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DECISION-MAKING SUPPORTS AND COGNITIVE DECLINE

By Rebekah Diller†

ABSTRACT

For persons with a range of cognitive disabilities, supported decision-making, rooted in a human rights approach to disability, has emerged as a tool that permits them to make legally binding decisions and avoid guardianship. As supported decision-making policy has evolved in the United States, state statutes have primarily focused on formal agreements through which individuals can designate trusted supporters to assist in obtaining information, processing that information, and communicating a decision. This Article argues that supported decision-making has promise for preserving the autonomy of persons living with dementia, but that the model of a supported decision-making agreement embodied in the state statutes does not fully address the circumstances of those experiencing cognitive decline. The different context requires a different and broader range of supports for decision-making. The Article proposes supplemental policy interventions to be more responsive to the needs of people experiencing cognitive decline. These include developing a values-based planning process that combines supported decision-making with advance directives, promoting enhanced guardianship diversion services, and more explicitly requiring decision-making accommodations by institutions that serve persons with dementia.

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† Clinical Professor of Law, Benjamin N. Cardozo School of Law. This article draws upon work the author did as a consultant to Project Guardianship Inc. in its planning of a pilot project to conduct supported decision-making with older adults. The author wishes to thank the Borchard Foundation for its support of this research. The author also wishes to thank Kristin Booth Glen, Tehya Boswell and Lesley Salzman for helpful comments on earlier drafts and gerontological psychologists Kyle Page and Patty Bamonti for generously sharing their practical wisdom. The author also wishes to thank the editors at Health Matrix.

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INTRODUCTION

When individuals are diagnosed with dementia, it is presumed that eventually they will cease to make decisions on their own behalf. Standard advice to the newly diagnosed includes executing powers of attorney and health care advance directives so that a surrogate will be able to make legally binding health care, financial, and legal decisions in the future.[1] These planning documents are meant to ensure that individuals retain some control over what happens to them when they are no longer able to communicate decisions.[2] These planning documents also help ensure that persons will not become subject to adult guardianship or conservatorship should there come a time when they are assessed to lack the capacity to make legally binding decisions.[3]

A newer recognized alternative to guardianship—supported decision-making ("SDM")—also has the potential to play a role in preserving decision-making rights for persons experiencing cognitive

1. *See, e.g.*, ALZHEIMER'S ASS'N, 770-10-0025, LEGAL PLANS: CONSIDERATIONS FOR HELPING A PERSON LIVING WITH DEMENTIA PLAN FOR THE FUTURE 4–5 (2019).

2. *Legal Planning*, ALZHEIMER'S ASS'N, https://www.alz.org/help-support/i-have-alz/plan-for-your-future/legal_planning [https://perma.cc/T3Gn-MZVD].

3. *Id.*; *see* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 102(13) (UNIF. L. COMM'N 2017) [hereinafter UNIF. GUARDIANSHIP ACT] (describing advance planning documents as less restrictive alternatives to guardianship). While some states use the term conservatorship to describe guardianship over a person's finances, this Article will refer to both guardianship over finances and guardianship over personal and health care decisions as "guardianship." *Legal Planning*, *supra* note 2.

decline.[4] By engaging in SDM, individuals retain the legal right to make decisions about their life and avoid the declaration of incapacity and loss of rights that result from guardianship.[5] Instead of having their decision-making power taken away and assigned to another individual or agency, individuals engaged in SDM receive the support they need to make and communicate their own decisions. SDM is, in some ways, an extension of what we all do when we turn to others for information, advice, guidance, and feedback about decisions, large and small.

As SDM policy has evolved in the U.S., legislative reform has focused on mechanisms by which one designates trusted supporters in a supported decision-making agreement ("SDMA") to assist in obtaining information, processing that information, and communicating a decision.[6] This is the approach taken by most of the supported decision-making statutes that have passed in the states.[7] These agreements, in turn, have primarily been used by persons with intellectual or developmental disabilities ("I/DD"), as opposed to older persons experiencing dementia or cognitive decline.[8] This trend is consistent with the SDM pilots that have operated domestically and around the world, which have also focused on the I/DD community, some of whom may be older but many of whom are younger adults whose families might otherwise seek guardianship over them when they reach adulthood.[9]

Much less has been done to explore how to implement decision-making supports specifically in the aging context, though older adults comprise a significant portion of the population under guardianship and dementia is one of the most frequently cited reasons for commencing a

4. *See, e.g.*, A.B.A. COMM'N ON L. & AGING, SUPPORTING DECISION MAKING ACROSS THE AGE SPECTRUM 1–3, 5 (2020).

5. *See* Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 UNIV. COLO. L. REV. 157, 169–70, 175, 179–82, 231–32 (2010).

6. Kristin Booth Glen, *Not Just Guardianship: Uncovering the Invisible Taxonomy of Laws, Regulations and Decisions That Limit or Deny the Right of Legal Capacity for Persons with Intellectual and Developmental Disabilities*, 13 ALBANY GOV'T L. REV. 25, 33–34 (2020) ("This use of 'supporters' is the primary form of SDM that has been piloted and employed around the world and that has been legally recognized by several states in the U.S.").

7. *See, e.g.*, N.Y. MENTAL HYG. Law §§ 82.01–.15 (Consol. 2023) (establishing process for recognition of supported decision-making agreements entered into after facilitation process).

8. NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION 133 (2018).

9. Cathy E. Costanzo et al., *Supporting Decision-Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 99, 112–14 (2022).

guardianship.[10] In light of this, the Fourth National Guardianship Summit in 2022—a convening of judges, guardians, attorneys, advocates, and academics—recommended the development and funding of SDM pilot projects specifically targeted at older adults at risk of guardianship.[11] This recommendation is in line with the recognition by many aging rights entities that SDM has the potential to preserve autonomy for older adults.[12]

This Article endorses the goal of developing models for SDM for persons with dementia. It cautions, however, that simply transporting the SDMA model into the cognitive decline context will not be sufficient. SDMAs are useful tools that may play a role in preserving the autonomy of persons with cognitive decline. However, the needs of persons with dementia and the context in which their decision-making rights are compromised differ significantly from the mostly younger individuals with I/DD who have successfully used SDMAs as a means of avoiding guardianship and asserting their rights to self-determination.[13] The unique trajectory of cognitive decline warrants a broader set of supports and accommodations and suggests a values-based planning process that bridges SDMAs and advance directives.

Retention of decision-making power is not just an abstract right. Being stripped of decision-making erodes one's sense of personhood, identity, agency, and dignity. Preserving autonomy and dignity, in turn, has been associated with better health and quality of life outcomes.[14] Persons with dementia interviewed about their involvement

10. Jean Callahan et al., *Guardianship Proceedings in New York State: Findings and Recommendations*, 37 BIFOCAL 83, 84, 86 (2016) (stating that dementia was cited in 41 percent of guardianship filings).

11. Recommendations Adopted by Summit Delegates, *Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability May 2021*, 72 SYRACUSE L. REV. 29, 29 (2022).

12. The concept of using supported decision-making in the aging context has been endorsed by entities such as the American Bar Association Commission on Law and Aging, the AARP, the U.S. Senate Special Committee on Aging, and the U.S. Department of Health and Human Services' Administration for Community Living. Morgan K. Whitlatch & Rebekah Diller, *Supported Decision-Making: Potential and Challenges for Older Persons*, 72 SYRACUSE L. REV. 165, 173, 178 (2022).

13. *See* Costanzo et al., *supra* note 9 at 138–39.

14. *See* Melanie H. Mallers et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin's Work on Gerontological Theory, Policy, and Practice*, 54 GERONTOLOGIST 67, 71–72 (2014); *see also* Heather L. Menne et al., *Decision-Making Involvement Scale for Individuals with Dementia and Family Caregivers*, 23 AM. J. ALZHEIMER'S DISEASE & OTHER DEMENTIAS 23, 23–24 (2008); Rebecca Davis et al., *Everyday Decision Making in Individuals with Early-Stage Alzheimer's Disease: An Integrative Review of the Literature*, 10 RSCH. GERONTOLOGICAL NURSING 240, 242–43 (2017). *See generally* Brian P. O'Connor & Robert J. Vallerand, *The Relative Effects of Actual and*

in decision-making have expressed how essential it is to preserving self-esteem and identity.[15] As Deirdre Fetherstonhaugh and colleagues summed up in the title of one article, "Being central to decision making means I am still here!" [16] When asked in surveys and interviews about decision-making, most older adults say they want to remain involved as long as possible and have the supports they need to do so.[17]

In contrast, when excluded from decision-making, individuals describe "feel[ing] insignificant, as though their identity as a person was under threat, and that they were nothing more than a 'piece of wood' . . . who should 'just go home and disappear.'"[18] Or, as self-advocate Theresa Flavin wrote, "[t]aking away a person's choices, however well-intentioned and for whatever reason, silences you. It robs you of your identity and sense of self . . . . For me, it makes me feel like I'm the 'walking dead'; physically here using resources, but irrelevant."[19]

This paper analyzes the laws that have promoted SDM in the United States and assesses the degree to which they are responsive to the needs of persons with cognitive decline. Whereas prior articles have argued for the use of[20]—or questioned the evidence base for[21]—SDM

Experienced Autonomy on Motivation in Nursing Home Residents, 13 CAN. J. ON AGING 528 (1994).

15. Craig Sinclair et al., "*A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making*, 16 BIOETHICAL INQUIRY 587, 594 (2019).

16. Deirdre Fetherstonhaugh et al., *Being Central to Decision Making Means I Am Still Here!: The Essence of Decision Making for People with Dementia,* 27 J. AGING STUD. 143, 143 (2013).

