Supported Decision-Making: What Parents Need to Know

Parents are often told that applying for Guardianship for their transition-aged child is a natural next step in protecting them as they enter the age of majority (18 years old). There is another option available to parents in Colorado and in a growing number of states who are passing laws to allow this alternative; it is called Supported Decision-Making (SDM). In 2021, Colorado Senate Bill 21-075 authorized such agreements as an *alternative* or *supplement* to Guardianship.

What is Guardianship? (Source: National Guardianship Association, 2023)

Guardianship is a legal process utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence. Guardianship is often overused and is typically the default option for individuals with intellectual/ developmental disabilities. Since establishing Guardianship may remove considerable rights from an individual, *it should only be considered after alternatives to Guardianship have proven ineffective or are unavailable*.

What is Supported Decision-Making (SDM)? (Source: Senate Bill 21-075)

SDM facilitates adults with disabilities in maintaining decision-making authority over their own lives while also encouraging these adults to recognize, create, and maintain supportive communities, through supported decision-making teams, that can assist adults with disabilities in making informed decisions.

Adults with disabilities who do not have a court-appointed guardian, or a court-appointed conservator, *have the right to independently make any decision without any supportive community member*, regardless of having entered into a supported decision-making agreement. (Source: <u>Senate Bill 21-075</u>)

Do you really need Guardianship over your Child? Ask yourself these questions:

- 1. Can your child make decisions either by themselves or with assistance? Yes/No
- 2. Does your child have an IEP (Individualized Education Program) with stated strengths and functioning level with goals listed to increase skills for independence? Yes/No
- 3. Do you have **trusted** support people in your child's life such as siblings, extended family members, case workers, therapists, coaches, clergy or spiritual supporters, or others? Yes/No If you answered "Yes" to any of these questions, **you may not need to apply for Guardianship.**

Guardianship may be needed in emergency situations when... (Source: The Arc of Colorado)

- The person did not previously identify how decisions should be made in that situation.
- There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means.

Guardianship supports people:

- Who face critical decisions and have no interest in or ability to make decisions.
- Who needs immediate protection from exploitation or abuse.

If you do pursue Guardianship, consider:

• Obtaining Limited Guardianship vs Full Guardianship as a less restrictive measure.

- Including a SDM agreement that can be incorporated into the legal Guardianship documents for more flexibility and to increase the likelihood of reversing Guardianships.
- Including a "Growth Clause" in the Guardianship document, specify when a person has gained <u>capacity</u>, how that will be measured, and by whom.

Why you should not go the Guardianship route, even if you are advised it is easier:

- Judges have the discretion to appoint Guardians, and it is not always the parent(s) appointed.
- Guardianship is the most restrictive method, with possible risks and long-term negative impacts.
 - People who exercise greater self-determination have a better quality of life, more independence, and more community integration. (Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little 2014; Wehmeyer & Shwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)
 - People who do not have a guardian are more likely to have a job, live independently, have friends other than staff and family, and socialize in the community, practice the religion of their choice. (Source: <u>National Core Indicators</u>, 2013-2014)
- Unforeseen circumstances or unintended consequences that are difficult to reverse such as:
 - A person is temporarily incapacitated, such as someone in an accident and is expected to resume their normal functioning level; or
 - In a situation where someone is changing psychiatric medications.
- Guardianship involves court fees and is time consuming as one needs to keep and maintain records to submit to the court annually.

An Alternative to Guardianship: Supported Decision-Making (SDM)

- A more person-centered and individualized approach is to customize the SDM process. A plan with built-in flexibility to make changes over time without involving the courts is Supported Decision-Making.
- People with decision-making support have increased self-confidence and are motivated to stay safe when they know they have autonomy and self-determination. (Martinis & Blanck, 2019)
- People who are labeled as having a disability still have human and <u>civil rights;</u> having a disability is not the proper criteria or reason to seek Guardianship.

What does the Supported Decision-Making process look like? (SDM) (Source: <u>NYS Transition Partners, 2019</u>) SDM is not limited to one person like Guardianship. It can be established with different **trusted** people who also exhibit qualities of respect and empathy as supporters (family, friends, professionals, advisors) depending on the situation.

