# Executive Summary

## How to Expand Supported Decision-Making and Increase Informed Choices

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A key feature of person-centered practices is respect and support for people's rights to make decisions about their own lives—both small and large. Having agency is important to feelings of self-worth, well-being, and unique identity, but for many people with disabilities and older adults who use long-term services and supports, the ability to shape the course of their lives is constrained by the appointment of a guardian as a substitute decision-maker. A national movement is growing to advance supported decision-making as an alternative to guardianship. The American Civil Liberties Union defines supported decision-making as follows:[1]

> Supported decision making (SDM) is a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. A person using SDM selects trusted advisors, such as friends, family members, or professionals, to serve as supporters. The supporters agree to help the person with a disability understand, consider, and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions.

The following table shows the differences between supported decision-making and guardianship:

| Guardianship | Supported Decision-Making |
|---|---|
| • Decision-making rights are removed from the individual and given to another person. | • Individuals keep all decision-making rights. |
| • Guardians make decisions *for* the individual – even if the guardian consults with the individual. | • Individuals make decisions *with help* from those people they select (even when extensive support to communicate and express decisions is necessary). |
| • Guardianship is rarely removed or reduced. | • Allows change as individual's preferences/needs change. |
| • Decisions are made by the guardian by "judging what is in the best interest of the person" standard. | • The individual's preferences are more important than best interest. |

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[1] American Civil Liberties Union (n.d.). Supported decision-making: Frequently asked questions.
https://www.aclu.org/sites/default/files/field_document/faq_about_supported_decision_making.pdf

SDM offers people with disabilities and older adults the possibility of gaining agency in their lives with the assistance of a circle of friends. However, guardianship often remains the default when people's ability to make informed decisions is questioned. The following is a series of strategies that stakeholders in human service systems can adopt to help expand SDM and reduce reliance on guardianship:

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| Establish coalitions to support legislation and SDM policies | To be successful in amending guardianship laws, it will be necessary to develop broad-based coalitions that encompass advocates for people with a variety of disabilities as well as older adults. |
| Implement pilot/ demonstration projects | SDM pilots can provide an opportunity for everyone to learn about how decision supports work in real lives, to test the validity of the concepts, to assess outcomes, and to continually improve the practice. |
| Develop and disseminate evaluations of the outcomes of SDM | To ensure the sustainability and expansion of SDM, it will be important to mount independent evaluations that assess the impact of the reform. |
| Identify SDM "champions" | The adoption and expansion requires SDM champions at community and state levels, including people with disabilities and their loved ones. |
| Support the leadership contributions of people with disabilities and others who may benefit from SDM | People with disabilities can effectively serve as trainers, peer supporters, and lobbyists for changes in law and policy. |
| Mobilize advocacy for SDM | Strong and sustained advocacy has been crucial to the passage of supported decision-making statutes around the country and to ensure that the spirit of reforms is carried out. |
| Create education and training opportunities | To ensure that SDM becomes a more frequently used alternative to guardianship, it will be important to invest in education and training. |
| Develop publications, videos, reports, websites | To improve the adoption of SDM, it is important to generate information about the practice in a variety of formats that are culturally and linguistically accessible. |
| Identify "best practice" networks | Another way to expand the practice of supported decision-making is to ensure that SDM is embraced by local, regional, state and national advocacy networks and other values-based networks. |

## About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services to help States, Tribes, and Territories to implement person-centered practices. It is administered by the Human Services Research Institute (HSRI) and overseen by a group of national experts with lived experience (people with personal, first-hand experience of using long-term services and supports).

NCAPPS partners with a host of national associations to deliver knowledgeable and targeted technical assistance.

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