17. Sinclair et al., *supra* note 15, at 594 (discussing that persons with dementia and family members interviewed in a study wanted the person with dementia to remain involved in decision-making as long as they could); s*ee* James Toomey, *Understanding the Perspectives of Seniors on Dementia and Decision-Making*, 12 AJOB EMPIRICAL BIOETHICS 101, 108–09 (2021); *see also* Karen B. Hirschman et al., *Do Alzheimer's Disease Patients Want to Participate in a Treatment Decision and Would Their Caregivers Let Them?*, 45 GERONTOLOGIST 381, 386 (2005) ("[M]ost patients with mild-to-moderate Alzheimer's disease want to participate in the process of making a decision about treating their dementia . . . .").

18. Fetherstonhaugh et al., *supra* note 16, at 148.

19. Theresa Flavin, *Supported Decision Making for People Living with Dementia*, 19 DEMENTIA 95, 96 (2019).

20. *See, e.g.*, Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decision Making*, 79 MD. L. REV. 257 (2020); Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L. J. 495, 499 (2016).

21. *See, e.g.*, Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1112

among older people experiencing cognitive decline, this paper assesses the policy agenda that has promoted SDM in the United States and intervenes to suggest several other strategies that can augment the utility of SDMAs and complement them when their use is not practicable.

This Article proceeds as follows. Part I discusses the ways in which dementia impacts cognition and the psychological and other literature concerning supports that can enhance decision-making ability. Part II surveys the legal landscape that has governed dementia and decision-making, examining the traditional, binary approach to capacity that has historically undergirded the law of advanced directives and guardianship, and contrasts those with an emerging disability rights framework that centers the experience and rights of persons with dementia. Part III assesses the ways that SDMA legislation may not fully address the needs of people with dementia and recommends policies to broaden the range of decision-making supports.

I. DEMENTIA, DECISION-MAKING, AND SUPPORTS

This Part briefly describes the impact of dementia on decision-making abilities and summarizes research on how persons with dementia remain involved in decision-making as well as the supports that can facilitate and prolong their involvement.

A. Cognitive Decline's Prevalence and Impact on Decision-Making

As the population ages, broadly speaking, there will be more people living with cognitive impairments.[22] Studies have shown that between 17 percent and 22 percent of people 65 or older have "mild cognitive impairment," a diagnosis applied when someone experiences "problems with memory, language and thinking" that are more significant than changes expected with healthy aging but do not limit everyday life.[23] It is estimated that about half of individuals experiencing mild cognitive impairment will develop dementia due to Alzheimer's disease; others will stay at the same mild level of impairment or even regain cognitive function.[24]

(2013); Nina A. Kohn, *Legislating Supported Decision-Making*, 58 HARV. J. ON LEGIS. 313, 313 (2021).

22. *See* Daniel L. Murman, *The Impact of Age on Cognition*, 36 SEMINARS HEARING 111, 112 (2015).

23. *2024 Alzheimer's Disease Facts and Figures, Special Report, Mapping a Better Future for Dementia Care Navigation*, ALZHEIMER'S ASS'N 1, 11, 24 (2024), https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf [https://perma.cc/ZS3J-KCRA].

24. *Id.*

Medical professionals diagnose dementia as a disorder when one or more cognitive domains—complex attention, executive functioning, learning and memory, language, perceptual-motor/visuospatial function, and social cognition—decline in a way that interferes with activities of daily living.[25] Other symptoms may mimic dementia but are reversible, such as confusion or withdrawal caused by depression, medication side effects, delirium (often from urinary tract infections), and other causes.[26]

Alzheimer's Disease, which is associated with specific biomarkers in the brain, is the leading cause of dementia.[27] About 6.9 million older adults, or 10.8 percent of all of those age 65 or older, currently are living with Alzheimer's dementia, with the prevalence increasing with age.[28] Other forms of dementia include vascular dementia caused by strokes and loss of oxygen to the brain, frontotemporal dementia, dementia with Lewy bodies, Parkinson's disease, or mixed dementia stemming from more than one cause.[29] Each form of dementia presents differently and has a different expected course.[30] Dementia is often classified along a spectrum from mild to moderate to severe, depending on how significantly symptoms impair an individual's functioning.[31]

For persons who develop dementia, decision-making ability is affected in multiple ways, and the impact varies depending on the type of dementia and stage. Dementia can diminish the ability to understand and appreciate information as well as to focus on the decision-making process.[32] The ability to understand and use words and language diminishes with dementia, and processing thoughts and expressing them

25. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC & STATISTICAL MANUAL OF MENTAL DISORDERS, at 667–72 (5th ed. Text Revision 2022) ("Dementia is subsumed under the newly named entity *major neurocognitive disorder*, although the term *dementia* is not precluded from use in the etiological subtypes in which that term is standard. Furthermore, DSM-5 recognizes a less severe level of cognitive impairment, *mild neurocognitive disorder*, which can also be a focus of care.").

26. ALZHEIMER'S ASS'N, 2023 ALZHEIMER'S DISEASE FACTS AND FIGURES 12 (2023), https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf [https://perma.cc/9YVZ-3XGR].

27. ALZHEIMER'S ASS'N, *supra* note 23, at 7.

28. *Id.*

29. *Id.* at 6.

30. *See* STEVEN R. SABAT, ALZHEIMER'S DISEASE: WHAT EVERYONE NEEDS TO KNOW 19 (2017).

31. *2024 Alzheimer's Disease Facts and Figures*, *supra* note 23, at 24.

32. *See* Jonathan Rubright et al., *A Memory and Organizational Aid Improves Alzheimer Disease Research Consent Capacity: Results of a Randomized, Controlled Trial,* 18 AM. J. GERIATRIC PSYCHIATRY 1124, 1125 (2010).

becomes challenging.[33] Engaging in hypothetical thinking becomes more difficult.[34] Impaired short-term memory can also be an obstacle in making decisions because of diminished ability to recall information or retrieve words.[35] However, "recognition memory" is better preserved than recall—meaning that if presented with information previously conveyed, the person may recognize it if given cues.[36]

In addition to challenges in making and communicating decisions, persons with dementia may face challenges in executing decisions due to impaired executive function that inhibits the ability to focus, plan, and carry out complex tasks.[37] As a result, instrumental activities of daily living necessary for independent living, such as remembering to take medications, arranging health care, and navigating transportation become more difficult.[38] The ability to manage finances—a complex task that requires not just making financial decisions at particular moments but also executing those decisions by engaging in purchases, paying bills, dealing with cash and credit cards, keeping track of bank accounts and their deposits and withdrawals, and other daily activities—may also deteriorate.[39] "Financial judgment," which pertains to the ability to recognize scams, may also be impaired.[40] In fact, an increasing body of evidence points to financial troubles as an early warning sign of dementia, occurring even before a diagnosis is made.[41]

33. SABAT, *supra* note 30, at 40.

34. *Id.* at 42.

35. *Id.* at 26.

36. *See id.*

37. *Id.* at 42.

38. *See* Jason Karlawish, *Measuring Decision-Making Capacity in Cognitively Impaired Individuals*, 16 NEUROSIGNALS 91, 91 (2008).

39. Peter Lichtenberg, *Assessment of Financial Exploitation*, *in* CAPACITIES OF OLDER ADULTS: A CASEBOOK TO GUIDE DIFFICULT DECISIONS 123, 124 (Jennifer Moye ed., 2020) [hereinafter APA Casebook]; Eric Widera et al., *Finances in the Older Patient with Cognitive Impairment*, 305 J. AM. MED. ASSOC. 698, 698–700 (2011); Daniel Marson, *Conceptual Models and Guidelines for Clinical Assessment of Financial Capacity*, 31 ARCHIVES CLINICAL NEUROPSYCHOLOGY 541, 542–43 (2016) (identifying the types of activities people must achieve to manage their finances independently).

40. *See* Marson, *supra* note 39, at 543, 552.

41. *See, e.g.*, CAROLE ROAN GRESENZ ET AL., FED. RSRV. BANK OF N.Y., THE FINANCIAL CONSEQUENCES OF UNDIAGNOSED MEMORY DISORDERS, 22, 23, 24 (2024), https://www.newyorkfed.org/medialibrary/media/research/staff_reports/sr1106.pdf?sc_lang=en [https://perma.cc/L6XE-B9W2].

Notwithstanding these challenges, "it is clear that people with dementia can and do make decisions[.]"[42] Moreover, a person's level of decision-making involvement is not determined exclusively by their level of cognitive impairment as measured by standard tests.[43] The level of decision-making involvement is significantly affected by other factors, such as "being informed, being listened to, ability to express opinion, time for reflection and reversibility of choice," the level of risk, the type of relationship with the carer, and the ability of the carer to employ support strategies. [44]

Impaired cognition also does not preclude individuals with dementia from being able to express values and preferences.[45] Though most studies about decision-making involve participants with mild to moderate dementia, there is evidence that "[e]ven with significant cognitive decline, persons with dementia can still be 'valuers' i.e. they can, on the basis of what they unreflectively identify with, still evaluate, interpret, and derive meaning in their lives."[46] The ability to value is independent of cognition and usually remains in the brain long after

42. Deirdre Fetherstonhaugh et al., *"The Red Dress or the Blue?" How Do Staff Perceive That They Support Decision Making for People with Dementia Living in Residential Aged Care Facilities?*, 35 J. APPLIED GERONTOLOGY 209, 210 (2016); *see also* Sinclair et al., *supra* note 15, at 587–88 (identifying that persons with dementia and their family members want the person with dementia to remain involved in decision-making as long as possible); Karen B. Hirschman et al., *Do Alzheimer's Disease Patients Want to Participate in a Treatment Decision, and Would Their Caregivers Let Them?*, 45 GERONTOLOGIST 381, 386 (2005) ("[M]ost patients with mild-to-moderate Alzheimer's disease want to participate in the process of making a decision about treating their dementia[.]"); Lynn Friss Feinberg & Carol J. Whitlatch, *Are Persons With Cognitive Impairment Able to State Consistent Choices?*, 41 GERONTOLOGIST 374, 380, 381 (2001) (demonstrating that persons living with dementia "possess sufficient capacity to state specific preferences and make care-related decisions" about daily living).

