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Addressing Gaps in Digital Supported Decision-Making (SDM) Resources for the Disability Community in California

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KEY TAKEAWAYS

> Digital information about supported decision-making (SDM) has significant gaps.

> Development of materials tailored for various languages, cultures, and disability types and expansion of sector-specific guidance are needed for full implementation of SDM.

Summary: Supported decision-making (SDM) offers an alternative to guardianship or conservatorship for individuals with disabilities, preserving their autonomy while providing tailored support for important life decisions. California recently enacted legislation recognizing SDM as a formal legal alternative to conservatorship (AB 1663); however, full implementation of SDM requires accessible resources on what SDM is and how to use it. This policy brief presents findings from analysis of digital SDM resources in California. Recommendations focus on developing tailored resources for populations at highest risk for conservatorship.

> **Supported decision-making** (SDM) is a process in which an individual who needs help making important life decisions chooses a trusted person or persons to aid them in decisions, congruent with their values and without impeding their self-determination.

BACKGROUND

Guardianship (called conservatorship in California) removes decision-making rights from individuals with disabilities, potentially diminishing their autonomy and quality of life. These legal arrangements affect an estimated 1 million to 3 million Americans, including thousands of Californians. Supported decision-making (SDM) offers an alternative approach, allowing individuals to retain autonomy while receiving assistance from someone they trust and whom they choose at a given time to provide them with support.

In 2022, California enacted the Probate Conservatorship Reform and Supported Decision-Making Act (AB 1663). This law promotes SDM as a legally recognized way to support and protect an individual's decision-making autonomy, thereby improving social inclusion, ensuring full civil rights, and preventing conservatorship and its resulting marginalization and isolation. However, full implementation of SDM in the lives of Californians with disabilities requires accessible, high-quality resources that provide specific information on what SDM is, how it is to be used, and how individuals can create formal SDM agreements.

KEY FINDINGS

Most SDM resources target adults as a general category (60.7%) and caregivers (84.5%), with fewer resources specifically designed for children, older adults (ages 65 and older), or transition-age youth (ages 16–25)(Exhibit 1).

While existing resources generally received "A" ratings for autonomy (78.6%) and strengths-based approaches (70.2%), they received significantly lower ratings in other domains (Exhibit 2).

Only 21.4% of resources were available in languages other than English, despite 44.1% of California households speaking a language other than English at home (data not shown).

DISTINGUISHING TYPES OF COLLABORATIVE DECISION-MAKING

Many people seek advice and support in making complex decisions, such as those involving health care, social services, or finances. Supported decision-making is one of several structured approaches to collaborative decision-making. Other types include shared and structured decision-making.
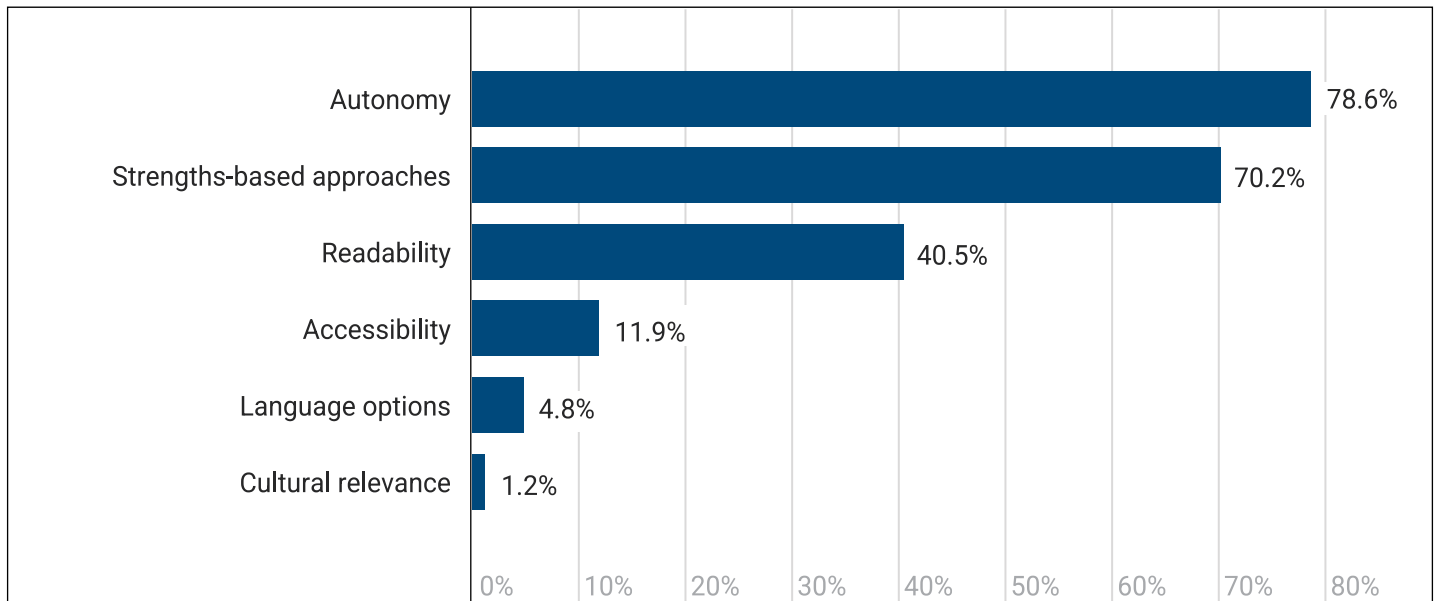
- **Supported decision-making** is based on the principle that people have the right to make their own decisions, with tailored assistance. Rather than having others decide for them, individuals receive the support they need to understand their options and express their preferences. This approach is particularly important for people with disabilities. The individual has final responsibility for making decisions.

