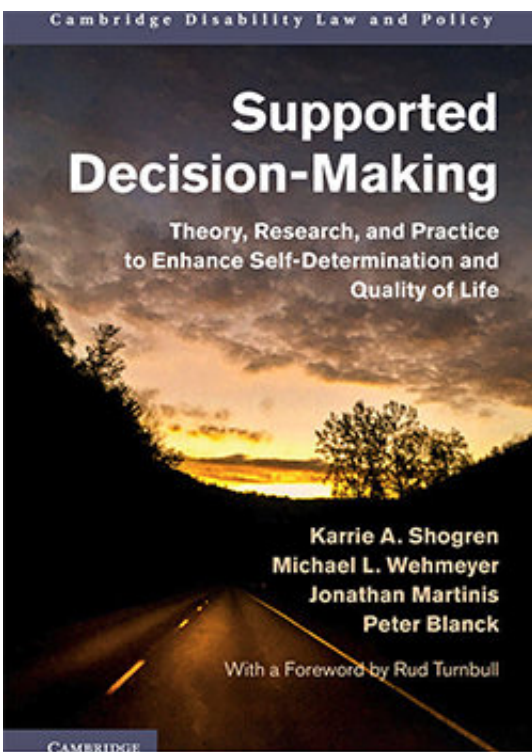


New book among first to examine how people with disabilities can take legal, decision-making lead in lives

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Credit: University of Kansas

For decades, increasing numbers of people with intellectual and developmental disabilities have lived their adult lives under legal guardianships. A new book co-authored by University of Kansas and Syracuse University researchers is among the first to explore a

fundamentally new way of empowering people with disabilities to retain legal agency while still receiving necessary assistance: supported decision-making.

"Supported Decision-Making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life" comprehensively examines supported decision-making and how it can be applied in policy and practice for people with intellectual and [developmental disabilities](#). Published by Cambridge University Press, the text was authored by Karrie Shogren, professor and senior scientist and director of the Kansas University Center on Developmental Disabilities; Michael Wehmeyer, Ross and Mariana Beach Distinguished Professor in Special Education and director of the Beach Center on Disability; and Jonathan Martinis and Peter Blanck of the Burton Blatt Institute at Syracuse University, New York.

"Supported decision-making is receiving increased attention in the U.S. and internationally. Essentially, it's all about providing alternative models to plenary guardianship that can enhance self-determination and quality of life," Shogren said. "The wholesale removal of legal rights under traditional plenary guardianship modes can be problematic, and we need alternatives that fully engage people with [disabilities](#) in decisions about their lives."

Research has shown that people with disabilities can be effectively supported to engage in decision-making about their education, employment, health care and legal matters. Further, this can lead to enhanced quality of life. The new book examines how individuals with disabilities and their families and support providers can use supported decision-making as a framework to enable people with disabilities to be fully engaged in the decision-making process and empower them to identify the people who will support them in that process.

The text summarizes research in supported decision-making and practical applications both within the United States and from other countries. The book highlights ongoing research to develop intervention and assessment strategies to enable support decision-making in practice. The legal section gives an outline of the frameworks to establish supported decision-making as an alternative to legal guardianships. Examples of legislation in various jurisdictions, including Texas and Delaware, are highlighted.

"It's exciting to see the concept of supported decision-making gain traction in the U.S.," Shogren said. "By focusing on legal, policy, research and practice implications, we can build the systemic supports to make supported decision-making a reality, and we attempt to target all of these areas in this text."

The book's practical application section includes guidelines and suggestions for how supported decision-making can be implemented, in practice, by individuals, their families, support providers and communities, even in states or jurisdictions where there is not legal precedent. Specifically, the practical applications provide guidance and recommendations for how families, individuals, communities, schools and support providers can work together across the lifespan to plan for and implement supported decision-making models. Guidelines for establishing legal and financial tools as well as community supports are covered as well, with an emphasis on the importance of thinking about all aspects of life in which decisions are made.

"I think this can help families who are wondering about what this kind of arrangement would look like in practice and enable the creation of more tools and resources that can be used to build systems of supports for people with disabilities across the life course," Shogren said. "Supported decision-making cuts across multiple areas and can help us think about how we work across sectors without limiting or artificially restricting an

individual's potential."

"Supported Decision Making" is part of a Cambridge University Press series on disability law and policy edited by Peter Blanck, who is also an author on this text. The book aims to provide a new way of looking at disability while also providing a roadmap for states, families, attorneys, policymakers, caregivers and others.

"The predominant model of legal guardianship is rooted in an antiquated understanding of disability. Supported [decision-making](#) is rooted in new ways of understanding disability that recognize the interaction of the person and the environment and focus on identifying and building the right system of supports to enable a person to fully participate in their lives and communities without artificially restricting their rights," Shogren said. "We all need supports. People with disabilities may need more supports in some areas of life, but we just need to be creative in devising these supports while ensuring the person has agency over the decisions in their lives."

More information: Karrie Shogren et al. "Supported Decision-Making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life." www.amazon.com/Supported-Decision-Making/dp/1108475647

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