43. For example, Feinberg and Whitlatch found that scores on the Mini-Mental State Examination ("MMSE"), a tool frequently used to assess level of cognitive impairment, were not reliable measurements of the "capacity to state preferences and make daily care decisions." Feinberg & Whitlatch, *supra* note 42, at 380.

44. Jem Bhatt et al., *The Nature of Decision-Making in People Living With Dementia: A Systematic Review*, 24 AGING & MENTAL HEALTH 363, 369, 370, 371 (2020).

45. *See* Michele J. Karel et al., *Reasoning in the Capacity to Make Medical Decisions: The Consideration of Values*, 21 J. CLINICAL ETHICS 58 (2010); Michele J. Karel et al., *Three Methods of Assessing Values for Advance Care Planning: Comparing Persons With and Without Dementia*, 19 J. AGING HEALTH 123, 129 (2007).

46. Kari Lislerud Smebye et al., *How do Persons With Dementia Participate in Decision Making Related to Health and Daily Care? A Multi-Case Study*, 12 BMC HEALTH SERVS. RSCH. 1, 2 (2012).

the ability to remember and to reason may have been damaged by Alzheimer's.[47]

B. Supports for Decision-Making

The degree to which persons with dementia are able to participate in decision-making depends in part on the attitude of and accommodations made by persons and systems with which they interact. While much of the psychological literature on dementia and decision-making focuses on assessing capacity and/or comparing and refining the various instruments for doing so,[48] newer guidance notably reconceptualizes capacity as more fluid and embraces the idea that there are strategies to enhance capacity.[49]

Supports for decision-making identified in the cognitive psychology, gerontology, and related literature[50] include the following:

Providing extra time. A person with dementia may need extra time to think and gather their thoughts as well as frequent breaks.[51]

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47. *Id.*

48. *See, e.g.*, Ana Amaral et al., *Decision-Making Capacity in Healthcare: Instruments Review and Reflections About its Assessment in the Elderly with Cognitive Impairment and Dementia*, 93 PSYCHIATRIC Q. 35 (2022); Jennifer Moye et al., *Capacity to Consent to Treatment: Empirical Comparison of Three Instruments in Older Adults with and Without Dementia*, 44 GERONTOLOGIST 166, 168 (2004); Jason Karlawish, *Measuring Decision-Making Capacity in Cognitively Impaired Individuals*, 16 NEUROSIGNALS 91, 91 (2008).

49. *See, e.g.*, Jennifer Moye et al.*, Neuropsychological Predictors of Decision-Making Capacity over 9 Months in Mild-to-Moderate Dementia*, 21 J. GEN. INTERNAL MED. 78, 81 (2006) (listing strategies in Table 5). This approach is also evident in the recent publication from the influential collaboration of the American Bar Association and the American Psychological Association. *See, e.g.*, AMERICAN PSYCHOLOGICAL ASSOCIATION, ASSESSING CAPACITIES OF OLDER ADULTS: A CASEBOOK TO GUIDE DIFFICULT DECISIONS 33 (Jennifer Moye ed., 2020).

50. In order to consider what supports individuals may need for decision-making, it is useful to identify the various steps of making a decision, which the organization Supported Decision Making New York has usefully summarized as follows: gathering information, understanding the information, considering alternatives and other options, considering the consequences of making any particular decision or not making the decision, weighing alternatives and deciding, communicating the decision to others, and implementing the decision. *See* Cathy E. Costanzo et al., *Supported Decision Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 99, 101 (2022).

51. *See* CRAIG SINCLAIR ET AL., COGNITIVE DECLINE PARTNERSHIP CENTRE (CDPC), SUPPORTED DECISION-MAKING IN DEMENTIA CARE: FINAL PROJECT REPORT, 14 (2019), https://cdpc.sydney.edu.au/wp-content/uploads/2019/07/CDPC_Supported_Decision-Making_Final_Project_Report.pdf [https://perma.cc/HVW4-TXG4]; Smebye et al., *supra* note 46, at 7; Fetherstonhaugh et al., *supra* note 42, at 217, 221; Jeanne Tyrrell et al., *Freedom of Choice and*

Following a clear structure. Breaking decisions down into stages and dealing with one topic at a time are important to avoid overwhelming the decision-maker. [52]

Minimizing distractions. Choosing a quiet, uncluttered environment, free of distractions, can enhance the ability to focus on the decision at hand.[53]

Using "cognitive prosthetics" or decision aids. Recognition memory—the ability to recall information when presented with a cue—may be better preserved than recall memory—the ability to retrieve information from scratch; therefore, visual aids with a list of options in simplified language can help compensate for short-term memory and executive function impairments.[54] For example, Veterans Administration hospital geropsychologist Kyle Page creates individualized aids that describe the person's medical condition in simplified terms and set out in bullet points the recommended and alternative treatments or options, as well as the risks and benefits of each option, for care and discharge decisions.[55]

Decision-Making in Health and Social Care: Views of Older Patients with Early-Stage Dementia and Their Carers, 5 DEMENTIA 479, 490 (2006) (describing results of interviews with persons with early dementia who felt unheard and rushed in making decisions about their care).

52. Theresa Wied et al., *Supported Decision-Making in Persons with Dementia: Development of an Enhanced Consent Procedure for Lumbar Puncture*, 12 FRONTIERS IN PSYCHIATRY 1, 4 (2021).

53. GERONTOLOGICAL SOC'Y OF AM., COMMUNICATING WITH OLDER ADULTS: AN EVIDENCE-BASED REVIEW OF WHAT REALLY WORKS 9 (2012), https://gsaenrich.geron.org/communicating-with-older-adults [https://perma.cc/5ZNQ-CMRR]. With dementia, it becomes harder to filter out distractions. SABAT, *supra* note 30, at 44.

54. Jonathan Rubright et al., *A Memory and Organizational Aid Improves AD Research Consent Capacity: Results of a Randomized, Controlled Trial*, 18 AM. J. GERIATRIC PSYCHIATRY 1124, 1124 (2010).

55. Kyle Page & Kathleen Matthews, *Evaluating Capacities in Persons With Dementia*, *in* ASSESSING CAPACITIES OF OLDER ADULTS: A CASEBOOK GUIDE TO DIFFICULT DECISIONS 27, 46 (Jennifer Moyer ed., 2020); s*ee also* Kyle Page Decision Aids (on file with author). Researchers have begun to analyze the efficacy of simplified consent forms; in one study, researchers presented persons with mild to moderate Alzheimer's Disease with a one-page summary of an informed consent form "at a sixth grade reading level" and found that the aid improved consent capacity. Jonathan Rubright et al., *A Memory and Organizational Aid Improves Alzheimer Disease Research Consent Capacity: Results of a Randomized, Controlled Trial*, 18 AM. J. GERIATRIC PSYCHIATRY 1124, 1124 (2010). The ENSURE project (Enhancing the Informed Consent Process: Supported decision-making and capacity assessment in clinical dementia research) in Europe is also identifying tools for "an enhanced consent procedure that minimizes verbal memory load in the informed consent process and facilitates verbal retrieval for people with dementia." The project's initial study identified and developed eight tools for simplifying informed consent

Going through the reasoning process together. A supporter can work through the reasoning process by "learning about the social and situational context" for a decision and "asking about the consequences of . . . alternatives for those contexts." [56] Knowing the person well and knowing their values can help with this aspect of decision-making.[57]

Simplifying language. Eliminating jargon, using concrete words instead of abstract concepts, and simplifying sentences to avoid complicated syntax can reduce cognitive load and promote understanding.[58] "Semantic elaborations," which entail looping in a keyword from one sentence into the next in order to expand on its meaning or further describe the keyword, also improve comprehension.[59]

Finding the appropriate time for making the decision. Persons with dementia have fluctuations in their cognitive function, with good and bad days and better and worse times of day.[60] In addition, health crises can sap energy needed for decision-making.[61]

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for lumbar puncture but does not appear to have tested their efficacy yet. Wied et al., *supra* note 52.

56. *See* Jennifer Moye et al., *Capacity to Consent to Treatment: Empirical Comparison of Three Instruments in Older Adults With and Without Dementia*, 44 GERONTOLOGIST 166, 166–75 (2004).

57. *Id.*

58. *See* Craig Sinclair et al., *Supported Decision-Making in Dementia Care: Final Project Report 14*, COGNITIVE DECLINE PARTNERSHIP CTR. (2019), https://cdpc.sydney.edu.au/wp-content/uploads/2019/07/CDPC_Supported_Decision-Making_Final_Project_RepFort.pdf [https://perma.cc/T35W-PZ94]; KATHRYN BAYLES ET AL., COGNITIVE-COMMUNICATION DISORDERS OF MCI AND DEMENTIA: DEFINITION, ASSESSMENT, AND CLINICAL MANAGEMENT 201 (Plural Publishing Inc. eds., 3rd ed. 2018). *See also* GERONTOLOGICAL SOC'Y OF AM., *supra* note 53.

59. *See* Wied et al., *supra* note 52, at 4. *See also* Tanja Schatz et al., *Improving Comprehension in Written Medical Informed Consent Procedures*, 30 GEROPSYCH 97, 98 (2017) (finding that semantic elaboration and simplified syntax improved comprehension).

