2022

Supported Decision-Making: Potential and Challenges for Older Persons

Morgan K. Whitlatch
Center for Public Representation

Rebekah Diller
Benjamin N. Cardozo School of Law, rebekah.diller@yu.edu

SUPPORTED DECISION-MAKING: POTENTIAL AND CHALLENGES FOR OLDER PERSONS

Morgan K. Whitlatch[†]

Rebekah Diller[††]

[†] Morgan K. Whitlatch, J.D., is the Director of Supported Decision-Making Initiatives at the Center for Public Representation. When this article was drafted for the Fourth National Guardianship Summit, she was the Legal Director at Quality Trust for Individuals with Disabilities.

[††] Rebekah Diller is Clinical Professor of Law and Co-Director of the Bet Tzedek Civil Litigation Clinic at the Benjamin N. Cardozo School of Law.

The authors wish to thank David Hutt, Elissa Gershon, Sally Hurme, Charlie Sabatino, and Erica Wood for their helpful review and feedback. The authors also thank Becky Kurtz for her thoughtful suggestions, as well as Mickey Schindler and Ornit Dan in Israel and Carrolyn Smith in Australia for their generous sharing of information regarding supported decision-making in their respective countries.

ABSTRACT

In recent years, supported decision-making (SDM) has gained traction as a recognized alternative to guardianship for persons with disabilities in the United States. To date, SDM has not been as widely recognized as an alternative for older people, particularly those struggling with cognitive decline. This paper explores some of the obstacles that have prevented SDM from being used more broadly by older people, identifies ways of surmounting some of those obstacles, and makes recommendations for ways that SDM can be used in the aging context.

Part I discusses the emergence of SDM in the United States and assesses what has and has not happened with regard to it for older people in the United States. It acknowledges the growing body of literature regarding the potential of SDM and describes how many commentators have endorsed the idea in theory and called for more research and practice. It also acknowledges that older people are vulnerable to guardianship for a variety of often overlapping reasons, not just cognitive decline.

Part II turns to some of the challenges that have arisen in implementing SDM in the aging context. These challenges include reluctance by service systems and courts to recognize SDM as a viable alternative for older people. This reluctance derives in part from an

orientation that prioritizes protection over autonomy for older adults, as well as assumptions about the dementia diagnosis that fail to account for the variety of ways in which it occurs. Many of these service systems have not embraced the rhetoric of independence and rights that systems serving individuals with intellectual and developmental disabilities have incorporated, at least on paper. As a result, this section argues that guardianship is misused to meet the needs of social institutions when service systems that are supposed to assist older persons fall short. This section also addresses the lack of support experienced by many people who age beyond family and friends and legitimate concerns about financial exploitation and undue influence. Finally, this section discusses the unique challenges posed by using SDM in a context in which further cognitive decline is likely to occur and in which cognitive decline is already significant. In the latter case, the article argues that a framework recognizing the right to legal capacity must work harder to determine what the person's will and preferences are by using their life history as a guide. Building on the pathbreaking work of Michael Bach and Lana Kerzner, who have formulated a model called "facilitated decision-making" to address when a person's will or preference cannot be determined, we explore how that status might apply to persons with advanced dementia in a way that preserves more legal status than our current guardianship framework in domestic law.

Part III starts by acknowledging that, although domestic pilots have included older adults, they have generally targeted people with intellectual and developmental disabilities (IDD) who are older, rather than people without IDD. It then explores what lessons can be learned from the experiences in Australia and Israel, both of which have either completed SDM projects in the aging context or have them currently underway. Finally, this section introduces a legal practitioner's perspective to ways in which to promote SDM and alternatives to guardianship in the courtroom for older adults at risk of permanent guardianship.

Part IV consists of recommendations for making SDM more accessible to older people, including persons living with dementia. These include integrating SDM with other advance planning; building in safeguards into the SDM agreement to prevent overreaching; continuing to challenge ourselves and others, including service systems and courts, to avoid ageism and ableism; ensuring that guardians follow their obligations to identify cases for restorations of rights; and developing pilot projects where older adults with cognitive decline test SDM models and frameworks so that there will be a

bolstered evidence base informing advocacy and policy-making in the aging context.

