

Supported Decision-Making for Older Adults with Age-Related Cognitive Decline

By Dari Pogach

A comparison of policy and procedure around supported decision-making for people with intellectual disabilities, and for people with age-related cognitive decline.

Ed, age 75, is sitting in his doctor's office, next to his wife Sally, when he learns he has dementia. The doctor shares the difficult news, turns to Sally, and begins discussing next steps. Ed sits quietly, realizing for the first time in his adult life that he is not in control, as his doctor and wife review the options for his medical care. This realization is as distressing as the dementia diagnosis.

A dementia diagnosis does not translate to an immediate or complete loss of decisional ability, but that often is the result. Even people closest to older adults with dementia often overlook their loved ones' ability to make decisions (Wright, forthcoming, 2020). Loved ones and institutional actors worry that a person with dementia will make "bad" decisions that could lead to self-neglect, abuse, and exploitation. In response, such stakeholders commonly curtail or remove the person with dementia's decision-making ability.

Surrogate decision-making may occur in intimate relationships: Sally might insist that Ed give up his car keys. Or individuals may choose legal options: Ed can appoint Sally or someone else as his agent via a power of attorney, authorizing a surrogate to make selected decisions

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now or in the future. In the most restrictive form of surrogate decision-making, a court can appoint a guardian to make some or all of a person's decisions.

Surrogate decision-making options may be the most expedient way to prevent or remedy harm, but also have the potential to cause harm. A surrogate decision-maker could take advan-

→**ABSTRACT** Supported decision-making is a new concept gaining recognition and acceptance as an alternative to guardianship, and is emblematic of the shift from surrogate decision-making to individuals making their own decisions with supports and services of their choosing. Until now, this concept has primarily taken hold in the disability rights community. This article considers the feasibility and merits of implementing supported decision-making for older adults with age-related cognitive decline, including dementia. | **key words:** *supported decision-making, older adults, age-related cognitive decline, dementia, disability rights movement, intellectual disabilities, autonomy*

tage of his or her authority to exploit the individual. Even if the surrogate decision-maker has the best of intentions, literature on decision making and independence for older adults shows a correlation between retaining control over daily life decisions and better mental and physical outcomes (Diller, 2016).

The disability rights movement, which is all too familiar with restrictions on autonomy, has challenged surrogate decision-making and guardianship, particularly for people with intellectual disabilities, as an inappropriate infringement on autonomy having negative consequences for emotional and physical well-being (Kohn, Blumenthal, and Campbell, 2013; Blanck and Martinis, 2015). Surrogate decision-making prevents individuals with disabilities from exercising self-determination, in which “people with intellectual and developmental disabilities, with appropriate resources and supports, can make decisions about their own lives and must be heard on issues that affect their well-being (The Arc, 2019; National Disability Rights Network, 2019).

Enter supported decision-making, a paradigm shift in the approach to decision making. According to a widely used definition, supported decision-making entails “supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts: to help understand the issues and choices; ask questions; receive explanations in language he or she understands; and communicate his or her own decisions to others” (Dinerstein, 2012; Blanck and Martinis, 2015).

Proponents of supported decision-making seek culture change: instead of assuming individuals with disabilities lack the capacity to make decisions, society should ask, what supports and services would enable individuals to make their own decisions?

Supported decision-making might serve as a model for other groups in addition to people with intellectual disabilities, including indi-

viduals with psychiatric disabilities, traumatic brain injuries, and dementia. Older adults and advocacy groups are only beginning to consider the application of supported decision-making for people with age-related cognitive decline, including dementia (Glen, 2018).

This article compares the application of supported decision-making for people with intellectual disabilities and people with age-related cognitive decline, including dementia (hereafter referred to as “people with dementia”). While cognizant of the imperfections of gen-

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eralizing, it addresses key concerns about supported decision-making for an aging population. Until now, such decision making has primarily been applied to younger people with intellectual disabilities.