- A person with a disability is always the decision maker and has the final say.
- The supporters agree to help the person understand, consider, and communicate decisions, giving the person the <u>tools</u> to make their own informed decisions.
- Supports may include:
 - helping find useful information
 - o helping weigh the pros and cons
 - o assisting in communicating the decision to third parties
 - and/or in carrying out the decision.

• Often the arrangement between the person and their supporters is written down in an SDM agreement so that all parties know and understand their rights and responsibilities.

Legal Documents needed by supporters to accompany a Supported Decision-Making Agreement:

- HIPAA Authorization for medical care and oversight provided by medical office
- Power of Attorney <u>learn more</u>
- Medical Durable Power of Attorney <u>learn more</u>
- Authorization to disclose educational information (typically a "release of information" form aka ROI)
- Conservator learn more
- Template for Legal Documents Tracking: <u>more</u> (make a copy, make your own changes, save)

Frequently Asked Questions by Parents and Supporters:

Question: Does Colorado have a standardized Supported Decision-Making Agreement?

Answer: Colorado State Statutes do not require a standard agreement form, although The Arc of Colorado created a <u>Standard SDM agreement form</u>. It is not necessary to have a Supported Decision-Making Agreement, although it is considered best practice thereby all parties know and understand their rights and responsibilities. If a person chooses to create their own SDM agreement, it must include certain information that can be accessed <u>here</u>.

Question: Do I need an attorney to prepare a Supported Decision-Making Agreement?

Answer: It is not necessary to have an attorney prepare a SDM Agreement, although it is advised to seek guidance and feedback from a disability lawyer.

Question: What is the best legal document that gives the primary support person access to all domains of a person's life?

Answer: A Power of Attorney (POA), although an accompanying Medical Durable POA (MDPOA) document must be completed and filed with the POA for anything medically related. A POA in Colorado does not need witnesses or to be notarized, but it is considered best practice. Because a POA should be tailored to individual's circumstances, it should be written by an attorney to ensure that the intentions are clearly stated. If one chooses not to have an attorney prepare a POA, the Colorado "<u>Statutory Form Power of Attorney</u>" is considered the best form to use. An agent must agree to act upon the wishes and decisions of the principal. Only a court can take away a principal's right.

Question: What do I do if a medical provider office will not accept a Medical Durable Power of Attorney?

Answer: All medical providers under the law must accept completed and notarized MDPOA. If an employee refuses to accept your MDPOA, find out why. Is there information missing? If there is no valid reason, speak to a supervisor. If it remains an issue, you can report the incident to <u>The Office of Civil Rights</u>. If a medical provider refuses to provide services due to a discriminatory perception of a person with a disability, then the office is violating that person's civil rights under the Americans with Disabilities Act (ADA). A complaint can be filed with the <u>Department of Justice</u> and the <u>Colorado Civil Rights Division</u>

Question: My adult child's medical office told me that it would be easier to get Guardianship instead of trying to use a Medical Durable Power of Attorney. What should I do?

Answer: Supported Decision-Making (SDM) is a new law and emerging practice. Not all employees have the knowledge or training to understand the critical issues of making a life-altering choice of Guardianship versus SDM. Consider that each person who gives advice has good intentions and gives an answer because that is what has always been done in the past. It is critical to consider who is a trusted advisor.

Question: If I am divorcing when my child turns 18, what should I do?

Answer: If you believe your child can make decisions with support, there is no need for legal Guardianship. Seek advice from your divorce lawyer as to the best way to move forward with a plan that meets your child's needs with the least restrictive measures for continuation of care. It may look like a parenting plan. A word of caution: if one parent seeks legal Guardianship and the other parent does not agree, there is a higher probability that the Judge will choose a **Public Legal Guardian.** There are many drawbacks to this approach.

Question: My adult child no longer wants me to be the Medical Durable POA. I do not agree with their choice. What can I do?

Answer: First, your commitment to acting as a Medical Durable POA is based on what the person wants and what is in their best interest. You do not have to agree with your adult child. Still the decision is theirs to make, including allowing the person the <u>dignity of risk</u> of making a decision you personally would not make. Your adult child will need to formally revoke a previous POA before creating a new one.

You can find this Supported Decision-Making Resource and additional resources at: <u>https://medschool.cuanschutz.edu/jfk-partners/resources/supported-decision-making</u>

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