60. Many people with dementia are at their best in the morning and become increasingly confused in the afternoon and evening, a phenomenon known as sundowning. *See Sundown Syndrome*, CLEV. CLINIC (Apr. 26, 2022), https://my.clevelandclinic.org/health/articles/22840-sundown-syndrome [https://perma.cc/PB3U-FEJ8]. Acute symptoms, fatigue, and stress may drain energy for decision-making and best practice may be to wait until the decision-maker has regained some strength. *See* Page & Matthews, *supra* note 55, at 42–46 (describing example of patient with dementia whose alcohol use had contributed to admission hospital and rehabilitation unit whose capacity improved over time until he was able to go home with supports from his son and home health aide).

61. S*ee* Page & Matthews, *supra* note 55, at 52 (describing example of patient who had made decision to eat special diet with medical team but then reverted to request for regular food when fatigued because "making decisions takes energy, and [one uses] heuristics to make a quick decision

Accommodating communication needs. Knowledge of a person's communication style and preferences can compensate for challenges in interpretation.[62] In addition, aphasia, which may accompany dementia and impairs speech and use of language, may require accommodations in communication modes, such as writing an answer to a question or pointing to a picture or word.[63]

Person-centered attitude. This approach involves engaging with individuals with dementia "as equal partners in the decision-making process, rather than taking over decision-making,"[64] engaging in active listening, and "taking the intentional stance" of assuming the person is trying to tell you something and engaging to figure it out, as opposed to labeling their statements as confused and dismissing them.[65]

Memory support systems. Calendars, note-taking, lists, alarms, reminder systems (on a computer, Alexa-type device, or phone), contact

and save energy."). Some temporary conditions, such as urinary tract infections, dehydration, and medication side effects can produce dementia-like symptoms that may recede with treatment *See id.* at 47–48.

62. Fetherstonhaugh et al. quotes a care worker describing interaction with a facility resident: "We had a resident here . . . His answer to everything we said was, 'Boom! Boom!' But we would know that sometimes 'Boom! Boom!' meant something and other times 'Boom! Boom!' meant something else. But that's because we got to know him and we got to know his likes and dislikes." *See* Featherstonhaugh et al., *supra* note 42, at 217.

63. *Aphasia, Symptoms & Causes*, MAYO CLINIC (June 11, 2022), https://www.mayoclinic.org/diseases-conditions/aphasia/symptoms-causes/syc-20369518 [https://perma.cc/LQH4-9Q5X]. Another example of a visual aid that has been shown to enhance communication between persons with dementia and their caregivers is Talking Mats™, described as "a simple system of picture symbols, placed on a textured mat, that allow people to indicate their feelings about various options within a topic by placing the relevant image below a visual scale." Joan Murphy & Tracy Oliver, *The Use of Talking Mats to Support People with Dementia and Their Carers to Make Decisions Together*, 21 HEALTH & SOC. CARE CMTY. 171, 173 (2013).

64. Theresa Wied et al., *Supported Decision-Making in Persons with Dementia: Development of an Enhanced Consent Procedure for Lumbar Puncture*, 12 FRONTIERS PSYCHIATRY 1, 3 (2021).

65. Renowned dementia expert Steven Sabat analogizes to a conversation with someone speaking a foreign language; one does not assume the person is speaking gibberish but rather engages to try to overcome the language barrier. He also recommends what linguistics calls indirect repair—a process of working together to figure out what the person is saying and "repair" the listener's understanding by checking if it is correct. SABAT, *supra* note 30, at 94–99.

lists, pill boxes, and similar tools can compensate for impaired memory and assist individuals in executing decisions.[66]

This list is not exhaustive, and each individual's support needs vary. In addition, the nature of the decision being made may dictate more or different supports in one realm than another. For example, the accommodations needed to provide informed consent for a medical procedure may vary from those needed to make a decision about where to live. But the existence of multiple strategies and accommodations that can support decision-making to some degree suggests that there is more the law can do to ensure persons with dementia are receiving the supports they need to make decisions and preserve autonomy.

II. LEGAL FRAMEWORK RELATED TO DEMENTIA AND DECISION-MAKING

This Part surveys the legal regimes that govern decision-making by persons with dementia. First, this Part describes what has long been the standard advice to anyone who receives a diagnosis of dementia or Alzheimer's, which is to plan for incapacity by using advance directives or risk becoming subject to guardianship. Then, this Section describes the emergence of a disability rights approach to dementia that centers the person in decision-making and contemplates how accommodations and support can facilitate continued involvement in decision-making for as long as feasible.

A. Binary Approach – Independent or Surrogate Decision-Making

The law broadly presumes capacity for all adults, but the precise definitions of capacity vary by type of decision to be made. Contract law requires that a party can understand the nature and consequences of entering into a particular transaction and manifest assent to the contract.[67] A mere diagnosis of Alzheimer's or dementia does not equate

66. *See* Liselotte De Wit et al., *Memory Support System Training in Mild Cognitive Impairment: Predictors of Learning and Adherence*, 31 NEUROPSYCH. REHABILITATION 92, 93 (2021).

67. *See* RESTATEMENT (SECOND) OF CONTS. § 15 (AM. L. INST. 1981) (A person is assumed to have capacity to contract unless "by reason of mental illness or defect (a) he is unable to understand in a reasonable manner the nature and consequences of the transaction, or (b) he is unable to act in a reasonable manner in relation to the transaction and the other party has reason to know of his condition."). Unfair terms, a confidential relationship with beneficiaries of a transaction, lack of other options and the presenting of a take it or leave it document are often cited by courts as indicative of fraud, duress, undue influence and/or a lack of capacity. *See, e.g.*, Gordon v. Bialystoker Ctr. & Bikur Cholim, Inc., 385 N.E.2d 285, 288–89 (N.Y. 1978); Loiacono v. Loiacono, 589 N.Y.S.2d 560, 560 (N.Y. App. Div. 1992) (shifting burden to defendants to establish bona fide transaction when person in position of trust benefits from a conveyance); RESTATEMENT (SECOND) OF CONTS. § 12 (AM. L. INST. 1981). *See also* Minelli Constr. Co., Inc. v. Volmar Constr., Inc., 917

to lack of capacity to enter into a particular transaction, though transactions have been set aside on that basis when evidence shows that the person was unable to comprehend a transaction.[68]

For medical decisions, the capacity to provide informed consent requires that an individual be able to communicate a decision as well as understand and appreciate the benefits, risks, and alternatives to the proposed care.[69] Informed consent is typically supposed to be determined by physicians.[70] The more significant the consequences of the patient's intended decision, the more closely physicians may scrutinize capacity.[71]

Contract and informed consent doctrine have historically both assumed that the capacity question is all or nothing: i.e., an individual

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N.Y.S.2d 687, 688 (N.Y. App. Div. 2011) ("In determining whether the parties entered into a contractual agreement and what were its terms, it is necessary to look . . . to the objective manifestations of the intent of the parties as gathered by their expressed words and deeds." (quoting Brown Bros. Elec. Contractors, Inc. v. Beam Constr. Corp., 361 N.E.2d 999, 1001 (N.Y. 1977))).

68. Feiden v. Feiden, 542 N.Y.S.2d 860, 862 (N.Y. App. Div. 1989) ("Persons suffering from a disease such as Alzheimer's are not presumed incompetent and may execute a valid deed"); *but see* In re Mary "J", 736 N.Y.S.2d 542, 545 (N.Y. App. Div. 2002) (finding that the trial court "properly revoked . . . [the] power of attorney and health care proxy since they were executed . . . during a time that [Respondent] was suffering from extreme dementia" (citing N.Y. MENTAL HYG. L. § 81.21(d))). *See, e.g.*, Matter of Nurse, 75 N.Y.S.3d 545, 549 (N.Y. App. Div. 2018) ("The evidence supports . . . that when the deed was executed . . . Rupert A.N. suffered from dementia and vascular disease which rendered him wholly and absolutely incompetent to comprehend and understand the nature of the transaction." Because "the existence of a confidential relationship was established," as "the appellants provided 24-hour care to Rupert A.N., who, as a result of his . . . ailments, was rendered wholly reliant upon his caregivers," "[t]he burden [s]hifted to the appellants, who, in turn, failed to demonstrate that the transaction was fair and free from undue influence." (citing Matter of Albert, 137 A.D.3d 1266, 1268 (N.Y. App. Div. 2016))); Campbell v. Thomas, 897 N.Y.S.2d 460, 472–73 (N.Y. App. Div. 2010) ("the record reveals that Nidia secretly entered into a marriage with a person whom she knew to be incapable of consenting to marriage, with the intent to collect, as a surviving spouse, a portion of his estate" and "Nidia 'shall have no legal rights and can claim no legal interest as a spouse of [Howard].'").

69. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2994-a(5) (Consol. 2023) (defining "Decision-making capacity," for purposes of the Family Health Care Decisions Act (§§ 2994-a to 2994-u), as "the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of and alternatives to proposed health care, and to reach an informed decision").

70. Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 N. ENG. J. MED. 1834, 1834 (2007).

71. *Id.*

either has capacity to make independent decisions or does not.[72] When someone is deemed to lack capacity to contract or consent to health care, the question becomes who, if anyone, is authorized to make decisions for the individual.[73] This is where the standard advice to plan for incapacity by executing advance planning instruments comes into play.

