interest.

When people without a disability make a bad decision, they may refer to it as a "learning experience." When people with disabilities make a bad choice, society is conditioned to conclude they must need a guardian. They are not allowed to learn from bad choices; rather, the right to make any choices is taken away. How can one learn from mistakes if the right to make those choices and those mistakes is taken away? The fact is, everyone makes bad choices, some more frequently than others. SDM provides the structure so that persons with disabilities are provided with information so that they can understand the issues or choices, weigh the options, and then make an informed choice based on that information and their own preferences. No, every choice may not be in the person's best interest, but if a bad choice is made, the person may be able to learn from that mistake and not make the same choice the next time. SDM allows the person with a disability to grow as an individual through the increased self-determination.

## **Need for Systemic Fundamental Change**

The notion that persons with disabilities are unable to make choices on their own behalf is historical – going back centuries. Supported Decision-Making is asking people and systems to change the way they have always done things. Change is always difficult, but changes in civil rights require *Fundamental Changes* in how we have always done things. United States history provides several examples. Prior to 1776, the colonies were ruled by a king. Until 1860, one could purchase, own, and sell another person. Prior to 1919, women could not vote. Until 1990, persons with disabilities had no rights (except against federally-funded entities). While SDM is growing, widespread use of SDM instead of guardianship would also require a fundamental change to how we have always done things. Jenny Hatch started that fundamental change in 2013.

## **Justice for Jenny**

Margaret Jean (Jenny) Hatch won the first court case in the country where Supported Decision-Making was ordered by the court. Jenny was about 28 years old and had lived in a group home. She has Down syndrome and her IQ had been evaluated to be about 50. Jenny had signed a POA giving her parents (mother and step-father) authority to make certain decisions and she had a third-party representative payee. Jenny had worked at a thrift store for five years and become friends with the owners, Jim and Kelly. Jenny hated living in the group home. A car hit her while she was riding her bike and she needed surgery. After the surgery, Jenny revoked the POA and she began living with Jim and Kelly. Her parents filed a petition for guardianship. The court granted an agency, Jewish Family Services (JFS), temporary guardianship until the case could be heard. Jenny was forced back into a group home and was not allowed to work at the thrift store. JFS took away her cell phone and laptop computer and restricted her visitation. All visitors had to first fill out a visitation form and be approved; all visitors were also forbidden from discussing the guardianship case with her. Because the temporary guardian would not allow Jenny's attorney, Jonathan Martinis, to discuss the case with her, he filed a motion to allow Jenny access to her counsel, which the court granted. At some point, the temporary guardianship was switched to Jenny's parents. After six days of testimony from May 1, 2013, to August 2, 2013, the court issued its decision on Jenny's parents' petition for guardianship.

For the first four pages of the decision, the court discussed statutes and evidence showing why Jenny needed a guardian. On the top of page five, Judge David F. Pugh, Circuit Court for the City of Newport News, Virginia, stated, “However....” Judge Pugh’s “**However**” changed history.

The court initially recognized the requirement to give deference to Jenny’s preferences, and because of Jenny’s animosity toward her mother, the court found it would not be in her best interest for the parents to continue as her guardian. The court instead appointed the thrift store owners, who had intervened in the case, as Jenny’s guardians, but placed several conditions on it. It was “a limited guardianship of limited powers and limited duration, with the ultimate goal of transitioning to the supportive decision making model. It is the intent of the Court that the Guardians shall assist [Jenny] in making and implementing decisions we have heard termed ‘supported decision making.’” The court set out an expiration date for the limited guardianship at one year. The guardians were given the power to make medical and safety decisions, “giving due deference to the wishes of [Jenny].” The court ordered the guardians to transition Jenny, “in accordance with her wishes, from her group home setting to a private residential environment.” The court strongly recommended that the guardians continue to provide supportive decision making assistance in anticipation of the termination of the guardianship at the end of one year.

Jenny got her wish of going home, meaning moving out of the group home and back in with her friends from the thrift store, Jim and Kelly, who were appointed her limited guardians for one year. Jim and Kelly’s temporary limited guardianship over Jenny ended in August 2014. Through use of SDM, Jenny now lives and works where she chooses, has friends she chooses, and encourages others to do the same. She has become a sought-after speaker, sharing her inspiring story across the country. The Jenny Hatch Justice Center was named in her honor. While a very determined and engaging young lady, Jenny does not have special abilities. She is a typical person who has Down Syndrome. What is different about her is that she is living her life without a guardian utilizing SDM. She just needed a little help. Her message to other persons with disabilities is simple: If I can do this, so can you.

## Conclusion

Supported Decision-Making has proven to be a viable less-restrictive alternative to guardianship. SDM, as well as a Durable Power of Attorney, should be considered prior to concluding a guardianship is required. When a guardianship (and/or conservatorship) is needed, it should be limited to only those areas where the person needs a guardian or conservator. If you have questions about SDM, POA, or guardianship, please contact DRSD.

## Sources:

<http://jennyhatchjusticeproject.org/home>

<https://youtu.be/2GnE9yWRL0g>

Quotes in boxes:

**“The typical ward has fewer rights than the typical convicted felon .... By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen.”** (House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper)).

**“Fifty years from now, the disability community will be talking about the Jenny Hatch case.”** The Washington Post (quoting Denille Francis).

**“For anyone who has been told you can’t do something, you can’t make your own decisions, I give you Jenny Hatch – the rock that starts the avalanche.”** The Washington Post (quoting Jonathan Martinis).