INTRODUCTION

"Dolores" was born in South America. When she moved to the United States (U.S.), she worked for the U.S. State Department, and then as a bilingual translator for several federal governmental agencies, including the Library of Congress and the Labor Department. Dolores is now in her eighties and lives in a subsidized building for seniors in the District of Columbia (DC). In 2015, she faced possible eviction after falling behind in her rent. Her landlord was willing to consider a payment plan for the rent arrears, but only if the DC Superior Court Probate Branch appointed her a guardian or conservator. Faced with the difficult choice of losing either her home or her decision-making rights, Dolores agreed to the appointment of a professional general (plenary) guardian and conservator over her finances. Under DC law, Dolores was then considered to be an "incapacitated individual," unable to manage her real and personal property, health care, and other daily affairs herself.[1] *Dolores valued her independence and soon realized that guardianship and conservatorship were more restrictive than she thought they would be. As she told a Washington Post reporter, "I felt very annoyed by having someone else taking care of everything." She knew where to go when she needed help—be it trusted family, church members, legal service providers, or a local senior service agency. She turned to an AARP (American Association of Retired Persons) affiliated organization, who referred her to Quality Trust for Individuals with Disabilities for representation. In October 2018, Dolores became the first older adult in DC to have her guardianship and conservatorship terminated in favor of "Supported Decision-Making" (SDM).*[2] *As Dolores said: "It makes you feel powerful to be in charge of your own life . . . You can have a lot of help everywhere, but you are your own boss."*[3]

Dolores's case illustrates the way in which formal recognition of SDM is gaining traction as a recognized alternative to guardianship

1. *See* D.C. CODE § 21-2011(11) (2021).

2. *See* Theresa Vargas, *This 87-Year-Old D.C. Woman Just Made it Easier for You to Keep Our Independence*, WASH. POST (June 27, 2018), https://www.washingtonpost.com/local/this-87-year-old-dc-woman-just-made-it-easier-for-you-to-keep-your-independence/2018/06/26/92636ce6-7962-11e8-80be-6d32e182a3bc_story.html.

3. *Id.*

for persons with disabilities—including older adults with disabilities and/or cognitive decline[4]—in the United States. While there is no singular definition or model of SDM, it generally occurs when people with disabilities—including those that are related to changes in memory or cognition—work with family, friends, professionals, and others they trust to help them understand the situations and choices they face, ask questions, receive explanations in language they understand, and communicate their own decisions to others.[5] It is usually contrasted with "substitute" or "surrogate" decision-making, which occurs when someone else (for example, a guardian or other legal agent) is legally designated (by legal instrument, court order, or other operation of law) to make decisions for, and instead of, the person.[6] Under SDM, it is the person with a disability or older adult who is the decision-maker, rather than the supporters involved.[7] SDM is designed to protect the right to autonomy with support, principles of equality, and non-discrimination based on disability.[8]

This paper explores the potential of SDM for older adults, identifies some of the obstacles that have prevented SDM from being used more broadly by this population, discusses ways of surmounting those obstacles, and makes recommendations for how we can move forward to ensure that older adults' human and decision-making rights are respected on an equal basis to others in the United States.

4. *See, e.g.*, Dari Pogach, *Supported Decision-Making for Older Adults with Age-Related Cognitive Decline*, 43 GENERATIONS: J. AM. SOC'Y ON AGING 87, 88 (Winter 2019–20); *see also* Michael Wald & Eli D. Pierce, *Elder Ethics*, 79 TEX. BAR J. 104, 105 (2016); Jennifer Lansing Pilcher, et al., *Supported Decision Making for Elders with Dementia: A Deep Dive*, J. AGING LIFE CARE 19, 19 (Summer 2019), https://www.aginglifecare.org/ALCA_Web_Docs/journal/ALCA%20Journal%20Sum19.pdf.

5. *See* Peter Blanck & Jonathan G. Martinis, *"The Right to Make Choices": The National Resource Center for Supported Decision-Making*, 3 INCLUSION 24, 26 (2015). *See* Robert 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, 10 (2012) ("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.").

6. *See, e.g.,* Piers Gooding, *Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law*, 20 PSYCHIATRY, PSYCH. & L. 431, 434 (2013); Jennifer Lansing Pilcher, et al., *Substitute Decision Making versus Supported Decision-Making: What is the Difference?*, J. AGING LIFE CARE 2, 2 (Summer 2019), https://www.aginglifecare.org/ALCA_Web_Docs/journal/ALCA%20Journal%20Sum19.pdf.