- **Shared decision-making** involves two or more people making a decision jointly, with each party contributing their expertise and preferences. In health care, this often means that a patient and health care provider collaborate as equal partners, combining the provider's clinical knowledge with the patient's values and preferences. Both parties share responsibility for the final decision.

- **Structured decision-making** refers to the use of systematic frameworks, tools, or processes to organize and inform decision-making. This might involve decision trees, scoring matrices, formal criteria, or step-by-step protocols. The goal is to make decisions more consistent, transparent, and evidence based by following a predetermined structure, regardless of who ultimately makes the decision.

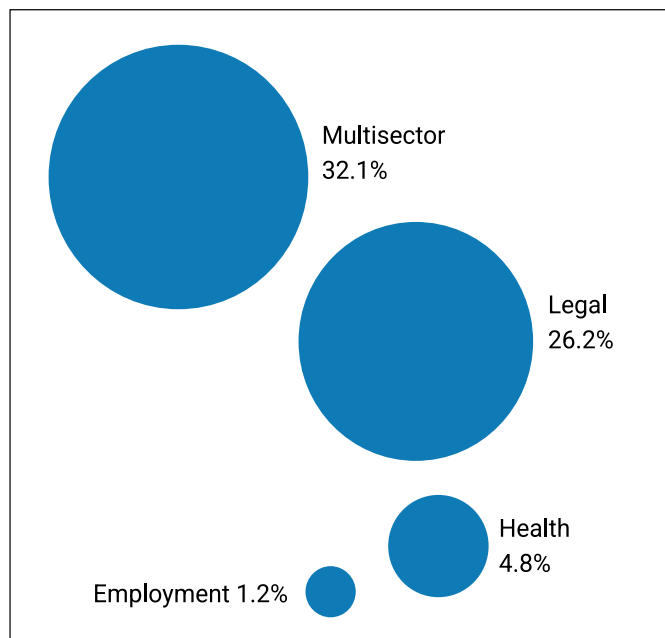### Exhibit 1 / Distribution of Resources by Audience Type
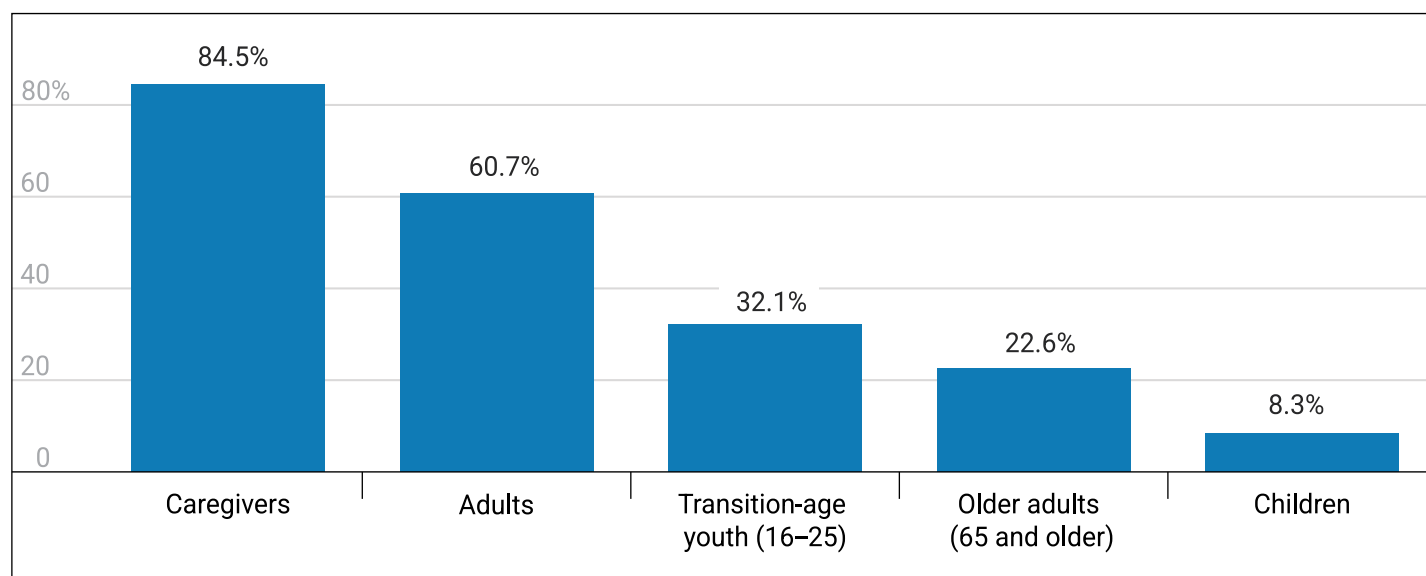
Source: Author analysis of data on digital SDM resources from the California State Council on Developmental Disabilities.