Advance planning ensures that an individual has some control over *who* will make future decisions should they reach a point at which they are deemed to no longer have capacity.[74] A broadly drafted durable power of attorney is effective immediately and ensures that a chosen agent can engage in a robust range of financial and legal transactions on the principal's behalf should it be necessary.[75] Alternatively, springing powers of attorney may become effective upon a determination that an individual is incapacitated; however, disputes about their validity with third parties are common and, therefore, they are not used as widely.[76]

Similarly, health care proxies (or medical powers of attorney, as they are called in some states) permit an individual to designate *who* they would like to make health care decisions on their behalf should they become incapacitated.[77] Many standard forms also permit the principal to add instructions to the health care agent, mostly about end-of-life decisions.[78] Individuals may alternatively execute living wills, which permit an individual to set forth how they want end-of-life

72. *See* RESTATEMENT (SECOND) OF CONTS. § 15 (AM. L. INST. 1981); *see* N.Y. PUB. HEALTH LAW § 2994-a(5) (defining "Decision-making capacity," for purposes of the Family Health Care Decisions Act (§§ 2994-a to 2994-u), as "the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of and alternatives to proposed health care, and to reach an informed decision"). *But see* UNIF. HEALTH-CARE DECISIONS ACT §3 (NAT'L CONF. OF COMM'RS ON UNIF. STATE LAWS 2023) (updating definition of capacity to make health care decisions to include possibility that person might communicate decision with supported decision-making or other reasonable accommodation).

73. *See generally* Lawrence A. Frolik & Mary F. Radford, *"Sufficient" Capacity: The Contrasting Capacity Requirements for Different Documents,* 2 NAELA J. 303, 314 (2006).

74. *See generally* Genevieve Mann, *It's Not OK, Boomer: Preventing Financial Power-Of-Attorney Abuse of Elders*, 82 MD. L. REV. 181, 187 (2023).

75. *Id.* at 194.

76. *See* John C. Craft, *Preventing Exploitation and Preserving Autonomy: Making Springing Powers of Attorney the Standard*, 44 U. BALT. L. REV. 407, 442 (2015).

77. *See, e.g.*, N.Y. PUB. HEALTH LAW art. 29-C.

78. *See* N.Y. PUB. HEALTH LAW § 2981(5)(b).

decisions to be made without appointing an agent to do so.[79] However, despite widespread campaigns to get older adults to execute health care directives, they remain underutilized.[80]

All of these tools are important instruments for someone with dementia and are widely recommended upon receiving a diagnosis.[81] Most people with mild dementia and many with moderate dementia will still have sufficient capacity to execute advance directives.[82] When successful, the directives operate with trusted agents who know the individual's wishes, and act in accordance with them.[83] But when the principal's wishes are not known, the standard for making a determination becomes the "best interest" of the principal as judged by the agent,[84] a standard that has been criticized for not respecting the person's unique will and preferences.[85]

When these instruments are not executed before cognitive decline progresses to an advanced state, or when agents fail to act—or worse, abuse their authority—guardianship may ensue and, as a result, the person becomes subject to substitute decision-making by a person or agency likely not of their choosing.[86] Diminished cognition alone is not a reason for guardianship.[87] Petitions for guardianship over older adults tend to be filed when health or financial crises arise that overwhelm planning or supports that the older person may have put in place, when disagreements emerge among family members over something that the older adult is doing (quite often with their money), or when there is

79. *See In re* Westchester Cnty. Med. Ctr., 72 N.Y.2d 517, 531 (1988).

80. Kuldeep N. Yadav et al., *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-Of-Life Care*, 36 HEALTH AFFS. 1244, 1244 (2017).

81. *See, e.g.*, *Planning After a Dementia Diagnosis*, ALZHEIMERS.GOV, https://www.alzheimers.gov/life-with-dementia/planning-after-diagnosis [https://perma.cc/6JQM-54ZB].

82. *See* Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decision Making*, 79 MD. L. REV. 257, 273 (2020); *cf.* Warren F. Gorman, *Testamentary Capacity in Alzheimer's Disease,* 4 ELDER L. J. 225, 241 (1996).

83. *See* John C. Craft, *Preventing Exploitation and Preserving Autonomy: Making Springing Powers of Attorney the Standard*, 44 U. BALT. L. REV. 407, 437 (2015).

84. UNIF. POWER OF ATT'Y ACT §114(a)(1) (UNIF. L. COMM'N 2006).

85. MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 91–94, 134–36 (2010).

86. *See generally* Jennifer L. Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J. L. & PSYCHIATRY 350 (2010).

87. UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 301 (UNIF. L. COMM'N 2017).

concern about self-neglect or exploitation.[88] The downsides of guardianship are well-documented.[89] In addition to the significant deprivation of rights that results from declaring someone incapacitated and taking away their personhood under the law, guardianship is often costly, cumbersome, ineffective, and subject to abuse.[90]

B. Emerging Disability Rights Framework and Its Application to Persons With Cognitive Decline

The binary approach to capacity and decision-making has given way to a third option: supported decision-making, which promises to preserve decision-making authority in the individual.[91] Supported decision-making has its roots in a human rights approach to disability that was embodied in the United Nations Convention on the Rights of Persons with Disabilities ("CRPD"), adopted nearly twenty years ago.[92] Article 12 of the CRPD reaffirmed that people with intellectual, developmental, psychosocial, and cognitive disabilities have an equal right to "legal capacity" as others.[93] The right to legal capacity, in turn, has been described as "the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)."[94]

In everyday life, the right to legal capacity translates into the right to make legally binding decisions: to enter into contracts like a lease or engage in banking transactions, to consent to medical care, to decide where to live, how to spend one's time and with whom, and to not be under a guardianship that wrests the power to make those decisions from an individual and vests it in someone else.[95] We all engage with

88. *See* Morgan K. Whitlatch & Rebekah Diller, *Supported Decision-Making: Potential and Challenges for Older Persons*, 72 SYRACUSE L. REV. 164, 176, 186 (2022).

89. *See, e.g.*, Rebekah Diller & Leslie Salzman, *Stripped of Funds, Stripped of Rights: A Critique of Guardianship as a Remedy for Elder Financial Harm*, 24 U. PA. J. L. & SOC. CHANGE 149, 158–59 (2021).

90. *See* NATIONAL COUNCIL ON DISABILITY, *supra* note 8, at 65–72.

91. *Id.* at 129–30.

92. The CRPD was adopted December 12, 2006 and was entered into force May 3, 2008. *Convention on the Rights of Persons with Disabilities (CRPD),* U.N. DEP'T ECON. & SOC. AFF., https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd [https://perma.cc/Y2FX-VLRF].

93. G.A. Res. 61/106, at Annex I, Art. 12, ¶¶ 2–4 (Dec. 13, 2006). *See generally* Kristin Booth Glen, *Introducing a "New" Human Right: Learning from Others, Bringing Legal Capacity Home,* 49 COLUM. HUM. RTS. L. REV. 1 (2018).

94. Comm. on the Rts. of Pers. with Disabilities, General Comment No. 1, Article 12: Equal Recognition Before the Law, at ¶ 2, no. 13, U.N. Doc. CRPD/C/GC/1 (May 19, 2014).

95. *See* Glen, *supra* note 6, at 30–31.

the world through a series of decisions like these, large and small. Gerard Quinn has called legal capacity "the *tool* by which the 'person' asserts him or herself in the lifeworld - in the myriad of tiny daily transactions that make up who we are."[96]

Preserving the right to legal capacity requires a shift away from what has historically been the widely accepted view that one's legal rights hinge on one's level of "mental capacity," or decision-making ability. Instead of taking away rights based on diminished mental capacity, under the CRPD framework, the government must "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."[97]

The CRPD was not ratified by the United States but it has influenced the direction of disability rights reforms and activism, particularly with regard to minimizing the use of guardianship.[98] Self-advocates and other disability rights activists have pushed for reforms to recognize supported decision-making as an alternative to guardianship.[99]

The CRPD was notable for the significant involvement of persons with disabilities in its drafting.[100] Article 12, which governs legal capacity, was shaped largely by and in response to concerns raised by persons with psychosocial disabilities and intellectual and developmental disabilities as well as non-governmental organizations that advocate for the rights of these communities.[101] Persons with dementia and aging rights organizations were not part of this process.[102] As a result, the implementation of Article 12 for persons with dementia has proven to be even more challenging than the implementation of Article 12 principles for others.[103]

At the same time, dementia has increasingly been understood as not just a medical diagnosis but as a disability that requires

96. Gerard Quinn, Lecture at the University of British Columbia: Rethinking Personhood: New Directions in Legal Capacity Law and Policy 11 (Apr. 29, 2011) (emphasis added).

97. U.N. Convention on the Rights of Persons with Disabilities, art. XII, ¶ 3, *opened for signature* Mar. 30, 2007, 2515 U.N.T.S. 3.

98. *See* Kristin Booth Glen, *Introducing A "New" Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 92 (2018).

99. *Id.* at 94–95; *see* NATIONAL COUNCIL ON DISABILITY, *supra* note 8, at 130.

100. *See* Mary Donnelly, *Deciding in Dementia: The Possibilities and Limits of Supported-Decision Making*, 66 INT'L J. L. & PSYCHIATRY 66, 66 (2019).

101. *Id.* at 67.

102. *Id.* at 66.

103. Glen, *supra* note 93, at 10, 33–34, 41–45 (discussing, generally, the challenges of implementing Article 12).

accommodation.[104] While efforts to develop better pharmacological treatments continue, there is a growing recognition that the quest for a cure may not deliver any miracles in the near future and that medical and social institutions need to do much more to ensure that persons living with dementia experience that period of their lives with care, dignity, and the opportunity for community engagement.[105]

In recent years, self-advocates with dementia have emerged and spoken out about the need for a human rights framework that respects their choices as opposed to a medical and care management model in which others choose what they think is best for the person.[106] Part of this agenda includes demanding the human rights protections of the CRPD, including the right to support in making decisions.[107]

The CRPD is rooted in the social model of disability, which views disability "as a product of the interaction between an individual and his or her built and attitudinal environment" as opposed to a product of inherent impairments.[108] What this means in the decision-making context is that instead of employing capacity assessments that look for deficits in decision-making skills, we ask: What would it take for this

104. *See, e.g.*, Megan S. Wright, *Dementia, Healthcare Decision Making, and Disability Law*, 47 J. L., MED. & ETHICS 25, 25, 27–28 (2019).

