

The Sibling Role in Supported Decision-Making (SDM)

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Background

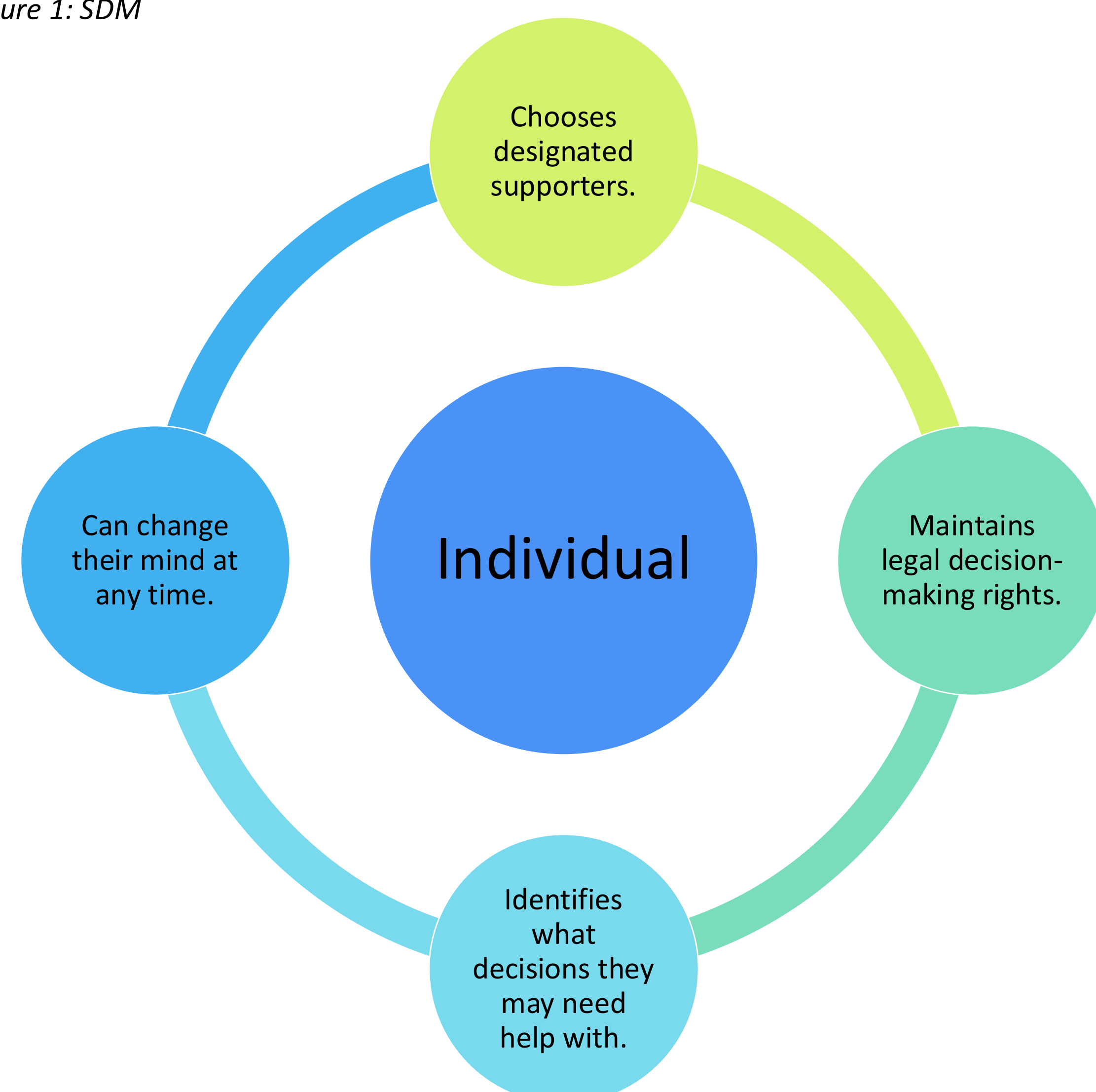
The Disability Rights Center of New Hampshire (DRC-NH) is a statewide non-profit organization dedicated to eliminating barriers for people with disabilities across NH. The DRC is the federally designated protection and advocacy agency for NH and has authority under federal law to conduct investigations in cases of probable abuse or neglect.



Introduction

On August 10, 2021, Governor Sununu signed SB 134 into law, officially recognizing Supported Decision-Making (SDM) as an alternative to guardianship for adults with intellectual and developmental disabilities (IDD) and their families. Guardianship is often seen as a necessary legal safeguard, granting a designated guardian full decision-making authority. However, this arrangement can restrict an individual's independence. SDM provides a person-centered alternative that maintains autonomy while offering needed support. Siblings of individuals with IDD often play a key role in their brothers or sisters' lives, particularly during the transition to adulthood and beyond. Many siblings are unfamiliar with alternatives to guardianship, despite the significant role they may have in decision-making (Burke et al., 2019). This research aimed to understand siblings' knowledge, perspectives, and role in SDM.

