Introduction

In May and June 2019, the Commission on Law and Aging convened advocates, experts, and policymakers in disabilities and aging to discuss decision supports for individuals across the age spectrum and to explore areas of consensus about supporting decision-making for all adults. Participants in the two forums, held in Washington, DC, agreed on some points and disagreed passionately on others, but universally demonstrated a commitment to a set of core principles and to the importance of decision supports for individuals who historically have been denied the right to make their own choices.²

We adopted the term “decision supports” to encompass all means of support, from formal practices to informal interactions, and to distinguish the concept from supported decision making. Supported decision making or SDM is a decision-making model in which an individual makes decisions with the support of trusted individuals. SDM is gaining recognition as an
alternative to adult guardianship in state statutes, case law, and social services. It has primarily been available for people with intellectual/developmental disabilities, although advocates, social service providers, and stakeholders have begun exploring the application of SDM for people with psychiatric disabilities, traumatic brain injuries, and age-related cognitive decline.

Our use of the term “decision supports” as discussed in the two forums acknowledges that in addition to the SDM model there are supports that can be individualized based on a person’s desires and life circumstances, and that these supports often overlap or work in tandem. Forum participants described many potential decision supports, ranging in degree of formality including:

- Informal support systems such as personal relationships, community settings, religious communities, cultural groups and traditions, and a myriad of other supports systems.
- Direct personal supports from one or more friends, family members or other individuals, including, communication, analytic, or emotional assistance.
- Technology supports (such as a smartphone app or interactive software developed to support particular decisions).
- Environmental supports (such as ensuring decisions are made in less stressful places or without time pressure).
- Financial supports (such as direct deposit, joint accounts, or trusted person designations).
- Contractual supports (such as SDM agreements or creation of a power of attorney or trust).
- Court supervised supports (such as the use of guardianship or conservatorship with decision support principles, or a protective arrangement for a single decision or action).

All methods of decision-making supports are person-centered and person-directed – meaning the values, priorities, and wishes of the individual drive the decision-making process. Individuals may need different kinds of supports depending on their circumstances, preferences, abilities, resources, and life experiences. The individual’s cultural context is also critical in determining the kind of supports that will be meaningful.

Some participants expressed the view that using this approach, even in guardianship, which in plenary form can legally limit virtually all a person’s decision-making autonomy, incorporating the values and practices of decision supports is possible when guardians use decision support principles that honor the values and wishes of the protected person.

In the first of the two forums, we brought together professionals who are implementing and expanding decision supports on a case by case basis and statewide - including judges, private elder law and legal services attorneys, social service providers, representatives from adult protective service and state agencies on aging, and social service organizations. A month later, we convened a meeting of experts and thought leaders who brought a national perspective to the discussion, including policymakers, academics, representatives in disabilities and aging from national legal services, adult protective services, and other advocacy organizations.

3 The term “guardianship” is used in this report interchangeably with “conservatorship” and any other term for the judicial process of appointing a fiduciary to manage all or part of the financial and/or personal affairs of an individual.
We invited as diverse an array of participants as possible to encourage a broad range of perspectives on decision supports. Many participants shared that they pursued careers in advocating for people with disabilities and/or older adults because they believed everyone should have the rights and resources to make their own decisions. Whether fighting an eviction notice, assisting with mental health services, or representing individuals to contest or revoke guardianships, participants viewed preserving their clients’ autonomy to be fundamental to their work.

Participants also included some of the leading experts on SDM, including: facilitators of two of the country’s best-known pilot programs, leaders of a national resource center, policy advocates who were instrumental in passing SDM legislation in their home states, attorneys assisting individuals in completing supported decision-making agreements, and authors of supported decision-making resources.

**Decision-Making: A Human Rights Framework**

Discussions in both forums were predicated on the belief that decision-making is an essential function of being human, and a human right. Historically, the right of people with disabilities and older adults to make their own decisions has often been supplanted by a substitute decision-maker who makes decisions based on his or her own determination of the individual’s best interest rather than the individual’s own values and preferences. In the last several decades, civil rights activism and advancements in technology have driven a culture change in expectations of autonomy, including the right to make one’s own decisions for people with disabilities and older adults. The growing acceptance of SDM demonstrates a major advance in advocacy to promote the self-determination rights of all adults to direct their own lives, adding new insights to the long history of advocacy promoting self-directedness and autonomy among adults of various population segments.

The United Nations’ Convention on the Rights of People with Disabilities (CRPD), adopted in 2006, has played an instrumental role in affirming the rights of individuals with disabilities to exercise legal capacity with the necessary supports to do so. The CRPD provides that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life,” and that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

The CRPD Article 12’s principles have served as a more recent starting point for materials on decision supports around the world, including a core set of values contained in a policy development guideline for aged care, published in Australia, based on the principles in the

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5 United Nations Convention on the Rights of People with Disabilities (CRPD), Article 12. The CRPD has been ratified by 181 countries. It has not been ratified by the United States.
United Nations Convention on the Rights of Persons with Disabilities. Participants in both forums responded favorably to this core set of values. The Australian publication also included more detailed Key Actions under each principle for purposes of implementation. The timing and scope of this initiative did not allow for discussion on the Key Actions at the two forums.