105. *See, e.g.*, TIA POWELL, DEMENTIA REIMAGINED: BUILDING A LIFE OF JOY AND DIGNITY FROM BEGINNING TO END 256–58 (2020). A parallel development has been the emergence of the "dementia friendly communities" movement, which aims to reduce stigma and promote inclusion and attention to the lived experiences of persons with dementia. One of its key tenets is "empowering people with dementia by recognizing their rights and capabilities so that they feel respected and, to the extent that they are able, empowered to take decisions about their lives." *Dementia Friendly Communities: Key Principles*, ALZHEIMER'S DISEASE INT'L, at 4, https://www.alzint.org/u/dfc-principles.pdf [https://perma.cc/EH5Y-RTR7].

106. Theresa Flavin, *Supported Decision Making for People Living with Dementia*, 19 DEMENTIA 95, 95–96 (2019).

107. *See* DEMENTIA ALL. INT'L, DEMENTIA: THE LEADING CAUSE OF DISABILITY (2019), https://dementiaallianceinternational.org/assets/documents/DAI-COSP12-Side-Event-Handout.pdf [https://perma.cc/6WEV-PXM3]. Longtime University of Manchester Professor Peter Mittler, who spent many years championing the rights of persons with intellectual disabilities before himself being diagnosed with dementia, argued that dementia should be treated as a disability and that people with dementia should enjoy the protections of the CRPD, while simultaneously recognizing that it has been challenging to practically implement Article 12. Tom Shakespeare et al., *Rights in Mind: Thinking Differently About Dementia and Disability*, 18 DEMENTIA 1075, 1082–83 (2019).

108. Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 9 (2012).

individual to make and implement decisions?[109] What supports are needed to receive and understand information, weigh and consider options and their various consequences, and communicate and implement a decision in this particular realm of their life?[110]

There is no one universal model of providing support for decision-making. Soon after the concept appeared in the U.S., Robert Dinerstein provided the following frequently quoted definition: "Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life."[111] Under this formulation, supports might come in many forms, including choosing people one trusts to assist with decision-making, obtaining information in simplified formats, receiving assistance with communication, or engaging in advance planning.[112] Supported decision-making also draws on the concept of "relational autonomy," an idea that none of us is wholly independent and self-reliant and "that autonomy occurs (or is thwarted) in interactions with others."[113] None of us is a completely autonomous subject who independently makes decisions—we all make decisions with support from others.[114] More, less, or different support may be needed depending on the decision-maker and the situation.[115]

III. THE SDMA APPROACH AND ITS LIMITS

This Section describes the main way in which policymakers have sought to implement SDM—through state statutes that recognize agreements between decision-makers and their supporters. This Section then discusses the limitations of this approach for people experiencing

109. *See* Glen, *supra* note 6 at 31, n. 27 (describing how functional assessments "should be done for the purpose of determining the supports necessary to enable a person to fully exercise her/his legal capacity.").

110. *See id.* at 31–34.

111. Dinerstein, *supra* note 108, at 10.

112. Comm. on the Rts. of Pers. with Disabilities, *supra* note 94, at ¶ 3, no. 17.

113. Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decisionmaking*, 79 MD. L. REV. 257, 280 (2020); *see also* Glen, *supra* note 6, at 73–76.

114. *See, e.g.*, Eniola Salami & Bonnie Lashewicz, *More Than Meets the Eye: Relational Autonomy and Decision-Making by Adults with Developmental Disabilities*, 32 WINDSOR Y.B. ACCESS TO JUST. 91, 94 (2015).

115. *See* N.Y. MENTAL HYG. Law § 82.01(a) (Consol. 2023) ("Everyone uses supports, as do people with disabilities; who may just need more or different kinds of supports.").

cognitive decline and suggests ways to complement these statutes with other policy interventions.

A. SDM Agreement Statutes

The main way in which states have approached supported decision-making is to enact supported decision-making agreement ("SDMA") acts.[116] Beginning with Texas in 2015, a total of 21 jurisdictions have passed statutes setting forth requirements for SDMAs—broadly speaking, instruments in which a decision-maker designates supporters from whom they wish to receive assistance in making and communicating decisions.[117]

These statutes have included requirements for the contents of and execution of an SDMA.[118] Some of these statutes contain threshold levels of capacity for entering an agreement such as "understanding the nature and effect of the agreement" and/or require that the person enter the agreement "voluntarily."[119] And most SDMA statutes include provisions requiring third parties to recognize them and immunizing those third parties from liability for doing so.[120]

116. *See generally* Kohn et al., supra note 21.

117. *See* ALA. CODE §§ 26-1B-1 to 10 (2024); ALASKA STAT. §§ 13.56.010–13.56.195 (2023); ARIZ. REV. STAT. §14-5721 (2023); CAL. WELF. & INST. CODE §§ 21000–21008 (Deering 2023); COLO. REV. STAT. §§ 15-14-801 to 15-14-806 (2023); DEL. CODE ANN. tit. 16, §§ 9401A–9410A (2023); D.C. CODE §§ 7-2131 to 7-2134 (2018); 755 ILL. COMP. STAT. ANN. 9/1–99 (2022); IND. CODE §§ 29-3-14-1 to 29-3-14-13 (2019); LA. STAT. ANN. §§ 13:4261.101–.302 (2020); MD. CODE. ANN., EST. & TRUSTS §§ 18–101 to 18–109 (West 2022); NEV. REV. STAT. §§ 162C.010–.330 (2019); N.H. REV. STAT. ANN. §§ 464-D:1–16 (2021); N.Y. MENTAL HYG. LAW §§ 82.01–.15 (Consol. 2022); N.D. CENT. CODE §§ 30.1-36-01 to 08 (2019); 42 R.I. GEN. LAWS §§ 66.13-1 to 10 (2019); TENN. CODE ANN. § 52-3-101 to 604 (2024); TEX. EST. CODE ANN. §§ 1357.001–.102 (West 2015); VA. CODE. ANN. §§ 37.2-314.3, 64.2-2000, 64,2-2003, 64,2-2007 (2024); Wash. Rev. Code §§ 11.130.700–.755 (2022); WIS. STAT. §§ 52.01–.32 (2018). For a helpful chronology of state legislation on SDM, *see* Benjamin A. Barsky, *Dual Federalism, Constitutional Openings, and the Convention on the Rights of Persons with Disabilities*, 24 U. PA. J. CONST. L. 345, 394–404 (2022).

118. *See, e.g.*, DEL. CODE ANN. tit. 16, §§ 9405A–9406A (2016); NEV. REV. STAT. §§ 162C.200–.220 (2019); N.Y. MENTAL HYG. LAW §§ 82.04–05, 82.08 (Consol. 2022).

119. *See* ALASKA STAT. § 13.56.010(b) (2018) (requiring that person enter into agreement "voluntarily and without coercion or undue influence" and that the adult "understands the nature and effect of the agreement"); *see also* DEL. CODE ANN. tit. 16, § 9405A(a) (2016); N.H. REV. STAT. ANN. § 464-D:7(d) (2021). TEX. EST. CODE ANN. § 1357.055(a) (West 2015) ("A supported decision-making agreement must be signed voluntarily, without coercion or undue influence, by the adult with a disability and the supporter . . . ").

120. *See, e.g.*, ALASKA STAT. § 13.56.140 (2018).

It is common in these statutes to set out the requirements for an SDMA form.[121] Most of the forms permit decision-makers to designate one or more supporters to provide assistance with obtaining information relevant to decisions, explaining options, assisting in the decision-making process by explaining the consequences of options, and communicating decisions.[122] They also permit the decision-maker to select the types of decisions they would like help with.[123] For example, Alaska's form agreement contains checkboxes that permit the principal to select the domains that they want help with, including food and clothing, living arrangements, health care, support services, finances, and legal matters.[124] Some statutes, like New York's, also require that the agreement say what type of decision-making support the decision-maker would like from each supporter.[125]

The statutes provide that the decisions under an SDMA are to be made by the principal and that supporters may not exert undue influence on the decision-maker, but do not generally spell out in detail how to ensure the decision remains that of the principal.[126] Recent legislation in New York takes a more robust approach to ensuring that the SDMA functions as intended by requiring a facilitation process to ensure that both the decision-maker and supporters have undertaken education about the supported decision-making process.[127] New York's law notes that supported decision-making may take other forms and can be used even without an agreement, but sets forth facilitation as a prerequisite for immunizing third parties who rely upon such agreements.[128]

Advocates of these models have pointed to the ways in which legislative recognition of agreements can mitigate the tendency of third parties such as financial and health care institutions to reject decisions made with support.[129] In that way, the statutes perform an anti-

121. *See, e.g.*, ALASKA STAT. § 13.56.030 (2018).

122. *See, e.g.*, ALASKA STAT. § 13.56.100 (listing types of assistance supporter may provide).

123. *See, e.g.*, ALASKA STAT. § 13.56.030.

124. ALASKA STAT. § 13.56.180.

125. N.Y. MENTAL HYG. LAW § 82.10 (5) (Consol. 2022).

126. *See, e.g.*, ALASKA STAT. § 13.56.11 (2018).

127. N.Y. MENTAL HYG. LAW §§ 82.11, 82.12 (Consol. 2023).

128. N.Y. MENTAL HYG. LAW §§ 82.01, 82.12 (Consol. 2023). The law does not preclude the use of supported decision making in other forms and for other populations and in fact encourages it. In its findings, the Legislature strongly urged the development of models to support older persons with cognitive decline so that legislative recognition could be expanded to processes serving that population.

