

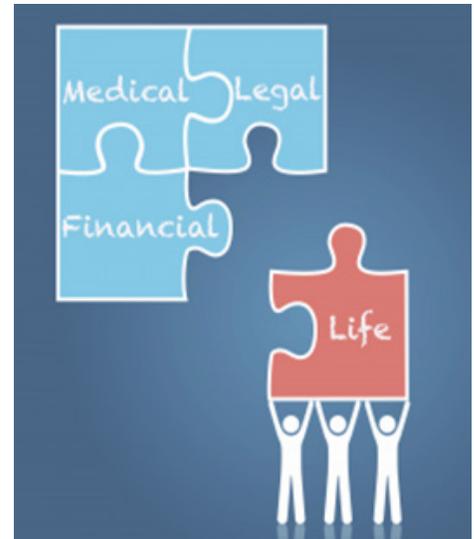
‘I Want to Live in an Apartment with My Own Stuff’

How Supported Decision-Making Can Work for People with Intellectual and Developmental Disabilities

Background

In Arizona, **guardianship** is the appointment by a court of an individual or entity to provide care and to make personal decisions for a minor or an adult, sometimes with a cognitive or intellectual disability. In 2017, 9 in 10 new petitions for guardianship for Arizonans with disabilities filed were approved. When guardianship is granted, rights such as voting, working, driving, making healthcare decisions, and choosing where to live can be taken away from a person. While guardianships in some cases cannot be avoided, the premise of guardianship is contrary to the goal of self-determination and should be used as a last resort.

Yet, the legal system continues to overwhelmingly rely on full guardianship over alternatives that would allow people with disabilities to retain their legal rights. Some families of young adults with disabilities may feel pressured to choose guardianship when their son or daughter turns 18. Are there other options that provide support without taking away someone’s independence? Yes, and an effort is underway nationally to educate the courts, lawmakers, families, and individuals about Supported Decision-Making (SDM)¹ as a viable alternative to full legal guardianship.



What is Supported Decision-Making (SDM)?

In the United States, everyone should have the right to participate in decisions impacting their lives. A 2015 poll of people with disabilities revealed that less than 50% of them say they speak for themselves all of the time.² Many stated they didn’t have to because someone did it for them. SDM is a process by which individuals with disabilities can make many of their own decisions with the help of a supporter only when they need it. Unlike a full or limited guardianship,³ the person with a disability is still legally the ultimate decision-maker. People seek help from trusted family members or friends in buying a home or choosing a dentist; SDM provides an opportunity for people with disabilities to make their own decisions with the assistance of a supporter when requested. SDM shifts the focus from the person’s limitations to their capabilities, resources, and strengths – all tenets of person-centered planning.⁴ Thus, the SDM process is considered a best practice for customizing support to the person’s unique needs without restricting independence, choice, or control like through a formalized guardianship process.

Why is SDM important?

Multiple studies have shown that SDM can produce several positive outcomes. Individuals who exercise higher levels of choice, control or self-determination have greater independence, higher self-esteem, better quality of life,⁵ and are better able to resist and avoid abuse.⁶ Further, these individuals are ultimately more likely to be employed, to participate in the community, and have friends outside of their family or their appointed caregivers.⁷

Alternatively, research has shown that a lack of opportunity to make decisions can prevent people from developing the necessary skills to make their own decisions.⁸ A guardian is responsible for making decisions on behalf of an individual with a disability and often makes decisions for them without their input. Guardianship operates under the assumption that people with disabilities are incapable of understanding the conditions surrounding consequential life choices. This assumption prevents people with disabilities from living as independently as possible.

Current guardianship laws in Arizona do not provide opportunities for people with disabilities to practice making their own decisions. These laws also do not consider how much support an individual already has from family, friends, or staff to help in decision-making. The statutes typically only consider the person's capacity to perform certain tasks, even though many people with disabilities are capable of making decisions. Capacity changes over time and a lack of capacity in one area does not mean a lack capacity in all areas.⁹ As is the case with people without disabilities, individuals with disabilities can certainly learn decision-making skills when given the opportunity. SDM gives individuals a chance to learn, to grow, and to be empowered in making choices they believe are best suited for them.

Decision-making skills are learned behaviors that require consistency, encouragement, and practice; the SDM process naturally aligns these opportunities. In addition, parents and family members play a critical role in the success of SDM arrangements and should be seen as important partners in establishing this process.¹⁰

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Policy Recommendations

Since current Arizona statutes and courts default to the most restrictive option, new legislation is necessary. Successful legislation on SDM would require language that families or caretakers shall first consider SDM arrangements before they consider more restrictive options. SDM agreements have already been implemented as a legal option in three states, with most others having initiatives to