The core values in the Australian guidelines are directly in alignment with Article 12 of the CRPD, and state:

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

The first principle, as noted above, was fundamental to the participants’ commitment to making decision supports available to the people they serve, as means for those individuals to make their own choices.

The second principle reflects the heart of what many of the participants do—asking what kinds of services and supports it will take for individuals to make their own decisions and implementing those supports. Participants broke into small groups to review case studies to prompt conversation about what kinds of supports are appropriate to specific situations. While all embraced the goal of support, views varied as to the means.

Participants also provided examples of how they respect the third principle, to ensure that the individual’s values and preferences drive decisions, and not the values and beliefs of the supporter or others. It was also recognized that some persons may be unable to make a choice or express any preference at all, in which case any surrogate decision-maker faces the additional challenge and duty of piecing together to the greatest extent possible the known values and preferences of the person.

The fourth principle prompted considerable discussion. While all participants agreed that safeguards are important, participants disagreed on the appropriate response to potential misuse and abuse. Some participants focused more prominently on the first principle - the right to make choices - even if those choices have unfortunate consequences. Others questioned how a decision

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made under circumstances implicating undue influence, abuse, or other potential harm by others could be a true choice.

An overall theme expressed at both forums was that these decision-support core values are relevant to the full range of adults across the age spectrum and across all models or tools for decisional support. Forum participants expressed interest in finding consensus on core values and applying these values to offering decision-supports to adults of all ages.

Areas of Consensus

Across all decision support approaches, participants expressed **consensus** on the following principles:

- While all adults seek support in making some kinds of decisions, they vary in the types of decisions and degree of support they want and need.
- Whenever a supporter is involved in exercising a decision support, the supporter must honor the person making the decision by, as appropriate, informing the person of the issue at hand, communicating in a way the person can understand, explaining risks and benefits of a decision, respecting the person’s choices and preferences, and assisting as needed and/or desired by that person in implementing the choice made.
- Decision supports reflect respect for autonomy and self-determination of adults.
- Even for someone totally incapable of decision-making, such as a person in a permanently unconscious state, decision support principles are still operative in that they imply an obligation on the part of the substitute decision-maker to learn of and honor the person’s values, goals, priorities, and wishes to the greatest extent feasible.

Participants at both forums repeatedly acknowledged that strong social supports and supporters’ familiarity with the person’s values and preferences were key to successfully implementing decision support strategies. Effective decision supports ultimately rest on trustworthy relationships. There is no autonomy without relationships. Participants expressed concern about the implications of social isolation and the limited availability of social and human service resources needed to make supports meaningful.

Legal and Legislative Advances in Promoting Decision Supports

Many participants have been involved in efforts to codify the use of decision supports in statute and establish precedents in court decisions, including nine states that, at the time of the forums, had adopted SDM agreement legislation.7

The *Uniform Guardianship, Conservatorship and Other Protective Arrangements Act* (UGCOPAA) and a growing number of state guardianship laws require courts to consider the

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viability of alternatives, including decision supports, before appointing a guardian. Some state statutes also direct the guardian to support the person whenever possible to make his or her own decisions.

Examples of decision support principles incorporated into the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act:

The person subject to a guardianship petition has the right:
- To an attorney who must advocate for the person’s wishes, and if the person’s wishes are not reasonably ascertainable, advocate for the result that is the least restrictive (§§305 and 406).
- To petition for termination of the guardianship (§§319 and 431).

The Court must:
- Not issue guardianship or conservatorship orders when a less-restrictive alternative is available, such as supported decision-making, technological assistance or an order authorizing a single transaction. (§§310 and 411).
- Must review annual reports to determine whether the guardianship or conservatorship should continue (§§317(e) and 423(e)).

A guardian or conservator must:
- Create an individualized plan that takes into account the person’s preferences, values, and prior directions to the extent known to or reasonably ascertainable (§§316 and 419).
- Make decisions the guardian reasonably believes the adult would make if able, unless doing so would cause harm to the adult.
- Promote the self-determination of the adult and, to the extent reasonably feasible, encourage the adult to participate in decisions, act on the adult’s own behalf, and develop or regain the capacity to manage the adult’s personal affairs. (§§313 and 418).

A few participants have represented individuals in court proceedings to modify or terminate guardianship, sometimes based on evidence of fully restored capacity, but increasingly based on the presence of sufficient supports and services. One participant encouraged advocates to seek written court decisions in favor of decision supports, where relevant, abrogating appointment of a guardian, instead of simply relying on a verbal ruling or summary order in favor of capacity. This can be helpful both at the initial petitioning stage and when restoration is sought.