There is little empirical research on the process, participation, and outcomes of supported decision-making arrangements (Kohn, Blumenthal, and Campbell, 2013; Diller, 2016). Therefore, this is a theoretical discussion based on anecdotal evidence and scholarly literature.

Supported Decision-Making for People with Dementia

Supported decision-making is not a one-size-fits-all solution; every arrangement must meet an individual’s unique needs. Stage of life plays a fundamental role in developing an effective arrangement. A person with an intellectual disability who anticipates a lifetime of decision making may seek to develop skills for their future in budget planning, employment, and romantic relationships. Someone with dementia may gladly delegate financial management, but wish to remain in control of end-of-life or health-care decisions.

Pilot programs, which primarily serve people with intellectual disabilities, explore different ways to implement supported decision-making strategies. In one highly regarded program, Supported Decision-Making New York (2019) (www.sdmny.org), a trained facilitator works with the decision maker and his or her chosen supporters, in three phases: first, the facilitator works with the decision maker on communication styles, relevant decisions, and to identify potential supporters; second, the facilitator educates supporters about supported decision-making and their role in supporting rather than making decisions for the decision maker; third, the facilitator works with the decision maker and supporters to negotiate an agreement that sets out the parties' obligations and responsibilities.

In another well-known pilot program in Massachusetts, led by the Center for Public Representation (CPR), a legal advocacy organization, and the social services provider Nonotuck Research Associates (CPR and Nonotuck Research Associates, 2019), participants entered a Representation Agreement that specified areas of assistance, designated supporters, and showed how supported decision-making would work for them. To support their choices, participants executed surrogate decision-making documents, such as a healthcare proxy or a power of attorney.

In addition to pilot programs, advocates, professionals, and loved ones are exploring informal modes of supported decision-making, such as sharing expert knowledge, interpreting (translating unfamiliar or complex language), prompting (identifying an opportunity for decision making), encouraging, actively listening and providing emotional support, questioning and raising issues, and providing reassurance about a decision and helping to see it through (Sinclair et al., 2018).

The Importance of Supporters

Trustworthy, consistent supporters are crucial to supported decision-making. People with intellectual disabilities may have more choices from

a pool of natural supporters than do older adults. Younger people with intellectual disabilities already may be engaged with family, service providers, school systems, and community-based resources, while older adults are at greater risk of isolation due to a loss of family members, friends, and other community resources.

Furthermore, the transition from friend or family member to supporter may seem more natural to a person with an intellectual disability. For instance, transitioning from primary decision-maker to supporter is a common experience for many parents as their children enter adulthood. While they may not readily admit to doing so, many young adults continue to consult their parents for advice even after reaching the legal age of independence.

When an individual with dementia seeks decision-making support, the transition from a romantic partner to a supporter may be more painful and uncomfortable for everyone involved. Australia's Cognitive Decline Partnership Centre provides a few documented cases of people with dementia practicing supported decision-making. Most of the supporters were spouses of people with dementia. While it may seem obvious that long-term romantic partners would make trustworthy supporters who are already familiar with the decision makers' values and preferences, there also are unique concerns (Cognitive Decline Partnership Centre, 2018a).

Proponents of supported decision-making, accustomed to its application to people with intellectual disabilities, might question some practices these couples described as supported decision-making. One wife who was acting as a supporter described interacting with her husband as a "negotiation," when he suggested doing something dangerous. Acknowledging that he had always been strong-willed, instead of saying "no," she offered him an alternative, saying, "Instead of climbing that tall pole, let's go to a concert."

Supporters described the benefits of supported decision-making, but also spoke of a personal toll. One husband described the burden

of transitioning from being in a relationship of two independent people, to functioning as “one” (Cognitive Decline Partnership Centre, 2018b).

Will There Be a Shift for People with Dementia?

Political and legal recognition of a right to decision making for people with disabilities is relatively new. In 2006, the United Nations adopted the Convention on Rights of People with Disabilities (CRPD) (United Nations, 2006), a landmark measure asserting the “right of persons with disabilities to enjoy legal capacity with others in all aspects of life.” The CRPD is the result of decades of activism working to transform perceptions of people with disabilities as objects of pity in need of charity, medical treatment, and social protection, to active members of society who exercise their rights to make their own decisions based on free and informed consent.