129. *See* Nina A. Kohn, *Legislating Supported Decision-Making,* 58 HARV. J. ON LEGIS. 313, 317–18 (2021) ("Formalized agreements have also been

discrimination function in that they make access to these institutions possible.[130]

Typically, the SDMA acts also identify the existence of an agreement as a less restrictive alternative to guardianship.[131] Several other states have incorporated SDM into their laws not by passing agreement acts but by explicitly recognizing SDM as a less restrictive alternative to guardianship.[132] The requirement that guardianship be a

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promoted as a tool for helping third-parties to understand and respect the relationship between an individual and the individual's supporter. This, in turn, is promoted as an antidote to disability discrimination on the grounds that it will reduce the likelihood that a third party will refuse to recognize decisions made by a person with a disability.").

130. N.Y. MENTAL HYG. LAW § 82.01 (Consol. 2023) ("People with intellectual, developmental, cognitive and psychosocial disabilities are often denied that right because of stigma and outdated beliefs about their capability."); *See also* Kohn, *supra* note 129, at 317–18 (stating that supported decision-making agreements are an "antidote to disability discrimination on the grounds that it will reduce the likelihood that a third party will refuse to recognize decisions made by a person with a disability."). In addition, some statutes have framed the right to supported decision-making explicitly as an accommodation to prevent discrimination against people with disabilities in laws governing organ transplantation. *See* ARK. CODE ANN. § 20-14-902 (2023) (Nondiscrimination in Access to Organ Transplantation); GA. CODE ANN., § 31-1-24 (2023) (Organ transplant protections for individuals with disabilities); KAN. STAT. ANN. § 65-3276 (2023) (Nondiscrimination in organ transplantation); MISS. CODE ANN. § 43-6-255 (2023) (Cole's Law; Prohibiting discrimination against recipients of organ transplants based on disability); OHIO REV. CODE ANN. § 2108.36 (LexisNexis 2023) (Definitions; prohibited actions based on physical disability by covered entity).

131. *See, e.g.*, MD. CODE ANN., EST. & TRUSTS §§ 18-102, 18-104 (LexisNexis 2023); N.Y. MENTAL HYG. LAW § 82.01 (Consol. 2023); VA. CODE ANN. §§ 64.2-2003, 64.2-2007 (2023); WASH. REV. CODE §§ 11.130.700–.755 (2023); WIS. STAT. § 54.10 (2023).

132. This is the approach taken in the most recent uniform guardianship law. *See* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 102(31) (UNIF. L. COMM'N 2017) [hereinafter UNIF. GUARDIANSHIP ACT] (defining "Supported decision making" as "assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions, which enables the individual to make the decisions, and in communicating a decision once made if consistent with the individual's wishes."); *see also* UNIF. GUARDIANSHIP ACT § 102 cmt ("These [supported decision making] arrangements may be purely informal, or may be formalized by an agreement between the individual and the person or persons providing assistance."); MINN. STAT. ANN. §§ 524.5-102, 524.5-310, 524.5-409 (LexisNexis 2023) (A court is able to appoint a guardian or conservator if "the respondent's identified needs cannot be met by less restrictive means, including but not limited to . . . supported decision making."); MO. REV. STAT. § 475.075(13)(4) (2023) (supported decision-making agreements are "a less restrictive alternative" consideration for the court when appointing

last resort, and that there be no less restrictive alternative, is already explicitly contained in most state statutes,[133] and constitutionally required as a matter of due process.[134] A related reform—which has occurred alongside some of the above reforms—is a change in the definition of "incapacity" in guardianship laws to require consideration of supports when evaluating capacity.[135] For example, when evaluating whether an individual is able "to receive and evaluate information or make or communicate decisions," the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act requires courts to consider that determination of capacity "with the use of appropriate supportive services, technological assistance, or supported decision making."[136]

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a guardian or conservator; however, this is not a statutory scheme for implementing the agreement); MONT. CODE ANN. §§ 72-5-305, 72-5-319 (West 2023) ("The petition for appointment of a guardian must contain . . . the reasons why the appointment of a guardian is sought, including . . . the reason why a less restrictive alternative [such as supported decisionmaking, § 72-5-305] is insufficient to meet the alleged incapacitated person's needs."). *See also* OR. REV. STAT. § 343.181 (2024) ("When a child with a disability reaches the age of majority . . . [t]o promote self-determination and independence, the school district shall provide the child and the child's parents with information and training resources regarding supported decision-making as a less restrictive alternative to guardianship").

133. *See, e.g.*, N.Y. MENTAL HYG. LAW § 81.02(a)(2) (Consol. 2021). The legislative findings of Article 81 also call for making available "the least restrictive form of intervention which assists [persons with incapacities] in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable." N.Y. MENTAL HYG. LAW § 81.01 (Consol. 2021).

134. *See, e.g.*, *In re* Guardianship of Hedin, 528 N.W.2d 567 (Iowa 1995). *See also* Leslie Salzman, *Using Domestic Law to Move Toward a Recognition of Universal Legal Capacity for Persons with Disabilities*, 39 CARDOZO L. REV. 521, 529–30 (2017) (examining state high court cases applying the least restrictive alternative test).

135. *See* UNIF. GUARDIANSHIP ACT § 401(b)(1)(A) (incorporating consideration of support into standard of appointment of conservator). ME. STAT. tit. 18-C, §§ 5-301(1)(A)(2), 5-102(14) (2023) ("the court may [a]ppoint a guardian for a respondent who is an adult if it finds by clear and convincing evidence that . . . [t]he respondent's identified needs cannot be met by a protective arrangement instead of guardianship or other less restrictive alternatives that provide adequate protection for the respondent" and "'Less restrictive alternative' includes supported decision making."); MINN. STAT. §§ 524.5-102, 524.5-310, 524.5-409 (2024) ("'Incapacitated person' means an individual who, for reasons other than being a minor, is impaired to the extent of lacking sufficient understanding or capacity to make personal decisions, and who is unable to meet personal needs for medical care, nutrition, clothing, shelter, or safety, even with appropriate technological and supported decision making assistance.").

136. UNIF. GUARDIANSHIP ACT § 401(b)(1)(A).

B. Limits of the SDMA Statutes for Persons With Dementia and Potential Solutions

1. Integrating Support with Advance Planning to Anticipate Fluctuating and Declining Capacity

SDMAs alone are not likely to fully address the support needs of persons with cognitive decline. In contrast to persons with I/DD who have been the primary users of SDMAs, where— broadly speaking— cognitive capacity is relatively stable, the capacity of older persons with dementia will fluctuate and is likely to decline over time.[137] As a result, if SDMAs are used, they might need to be revisited at least every year to account for changed circumstances.[138] In addition, as cognitive decline becomes more significant, it will be harder to support a person's growing support needs.[139] There may come a time when the person is no longer able to make and/or communicate a decision, even with significant supports.[140]

For these reasons, SDMAs should be considered part of a package of supports for decision-making by persons with dementia, with the recognition that needs will change over time and that it is advisable to plan for incapacity with advance directives, even if the goal is to put

137. On the progressive nature of Alzheimer's dementia, *see 2024 Alzheimer's Disease Facts and Figures*, *supra* note 23, at 7.

138. *See* Sinclair et al., *supra* note 15, at 601.

139. *See* MICHAEL BACK & LANA KERZNER, L. COMM'N ONT., A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 91 (2010); ISRAEL DORON, BIZCHUT, SUITABILITY OF THE MODEL TO SENIOR CITIZENS 76 (2017), https://sdmny.org/wp-content/uploads/2017/07/Bizchut._SDMService4PersonswDisabilitiespdf.pdf [https://perma.cc/8F8Y-R9Z3].

140. The General Comment to the CRPD has endorsed advance planning for this possibility, stating:

> For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.

U.N. Convention on the Rights of Persons with Disabilities, *General comment No. 1*, ¶ 17, U.N. Doc. CRPD/C/GC/1 (May 19, 2014).

off the need to turn to surrogates for as long as possible.[141] Advance directives also can ensure that a surrogate is empowered to act if a medical or other crisis arises that requires an immediate decision.[142] Combining SDMAs with advance directives also can accommodate the preference that many people with dementia have "to delegate some or all of their decision-making to trusted others through formal and informal mechanisms."[143]

For those who do not execute advance directives, or whose planning otherwise fails, one-shot judicial approval of legally significant decisions may be necessary as a supplement to supported decision-making if cognitive decline is advanced.[144] In contrast to younger persons aging out of special education, over whom guardianship is sought routinely, older persons are likely to face guardianship during a health or financial crisis.[145] The time to engage in a lengthy process of choosing and educating supporters and arriving at an agreement may not be there, and if the person has not executed advance directives, court approval for a critical decision may be required.[146] In order to minimize the infringements on a person's rights, the least restrictive guardianship order possible should be used—often one that is limited to the transaction or emergency situation at hand.

Given the ways in which a person with dementia continues to hold values, even after cognition has declined significantly, a more robust planning process that documents the person's values and considers dementia-specific situations can serve as the foundation to inform future decisions, should surrogate decision-making become necessary.[147]

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141. Australia's Cognitive Decline Partnership Centre has termed this a "spectrum model" of supported decision-making. *See* Sinclair et al., *supra* note 15, at 601.

142. *See* DORON, *supra* note 139, at 70–71.

143. *See* Sinclair et al., *supra* note 15, at 603.

144. *See* N.Y. MENTAL HYG. LAW § 81.16(b) (Consol. 2024).

145. *See* Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in A Snapshot of Adult Guardianship Cases in New York City*, 16 GEO. J. ON POVERTY L. & POL'Y 315, 333–34 (2009).

146. *See* Terry Carney, *Guardianship, 'Social' Citizenship & Theorizing Substitute Decisionmaking Law in* BEYOND ELDER LAW: NEW DIRECTIONS IN LAW AND AGING 1, 12–14 (Israel Doron & Ann M. Soden eds., 2012) (setting out "Stepped Care" Legal Toolkits, in which the state provides an increasing level of resources as the individual's cognitive abilities decline: use of supported decision-making, then supported decision making augmented by court approvals of single-transactions, then private guardians supported by the public guardian, then the appointment of the office of the public guardian).