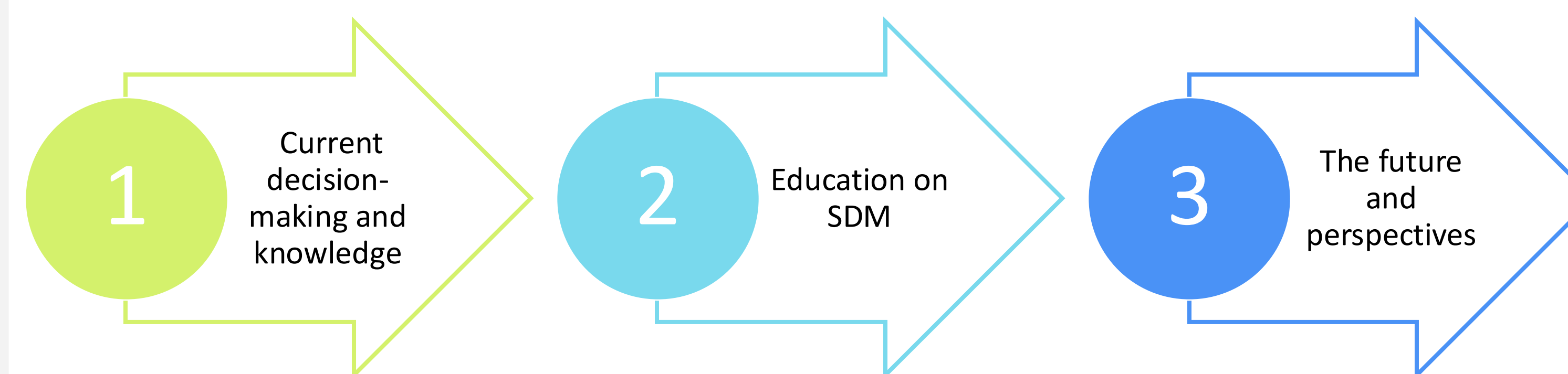
Figure 1: SDM



Methods

This study employed a qualitative approach to explore sibling perspectives on guardianship and SDM for adults with IDD. Participants were recruited through personal networks and advocacy groups. Three siblings of adults with IDD took part in semi-structured Zoom interviews, while four additional siblings completed an online survey. Both the interviews and surveys were conducted in three phases.

Figure 2: Phases



Data Analysis

Interview and survey responses were analyzed to identify key themes. Themes were developed using an inductive approach, allowing insights to emerge directly from participant responses.

Results

The following themes were identified from the data analysis:

Figure 3: Key Themes

AUTONOMY While the participants' siblings had some independence in daily choices, they required significant support for major decisions. All parents served as legal guardians.	BARRIERS Siblings cited cognitive limitations and communication differences (e.g., nonverbal) as reasons for maintaining guardianship and emphasized what their sibling "can't" do.	FUTURE ROLE All siblings anticipated playing a role in their sibling's life as they age, with most expecting to take on caregiving responsibilities.
AWARENESS Most participants were unaware of alternatives to guardianship, and all were unaware of SDM.	PERSPECTIVES Following education, participants were open to trying SDM with their siblings, although they also voiced concerns.	OUTREACH Siblings expressed a need for more resources and education on guardianship and its alternatives.

Conclusions

The findings highlight that siblings of individuals with IDD anticipate playing a significant role in their sibling's life as they age, often assuming future caregiving or guardianship responsibilities. However, siblings exhibited a significant lack of awareness regarding alternatives to guardianship and SDM. Additionally, participants overwhelmingly viewed cognitive limitations and communication differences as justifications for guardianship, suggesting a deeply ingrained belief that decision-making autonomy is not feasible for their sibling. As a result, there is a risk that future decision-making will remain limited for their sibling as they become increasingly involved in their care, with major life choices largely managed by guardians. Following education about SDM, siblings expressed openness to exploring it as an alternative but also voiced concerns and emphasized the need for more information and support. This research indicates a potential gap in available education and outreach efforts directed towards siblings of individuals with IDD in NH.

Recommendations

By implementing these recommendations, the DRC-NH can play a crucial role in empowering siblings with the knowledge and tools they need to support their loved ones while exploring less restrictive alternatives to guardianship:

- Extend outreach to siblings to inform them of alternatives to guardianship such as SDM.
- Partner with sibling support organizations to share resources and facilitate discussions on future planning.
- Create guides or toolkits to help siblings support their brother or sister in making daily and long-term decisions.
- Start a sibling support group with a focus on future planning, decision-making, and legal options.

References

Burke, M. M., Lee, C. E., Hall, S. A., & Rossetti, Z. (2019). Understanding decision making among individuals with intellectual and developmental disabilities (IDD) and their siblings. *Intellectual and Developmental Disabilities*, 57(1), 26–41. <https://doi.org/10.1352/1934-9556-57.1.26>

Disability Rights Center - New Hampshire. (n.d.). *Supported decision-making in New Hampshire*. <https://drcnh.org>