9 E.g., see Matter of Capurso 63 Misc.3d 725 (Surr.Ct., Westchester County, N.Y., 2019); In re Guardianship of Sands, 301 P.3d 128 (Wyo., 2013); In re Guardianship of Dameris L., 956 N.Y.S.2d 848 (Sur. 2012); In re Penson, etc., 289 A.D.2d 155, 735 N.Y.S.2d 51 (N.Y.S. 2001).
Abuse, Neglect and Exploitation

Participants did not always agree on how best to address the risks of abuse, neglect, and financial exploitation in utilizing decision supports, reflecting the inherent tension related to trust in the conversation about decision supports between the dignity of choice and the potential for abuse, neglect, and exploitation.

While in theory the range of decision support mechanisms are neither a cause nor a solution to abuse, neglect, or financial exploitation, all agreed that any decision support, from a supported decision-making agreement to a power of attorney or joint bank account, or guardianship, poses a risk of abuse, neglect, and exploitation. Some participants expressed concern about the lack of accountability or reporting across decision support methods, from the most informal to the most formal. Other participants responded with a discussion about strategies for oversight and accountability to mitigate these risks. In some cases, participants suggested that decision supports themselves can deter abuse and neglect. For example, if decision supports encourage individuals to build relationships with more than one person, the supporters or community members may be more likely to notice and respond to abuse or neglect.

The discussion about the risks of decisions supports turned to a more specific examination of the risk of SDM agreements. Some participants felt that the concerns were misplaced, since they have not proven to be of higher risk than conventional forms of surrogate decision making or guardianship. Others expressed concerns that SDM agreements posed a new risk for undue influence. Intentionally or unintentionally, a supporter may guide the person making decisions towards decisions that are in the interests of the supporter rather than the person. One participant raised the need to discuss how to create and teach the ethical duties of a supporter. Some participants expressed the view that the supporter relationship to the decision-maker may be fundamentally different than that of a surrogate decision-maker. The latter’s power and opportunity to misuse their power is ostensibly greater than that of a supporter, so the risk to individuals may be greater in models relying on substitute decision-makers. However, participants recognized that all forms of decision supports and surrogate decision-making options ultimately depend on trusting relationships that always carry at least some risk of violation. As noted above, effective decision supports across the whole range of options ultimately depend on careful assessment of trustworthy relationships.

Decision Supports and Guardianship/Conservatorship

Participants also discussed the role of guardians in encouraging decision supports. At least one state statute (Alaska) allows individuals with guardians to complete supported decision-making

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agreements. Furthermore, the National Guardianship Association’s Standards of Practice direct guardians to involve individuals in decision-making whenever possible.\textsuperscript{11}

Participants discussed the need for decision supports to address “guardianship pipelines” where institutional frameworks favor seeking guardianship in response to certain situations even when less restrictive options are available. Advocates for individuals with intellectual and developmental disabilities described the “school to guardianship pipeline,” when educational staff advise parents to seek guardianship as soon as their child turns eighteen. Other participants expressed a similar concern about medical and social services institutions creating a similar pipeline to guardianship for older adults. For example, when a hospital has difficulty discharging a patient, hospital staff may seek a guardian to consent to discharge and admission to another facility. Or, service providers may not be aware of lesser restrictive options to support decision-making for elders who demonstrate some cognitive decline and may be quick to advise families to seek guardianship, even if a guardianship is not necessarily an optimal solution. Finally, if an older adult is the victim of abuse, neglect, or exploitation, social services agencies may recommend seeking guardianship even if less restrictive alternatives might suffice to mitigate the risk of re-victimization while restoring the elder’s self-determination.

Participants discussed the need for education and training of families, school systems, courts, health care and social services providers, and adult protective services professionals to divert individuals from these pipelines. However, it was noted that education itself is not enough, and that institutional rules, processes, and resources need improvement to promote less restrictive alternatives to guardianship.

Next Steps: Ongoing Need for Research

Participants in both forums recognized that much more research is needed to determine the effectiveness of various approaches to decision supports. A consensus research agenda would be a fruitful next step.

At the first forum, participants were asked to identify areas of needed research. All agreed that more data on the use of decision supports is essential, including the most basic data on the number and nature of guardianships/conservatorships in each state, as well as data on the use of SDM agreements, Powers of Attorney, and other decision supports and their outcomes. Participants described the challenges of developing and implementing best practices with minimal data on which to base policy, research, training and practice directions.

Other salient research questions included, among others:

- Understanding the community of isolated adults who do not have natural trusting relationships that could enable decision supports.
- Strategies for creating a robust and sustainable community of supporters, with effective measures of success, including strategies to reduce social isolation and mitigate risks of abuse or exploitation.

- Strategies and practices that could effectively infuse all decision supports with a self-determination philosophical framework. This could include more study of the standards of decision making imposed by state law on guardians.
- The costs of the differing types of decision supports.
- What training about decision supports would assist professionals in different disciplines: education professionals, lawyers, clinicians, social workers, long-term care staff, etc. in promoting decision supports and promoting the agency of the adults they serve.
- What are the benefits and risks of SDM agreements, which are a relatively new tool.
- Objective, evidence-driven comparative evaluations of decision-making support projects and pilots, including but not limited to those involving SDM.