147. The author is part of a working group convened by Project Guardianship Inc. to plan for the development of such instruments. On the need for planning instruments with dementia-specific terms, *see* Martina

Such instruments could document how individuals want decisions to be made; with what support and/or by whom; when, if, and by whom they want a determination of their inability to make particular kinds of, or all, decisions; and, assuming surrogate-decision making must take place, what values they would like prioritized.

Models for values-based planning exist in the health care sector.[148] One of the most developed projects to document values for future decision-making on a large scale has been in the Veterans Administration hospital system, in which providers are required to have "goals of care conversations" in order to "determin[e] the patient's values, goals, and preferences for care," so that if decisions must be made about life sustaining treatments, those factors have been documented in the patient's record.[149] However, the health care values work is notably confined to end-of-life decisions.[150] What is missing is the instrument to document values to inform decisions for how one would like to live.

2. Expanding Support for Implementing Decisions and Addressing the Limitations of Relying on Caregivers

Under the CRPD, the government has an obligation to ensure individuals have the supports they need to exercise their right to legal capacity.[151] For many older people with dementia, providing support in decision-making matters is not just about reaching decisions but also about implementing them.[152] And the implementation of decisions often entails navigating institutions to obtain care, accessing benefits, managing finances, or engaging in the other sets of complex tasks necessary for independent living.[153]

By framing the supporters' job as one of obtaining information, working through options, and communicating decisions, many of the SDMA statutes do not fully contemplate how decisions will be implemented.[154] Just like guardianship entails a transfer of decision-making authority and not a package of services, so too do SDMAs not

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Schmidhuber et al., *Advance Directives as Support of Autonomy for Persons with Dementia? A Pilot Study Among Persons with Dementia and Their Informal Caregivers*, 7 DEMENTIA GERIATRIC COGNITIVE DISORDERS 328, 336 (2018).

148. *See* DEP'T OF VETERANS AFFAIRS, VETERANS HEALTH ADMINISTRATION, VHA HANDBOOK § 1004.03(3), at 4 (2022).

149. VHA HANDBOOK § 1004.03(3), at 4. The VHA Policy delineates certain circumstances that must trigger Goals of Care Conversations. *Id.*

150. *Id.*

151. G.A. Res. 61/106, ¶ 3 (Jan. 24, 2007).

152. *See supra* text accompanying notes 36–40.

153. *See supra* text accompanying notes 36–40.

154. *See, e.g.*, ALASKA STAT. ANN. § 13.56.100 (West 2023).

guarantee that the decision-maker will receive other necessary supportive services. An active set of trusted supporters may assist a decision-maker in checking bank statements, wrangling with Medicaid managed care to implement a decision to accept home care, or setting up Meals on Wheels after assisting with making related decisions, but they also may not follow through on those tasks as part of the role of supporting decision-making.

In addition, the SDMA models in the U.S. largely rely on preexisting networks of support, drawn largely from trusted family and friends. The problem with family and friends who are already engaged as caregivers is that they may be overwhelmed as it is, have their own interests, be looking for what is most expedient, and/or just take over control.[155] Then there are those who do not have people in their lives to help them; for them, the SDMA model will not work unless creative approaches are taken to providing support, either through agencies of professionals or by developing peer support and/or volunteer models.[156]

For these reasons, policymakers should create more comprehensive guardianship diversion programs that have the potential to assist persons with dementia.[157] Such programs can connect persons with dementia with needed services like financial management, geriatric care management, and assistance with health care access so as to avert the crises that often give rise to guardianship.[158] In recently updated regulations, the Administration for Community Living has called upon state recipients of funding under the Older Americans Act to foster "approaches to be connected to resources and education to manage their finances and the decisions they make about their lives so as to limit their risk for guardianship, conservatorship, or more restrictive fiduciary proceedings."[159] This connection of service provision to decision-making support is a promising start.

155. *See* Geraldine Boyle, *Recognising the Agency of People with Dementia*, 29 DISABILITY & SOC'Y 1130, 1136–37 (2014) ("[S]ome spouse-carers took over major decision-making without fully considering whether their spouses had extant capacity to make such decisions, such that people with dementia experienced unnecessary constraints on their agency. Consequently, it was not necessarily the dementia (or a lack of 'rationality') that prevented them from influencing their lives. Instead, a lack of recognition or acknowledgement of their decision-making capacity partly explained why carers constrained their agency . . . . Therefore, while the agency of people with dementia is often facilitated by their carers, it may also be constrained by them.").

156. *See* Whitlatch & Diller, *supra* note 88, at 219.

157. *See* National Guardianship Summit, *Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability May 2021*, 72 SYRACUSE L. REV. 29, 35 (2022) (adopting Recommendation 3.3).

158. *Id.* at 37–38.

159. Older Americans Act, 59 Fed. Reg. 11566, 11698 (Feb. 14, 2024) (codified at 45 C.F.R. § 1324.303(a)(4)(ii)).

3. Requiring More Robust Accommodations for Persons Experiencing Cognitive Decline

There is a still-emerging body of literature from the health care context that suggests that people with mild to moderate dementia can continue to make many more decisions than society gives them credit for, particularly when accommodations are made to enhance capacity.[160] The SDMA approach relies exclusively on the individual to designate and have a preexisting set of supporters.[161] But entities that engage with persons with dementia should not be relieved of their obligations to provide accommodations, regardless of whether someone has a supporter designated in an SDMA.

As the major law prohibiting disability discrimination in public life, the Americans with Disabilities Act ("ADA") has great significance for persons with dementia seeking to engage with entities in interactions that involve decision-making.[162] Under Title III of the ADA, private entities that are considered places of public accommodation are barred from discriminating against persons with disabilities.[163] Discrimination includes "the failure to make reasonable modifications in policies, practices, or procedures" unless such a modification would "fundamentally alter" the services provided.[164] Public accommodations include the many places with which persons with dementia must engage in decision-making—health care offices, hospitals, banks, lawyer's offices, senior centers, as well as residential facilities such as assisted living and nursing homes.[165]

And under Title II of the ADA, governmental entities must make their programs accessible to persons with disabilities.[166] Similarly,

160. *See supra* text accompanying notes 72–97.

161. *See, e.g.*, N.Y. MENTAL HYG. LAW § 82.02(k) (Consol. 2023) (defining supporter as someone who has voluntarily entered into an SDMA).

162. *See, e.g.*, Megan S. Wright, *Dementia, Healthcare Decision Making, and Disability Law*, 47 J. L. MED. & ETHICS 25, 28–29 (2019); Sharona Hoffman, *Cognitive Decline and the Workplace*, 57 WAKE FOREST L. REV. 115, 139–40 (2022).

163. *See* 42 U.S.C. § 12182(b)(2)(A)(ii) (defining discrimination to include the "failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations.").

164. 42 U.S.C. § 12182(b)(2)(A)(ii).

165. 42 U.S.C. § 1218(7); s*ee also* Hubbard v. Twin Oaks Health & Rehab. Ctr., 408 F. Supp. 2d 923, 929 (E.D. Cal. 2004) (applying Title III of the ADA to a skilled nursing facility as a public accommodation).

166. *See* 28 C.F.R. § 35.149 (1991) ("[N]o qualified individual with a disability shall, because a public entity's facilities are inaccessible to or unusable by

Section 504 of the Rehabilitation Act of 1973 prohibits entities that receive federal funds from engaging in disability discrimination.[167] Governmental entities are beginning to identify SDM as a reasonable modification to policies and procedures governing the provision of services.[168] In revising regulations implementing Section 504 of the Rehabilitation Act as it applies to health care facilities, the U.S. Department of Health & Human Services recently noted that "[r]easonable modification" to access covered programs could include "permitting the use of supported decision-making or a third-party support, where needed by a person with a disability."[169]

The recognition of SDM as a reasonable modification and the endorsement of the use of supporters are important complements to the state statutes that have been passed. They ensure that persons with dementia and other cognitive disabilities will be able to use supporters with or without a legislatively recognized agreement and open the door to accepting SDM in many other settings with which persons with dementia interact.

More widespread recognition of SDM as an accommodation can also be accomplished through additional enforcement of the ADA and other anti-discrimination laws. Research supporting the efficacy of simplified consent forms and decision aids suggests that entities can further accommodate persons with dementia by modifying their practices and providing auxiliary communication aids.[170]

IV. CONCLUSION

Persons experiencing cognitive decline, when provided with accommodations and support, can continue to be involved in decision-making for longer than currently assumed. Supported decision-making offers an important means for preserving autonomy and rights. However, the implementation of the concept through SDMA legislation has not been fully responsive to the dementia context. Integrating

individuals with disabilities, be excluded from participation in, or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.").

167. 20 U.S.C. § 794; *Your Rights Under Section 504 of the Rehabilitation Act,* U.S. Dept. of Health & Human Services Office for Civil Rights, https://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.pdf [https://perma.cc/R3ZC-UEPB].

168. *See, e.g.*, 88 Fed. Reg. 63392, at 63474 (Sept. 14, 2023) (codified at 45 C.F.R. § 84).

169. *Id.*

170. *See* 28 C.F.R. § 35.160 (requiring public entities to furnish appropriate auxiliary aids and services to ensure effective communication); 28 C.F.R. § 35.104 (defining auxiliary aids and services to include written materials as well as "other similar services and actions"); *see also* Rubright et al., *supra* note 55.

SDMAs with advance planning, expanding services for managing social service and financial needs, and ensuring that public entities accommodate persons with dementia by simplifying procedures and permitting them to use support in decision-making are important measures that can augment the utility of SDMAs and further promote the right to legal capacity.