Exhibit 2 / Received "A" Ratings by Domain

Domain	Percentage
Autonomy	78.6%
Strengths-based approaches	70.2%
Readability	40.5%
Accessibility	11.9%
Language options	4.8%
Cultural relevance	1.2%

Source: Author analysis of data on digital SDM resources from the California State Council on Developmental Disabilities.

Exhibit 3 / Distribution of Resources by Sector Focus

Multisector 32.1%

Legal 26.2%

Health 4.8%

Employment 1.2%

Source: Author analysis of data on digital SDM resources from the California State Council on Developmental Disabilities.

Most resources were focused on multisector systems (32.1%) or the legal sector (26.2%), with very few resources developed specifically for the health care or employment sectors (Exhibit 3).

IMPLICATIONS

The gap analysis highlights critical gaps in current SDM resources that may limit their effectiveness and reach, particularly for diverse populations. The low ratings for cultural relevance are especially concerning given that racial and ethnic minority groups are disproportionately represented in conservatorships. Additionally, the limited availability of resources in multiple languages creates barriers to access in a linguistically diverse state like California.

The lack of sector-specific resources, particularly in health care and employment, represents a missed opportunity to provide guidance in areas central to many SDM agreements. Finally, the scarcity of information specific to certain disability populations at high risk for conservatorship (such as those with dementia, neurological impairments, or serious mental illness) leaves individuals in these groups without adequate SDM resources.

POLICY RECOMMENDATIONS

Based on these findings, we recommend the following priorities for SDM resource development:

- **Develop targeted resources for high-risk populations.** Create tailored SDM resources for individuals with dementia, neurological disorders (e.g., traumatic brain injury, cerebral palsy), serious mental illness (e.g., schizophrenia), and transition-age youth, all of whom face a heightened risk of conservatorship.

- **Improve linguistic accessibility.** Develop resources in multiple languages that reflect California's diverse population, with a priority on Spanish and other languages widely used in the state.

- **Enhance cultural relevance.** Create resources that consider cultural differences in decision-making, and ensure that these include provisions for specifying cultural preferences and values related to religion, ethnicity, traditions, and communication styles.

- **Expand sector-specific guidance.** Develop specialized resources for implementing SDM in health care and employment settings for patients, providers, and staff, as these areas are central to many SDM agreements.

At higher risk for conservatorship: populations with dementia, neurological impairments, or serious mental illness, and transition-age youth.

- **Improve accessibility.** To accommodate various disabilities, ensure that resources are accessible through multiple formats, such as audio, visual (including alt text), and plain language (simplified syntax and grade school vocabulary). Resources should follow established accessibility standards, such as the international Web Content Accessibility Guidelines (WCAG).

- **Invest in SDM research.** Support community-based and participatory research to evaluate best practices and the effectiveness of SDM interventions, with a focus on involving individuals with lived experience of disability.

- **Develop professional resources.** Create materials for professionals in systems serving people with disabilities — such as health care, education, and employment — to reduce the burden of self-advocacy and promote shared responsibility for SDM implementation.

- **Launch social marketing initiatives.** Develop campaigns to improve the uptake of SDM resources and normalize autonomy-conserving decision-making processes.

CONCLUSION

While California has made legislative progress in recognizing SDM as a legal alternative to conservatorship, there are significant gaps in digital resources that can support application of SDM in the lives of Californians with disabilities. Addressing these gaps through focused resource development can help ensure that SDM fulfills its potential to preserve autonomy and improve quality of life for individuals with disabilities. By prioritizing accessibility, cultural relevance, and targeted resources for underrepresented populations and key sectors, California can promote a more comprehensive and effective SDM implementation.

Methodology

In 2024–25, UCLA researchers conducted a study evaluating 84 digital SDM resources identified from the California State Council on Developmental Disabilities website and from SDM legislation in other states. Resources were classified by audience, disability type, format, language, type, and sector. Six quality domains were graded using an "A, B, C" rating schema: accessibility, strengths-based approach, promoting autonomy, cultural relevance, language, and readability.

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