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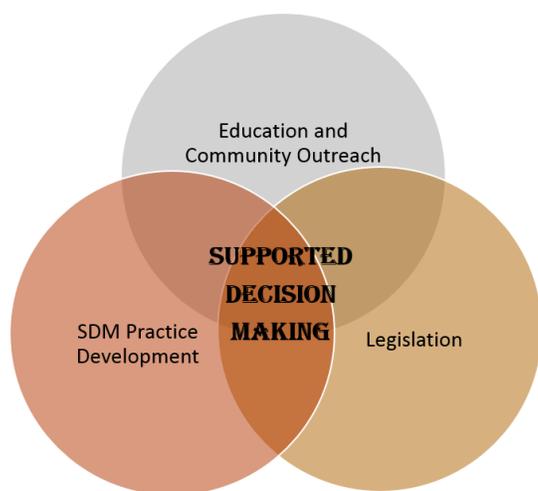
Right now, I am living my adult life by having my own place, working part time at a daycare, and going to college for my career as pre-school assistant teacher...I have the right to make my own decisions because I am no different from people who [don't] have disabilities.

<http://mofamilyofamily.org/>

promote the practice. Specifically, each of these states offer people with disabilities an SDM Agreement. In a legal SDM arrangement, there is typically an agreement that is either notarized or signed by an independent witness. Generally, the agreements are valid for one year from the date they are signed and can be voided by either party at any time. The SDM Agreement identifies, prioritizes, and documents the preferences for the individual with a disability, and identifies who the individual elects as his or her designated “supporter.” The agreement outlines the areas in which the individual is seeking support and the areas they do not need or want support. For example, an individual could choose to seek help in renting an apartment or making medical appointments but not where to work. A successful SDM agreement offers customized support for the individual so they can participate in the decision-making process in all facets of their life.

Paths to SDM

To establish SDM as a viable alternative to guardianship in Arizona, a clear plan to implement these new ideas within the framework of the existing guardianship process must be put in place. Education and community outreach, SDM practice development, and drafting and implementing legislation are all necessary components of creating a practical SDM system in Arizona.



Community members, stakeholders, and government require education about SDM and how it can be used to promote self-determination. Through education and awareness, community members’ perception and expectation of the capabilities of individuals with I/DD can evolve. The inclusion of SDM as part of the transition to adulthood should include reforming guardianship to limit the authority a guardian has and increase access to limited guardianships and other alternatives. Improvements in monitoring, documentation, and data tracking of general and limited guardianships are necessary to inform further research about how SDM can be individualized to meet the needs of Arizonans with disabilities.

Families will also need education and support to see SDM as a viable option. Support in productive communication skills and forming agreements is especially relevant for families creating a tailored SDM for their child. Furthermore, self-advocacy trainings should be conducted to inform individuals with disabilities about SDM. Peer-to-peer SDM support models should be implemented as much as possible to guide individuals through their SDM development. Resources providing planning tools and highlighting best practices should be made easily available to all families.

Next Steps

The Arizona Developmental Disabilities Planning Council awarded a grant to Southwest Institute for Families and Children, Arizona Center for Disability Law and The Arc of Arizona to start a stakeholder coalition that will move the state towards SDM. The inaugural meeting of this group will take place in December 2018. The goal of the coalition is two-fold: to educate persons with developmental disabilities, their families and caretakers, court personnel, and other stakeholders on SDM as a viable option; and to draft legislation to bring to the state legislature that will include SDM as a legal alternative to guardianship. To everyone else, SDM is just decision-making, but the 'supported' in front of it assures that it is its own process that can be formalized through the legal system so that the rights of people with disabilities to pursue their own dreams are protected.

If Arizona is to make any real change in employment, education attainment, or independent living outcomes among people with disabilities, it has to first consider the types of opportunities people with disabilities are offered to have their voices heard. SDM offers an opportunity for people to make real decisions over what they want in their own lives, gain confidence, and build support. People with disabilities should have the same rights and opportunities as everyone else – and that is to make decisions over their own life with as much or as little support as they need to do so.

Endnotes

- 1 More information about the SDM movement can be found at www.supporteddecisionmaking.org.
- 2 McFadden, E. (2016). *Comprehensive Review and Analysis: Arizona's Services, Supports, and Unmet Needs for Individuals with Developmental Disabilities and their Families*.
- 3 Not defined by Arizona statutes, but guardian has only those powers specifically granted by the court order appointing the guardian.
- 4 Werner, S. & Chabany, R. (2015). Guardianship law versus supported decision making policies: perceptions of persons with intellectual or psychiatric disabilities and parents. *American Journal of Orthopsychiatry*, 5, 486-499.
- 5 Jameson, J. M., Riesen, T., Polychronis, S., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research & Practice for Persons with Severe Disabilities*, 40(1), 36-51.
- 6 Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal on Mental Retardation*, 110, 193-204.
- 7 Jameson et al., 2015.
- 8 Salzman, L. (2010). Rethinking guardianship (again): Substituted decision making as violation of the integration mandated of title II of the Americans with Disabilities Act. *University of Colorado Law Review*, 81(1), 157-246.
- 9 Dwight, J. (2010). Guardianship for your own good: Improving the well-being of respondents and wards in the USA. *International Journal of Law and Psychiatry*, 33, 350-368.
- 10 Werner, S. & Chabany, R., 2015.