Nations that have adopted the CRPD are grappling with whether guardianship can exist in conjunction with the CRPD’s assertion that every individual has the right to legal capacity (Glen, 2018). While the United States has not ratified the CRPD, its principles have undeniably influenced the discourse on disability rights and guardianship reform (The Arc, 2016).

Despite the CRPD’s influence, supported decision-making proponents may never see this fundamental shift without demonstrating the relevance of supported decision-making for people with dementia, who constitute a significant percentage, if not a majority of people with guardians (Diller, 2016).

Some of the values and priorities upon which the CRPD and supported decision-making are based have not held as central a role for people with dementia. The prioritization of autonomy is fundamental to any shift. Advocacy groups supporting older adults with cognitive decline have focused on urgently needed research, treatment, and caregiving (Diller, 2016). The platform for the rights of people with intellectual disabilities prioritizes self-advocacy and self-determination.

The successes of a supported decision-making pilot program—participants experiencing increases in pride and self-confidence, willingness to try new experiences, taking greater control of their health and mental health care, and helping others more—may not be the goals of people with dementia (CPR and Nonotuck Research Associates, 2019).

Advocates also have different perspectives on potential risks that accompany assertions of autonomy. Supported decision-making proponents invoke the expression “dignity of risk,” to point out the inequity of denying choice to people with disabilities when others are free to make and learn from “bad” decisions. In con-

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trast, advocates for older people seek to protect personal safety and quality of life. An elder justice expert describes cringing when she hears the expression “dignity of risk” because decades earlier, some assisted-living providers used the same expression to justify inadequate care.

In addition, advocates and scholars concerned for people with dementia are wary of supporters or third parties using supported decision-making as a vehicle to exploit decision makers. There are no empirical data, but there is strong anecdotal evidence suggesting exploitation and abuse do occur in a significant number of guardianship cases. As variable as it may be, guardianship cases guarantee at least minimal court oversight and accounting. There is no similar safeguard for supported decision-making arrangements.

Given that many perpetrators of elder abuse are family members, and family members often will be a natural source of support, there is a concern that supported decision-making could provide an easy means for abuse (Acierno et al., 2009). Furthermore, it may be difficult to distin-

guish undue influence from support: a supporter may unintentionally influence a decision maker to achieve a desired outcome (Kohn, Blumenthal, and Campbell, 2013).

Advocates for supported decision-making acknowledge the risk of abuse (Kohn, Blumenthal and Campbell, 2013). However, the benefits of supported decision-making may outweigh the risks. Supported decision-making can combat isolation, a major cause of abuse for people with disabilities and for older adults. By building relationships with supporters, the decision maker expands the network of people to identify abusers. Consistent with this argument, an independent evaluation of the Center for Public Representation's supported decision-making pilot program found participants did not experience abuse, neglect, or financial exploitation (Center for Public Representation [CPR] and Nonotuck Research Associates, 2019). The risk of abuse was further reduced because the participants chose their supporters and, in what has proven to be a critical safeguard, had more than one supporter.

Eventually, elder abuse prevention studies may examine the role of supporters in a supported decision-making network as a preventive factor of elder abuse. Acierno and colleagues' seminal study (2009) found that "social support has emerged as a central risk or protective factor for virtually all forms of elder mistreatment." The study defines social support as emotional (someone available to love you and make you feel wanted), instrumental (someone available to help you if you were confined to bed), and appraisal (someone available to give you good advice in a crisis). The study's recommendations included offering social support resources, which would align with supported decision-making principles and practices: "Programs that enhance and build relationships between older adults and members of their community, that is programs that act against the age-related forces of isolation . . . have the potential to yield extremely high benefits" (Acierno et al., 2009).

