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POLICY

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IDRPP Position Statement: Supported Decision-Making in Utah

Introduction

Supported decision-making (SDM) emerged as an alternative to traditional plenary or limited guardianship. Traditional guardianship assumes that an individual with a disability lacks the capacity to make informed decisions, and a court appoints a guardian with decision-making authority over that person. SDM recognizes that individuals with disabilities can make their own choices, even if they need support in doing so. By providing individuals with trusted advisors and tools to understand and communicate their decisions, SDM empowers them to exercise their agency and live with greater dignity and independence. The importance of SDM lies in its respect for individual autonomy, its ability to promote self-reliance and inclusion, and its potential to prevent unnecessary guardianship interventions.

Utah is one of the few states that does not currently have SDM as a legal alternative to guardianship for individuals with disabilities. This year (2024), the Utah legislature will consider adopting SDM (HB 0197), which will help individuals with disabilities exercise more autonomy and control over their lives. By enacting SDM legislation, Utah would formally acknowledge the rights of individuals with disabilities to make their own choices and receive tailored support from their chosen trusted advisors. The IDRPP strongly supports these efforts.

SDM provides a supportive framework to help individuals express their preferences and make choices in various areas of life, such as education, healthcare, housing, relationships, finances, and even activities of daily living like shopping, cooking, and working. SDM gained national visibility through a 2013 Virginia court case (Ross and Ross v. Hatch) where a 29-year-old woman with Down syndrome, Jenny Hatch, successfully argued her case for using SDM in lieu of guardianship (Martinis et al., 2023; Quality Trust for Individuals with Disabilities, 2013). Since 2013, many states have started to officially recognize SDM as a less restrictive alternative to guardianship for people with disabilities. Currently, 18 U.S. states have passed legislation that supports SDM (National Resource Center for Supported Decision-Making, n.d.a).

Numerous reports and studies have documented the benefits of SDM, including:

- Increased self-determination and quality of life: Individuals with disabilities who utilize SDM often experience greater control over their lives and a sense of empowerment (Martinis et al., 2023; National Resource Center for Supported Decision Making, n.d.b).
- Improved access to employment: SDM can help individuals with disabilities overcome barriers to employment by providing them with the tools and support they need to make informed career decisions (Shogren et al., 2015).
- Enhanced engagement in community settings: SDM empowers individuals with disabilities to participate more fully in their communities, fostering a sense of connection and belonging (Salzman, 2010).

• Greater involvement in life experiences: SDM allows individuals with disabilities to experience both positive and negative life events, essential for personal growth and development (National Resource Center for Supported Decision Making, n.d.b).

By enacting SDM legislation, Utah would formally acknowledge the right of individuals with disabilities to make their own choices and receive tailored support from their chosen trusted advisors. This would empower individuals with greater autonomy and self-determination and promote their inclusion and participation in society. Through SDM, individuals can express their preferences, access information, and make informed decisions in areas such as healthcare, finances, and personal relationships. This framework allows for flexibility and customization to meet each individual's unique needs and goals, ensuring their voices are heard and respected. By implementing SDM legislation, Utah can create a more inclusive and supportive environment for individuals with disabilities, fostering their independence while safeguarding their rights.

Proposed Legislation (HB 0197)

Utah Representative Marsha Judkins has proposed legislation (<u>HB 0197</u>) that would establish <u>SDM</u> within the state's legal framework. This pivotal legislation will provide official and legal recognition to SDM agreements, allowing individuals with disabilities greater control and decision-making that impacts their lives. The proposed legislation specifically outlines that individuals over the age of 18 with disabilities can enter into an SDM agreement with at least one trusted individual of their choice, empowering them to receive personalized support while exercising their right to self-determination. This innovative approach marks a significant shift away from traditional guardianship models and paves the way for a more inclusive and supportive environment for individuals with disabilities in Utah.

IDRPP's Position and Rationale

The Utah State University Institute for Disability Research, Policy & Practice stands firmly behind the belief that all people, regardless of ability, deserve autonomy and independence to the maximum extent appropriate. Supported decision-making (SDM) offers a valuable method for individuals to retain their fundamental rights to make decisions about their own lives, and the IDRPP wholeheartedly supports HB 0197, which aims to establish a legal framework for SDM in Utah. This legislation will provide Utahns with disabilities with a much-needed alternative to guardianship. This shift aligns with the positive sentiments expressed by advocates, families, researchers, and other professionals who have witnessed the transformative power of SDM in the lives of individuals with disabilities and their families.

By enacting (<u>HB 0197</u>), Utah will join a growing number of states that recognize the importance of SDM. This legislation has the potential to significantly improve the lives of countless individuals with disabilities, offering them more options and opportunities to lead self-directed lives while receiving the support they need. The IDRPP urges Utah lawmakers to pass <u>HB 0197</u> and empower individuals with disabilities to make their own choices and to build full, self-determined lives within our state and communities.

Additional Resources

Past Legislation During Utah 2023 General Session: <u>HB 510, Proposed Legislation on Supported</u>
 Decision-Making Agreements

- Utah Parent Center: Benefits and Considerations of Supported Decision-Making
- Utah Disability Law Center: Requirements for Supported Decision-Making Agreements Legislation
- Utah Disability Law Center: <u>Supported Decision-Making and Guardianship Comparison</u>
- Utah Developmental Disabilities Council: <u>My Voice Counts: A Self Advocate's Guide to Supported Decision-Making</u>
- National Resource Center for Supported Decision-Making: Frequently Asked Questions

Citations

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- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education*, 48(4), 256-267. https://doi-org.dist.lib.usu.edu/10.1177/0022466913489733