Ideally, a supported decision-making network should support the values of elder abuse scholars and address concerns of dementia advocates. Empirical research has shown older adults experience positive outcomes when they ask for help, which leads to building relationships and community involvement (Diller, 2016). "Social supports" are as fundamental to supported decision-making as the practice of autonomy. The paradigm shift from surrogate to supporter does not mean the decision maker is functioning alone, but rather recognizes the individual as the primary decision-maker whose role is enhanced by support, guidance, and assistance, so long as it is of the individual's choosing (Dinerstein, 2012).

Domains of Change for Supported Decision-Making

Judicial Reform: Most documented court cases restoring the rights of a person with a guardian in favor of supported decision-making have restored the rights of a person with an intellectual disability. These cases typically are brought by advocates and publicized as impacting court practice and raising public awareness (see Jenny Hatch Justice Project; *In the Matter of the Guardianship of Dameris, L.*, 2012; Emery, 2018).

There are documented cases of restoring the rights of older individuals (Wood, Teaster, and Cassidy, 2017), including at least one that was featured in *The Washington Post* (Quality Trust for Individuals with Disabilities, 2018). It appears that older adults with dementia are not likely to seek guardianship termination. Possible reasons include the litigious and time-consuming nature of court cases, and the fact that although disability legal advocacy organizations may be interested in test cases, they may not have the resources or mission to represent people with dementia.

Legislation: Since 2015, at least eight states—Texas, Delaware, Wisconsin, Alaska, Indiana, North Dakota, Nevada, and Rhode Island, and Washington, D.C., have passed legislation recog-

nizing supported decision-making agreements. Moreover, the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (American Bar Association, 2018) emphasizes supports and supported decision-making throughout its provisions, and provides that a court may not appoint a guardian without examining the availability of “appropriate supportive services, technological assistance, or supported decision making,” per Sec. 301(a)(1)(A) of the Act.

Current supported decision-making laws apply to all guardianships, whether for a younger person with an intellectual disability or for an older person with dementia. It is too early to determine whether they will be applied more frequently to a specific population.

Educational and Institutional Entities:

Disability rights advocates have identified a “school to guardianship pipeline” when school staff or other service providers advise parents that if they do not seek guardianship when their child turns age 18, they will not be able to participate in their child’s education or provision of services. Disability rights advocates have developed educational materials and trainings for parents about supported decision-making and advocated for school systems to require the provision of such information. Some school systems and state disability services providers are creating supported decision-making policies and laws to facilitate a student’s transition at age 18 to legal adult status.


In contrast, institutional providers for people with dementia may find providing information about, much less encouraging, alternatives to guardianship to run counter to the institution’s interests. A hospital may seek appointment of a guardian to facilitate a person’s discharge; a nursing home may want a guardian to obtain payment; a state agency may find a guardian is the most expedient way to address a dangerous situation. While there arguably is a role for supported decision-making in these instances, there is no obvious route to creating a supported decision-making network (Diller, 2016).

Federal Policy: The U.S. Department of Health and Human Services’ Administration for Community Living (ACL) has funded interdisciplinary roundtables for advocates and scholars to examine supported decision-making. In 2014, the ACL provided a five-year grant to create the National Resource Center for Supported Decision-Making (NRC-SDM). The NRC-SDM has provided many services related to supported decision-making, including, “developing a strategy that measures and demonstrates the impact of supported decision-making on the lives of people with intellectual and developmental disabilities and older Americans” (ACL, 2014).

Guardianship Professional Standards:

The National Guardianship Association has incorporated supported decision-making principles into its standards. For example, “the guardian shall encourage the person to participate, to the maximum extent of the person’s abilities, in all decisions that affect him or her, to act on his or her own behalf in all matters in which the person is able to do so, and to develop or regain his or her own capacity to the maximum extent possible” (National Guardianship Association, 2013).

Conclusion

Recognition and acceptance of supported decision-making is likely to grow among advocacy communities, state agencies, courts and legislatures, and the public. As it does, it is important for proponents, practitioners, and scholars to examine the possible role of supported decision-making for old adults with age-related cognitive decline, including dementia. New considerations will improve practice, lead to better outcomes, and foster a true paradigm shift for all people with disabilities. 

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