7. *See* Gooding, *supra* note 6, at 434.

8. *See id.* at 440.

I. SUPPORTED DECISION-MAKING: STATE OF AFFAIRS FOR OLDER ADULTS IN THE UNITED STATES

SDM is emerging in state and national discourse as a way of supporting people in making their own decisions and determining their own path in life, and this paper argues it holds promise in promoting the self-determination of older adults.

A. Emergence of Supported Decision-Making in the United States

Many point to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as the impetus of current reform efforts advancing SDM.[9] Its Article 12 requires signatory nations to "recognize that persons with disabilities enjoy legal capacity on an equal basis to others in all aspects of life" and "take appropriate measures to provide access by a person with disabilities to the support they require in exercising their legal capacity."[10] General Comment No. 1 of the CRPD defines "legal capacity" as including "the capacity to be a holder of rights," entitling "the person to full protection of his or her rights by the legal system," and "the capacity to be an actor under law," recognizing "the person as an agent who can perform acts with legal effect."[11] As the CRPD Committee explained, the term "Supported Decision-Making" describes one of the ways a person may be assisted in exercising legal capacity.[12]

The move from substitute decision-making to SDM is a paradigm shift in how society considers the decision-making abilities of people

9. *See, e.g.,* Dinerstein, *supra* note 5, at 8–9 (describing CRPD Article 12's emphasis on legal capacity and the choice-making); *see also* NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION 60 (2018), https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf (last visited Mar. 12, 2022) (describing "the dawn of supported decision-making," with the CRPD leading "to a sea of change in guardianship laws of signatory countries, and, philosophically, it has impacted the way that guardianship is understood in the United States). *But see* Robert M. Gordon, *The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making*, 23 INTL'L J. L. & PSYCHIATRY 61, 61, 62–63, 66 (2000) (tracing SDM emergence pre-CRPD and in Canadian legal frameworks).

10. G.A. Res. 61/106, art 12, ¶ 2 (Dec. 13, 2006).

11. *See* Convention on the Rts. of Persons with Disabilities, on Its Eleventh Session, U.N. General Comment on Art. 12 ¶ 11 at 3–4 (Nov. 25, 2013) https://digitallibrary.un.org/record/779679?ln=en. *See also id.* at ¶ 12 at 4 ("Legal capacity and mental capacity are distinct concepts. . . . Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.").

12. *See* Clíona de Bhailís & Eilionóir Flynn, *Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD*, 13 INT'L J. L. CONTEXT 6, 13 (2017).

with disabilities and older adults.[13] The United States—which has signed, but not ratified the CRPD—has generally lagged behind the international community in moving in that direction.[14] However, a notable shift began near the beginning of the last decade, as SDM pilot projects began emerging,[15] the first seminal court cases terminating guardianship in favor of SDM were decided, and stakeholders were initially convened to begin to identify barriers to more widespread adoption of SDM approaches in the United States.[16]

Since the first state made reference to supported decision-making in statute in 2009,[17] recognition of SDM has become more widespread. In 2014, the U.S. Department of Health and Human Services, Administration for Community Living (ACL), awarded a five-year grant to create a National Resource Center for Supported Decision-Making (NRC-SDM).[18] Its purpose was to advance the "Right to Make Choices" of people with disabilities and older adults through a multi-modal strategy of research, information-sharing, technical assistance, training, and promotion of promising practices in SDM.[19] In addition to making hundreds of in-person presentations on SDM that reached thousands of stakeholders around the country, the NRC-SDM supported eighteen SDM projects spanning the District of Columbia and fourteen states through its state grant program's community of practice. [20] It also developed the first research tool to

13. *See generally* Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 97, 137 (2012) (noting the shift to supported-decision making is a paradigm shift).

14. *See* Robert Dinerstein, et al., *Emerging International Trends and Practices in Guardianship Law for People with Disabilities*, 22 ILSA J. INT'L & COMP. L. 435, 451 (2016); *The Convention on the Rights of Persons with Disabilities*, NAT'L COUNCIL ON DISABILITY, https://ncd.gov/policy/crpd (last visited Mar. 12, 2022).

15. S*ee generally* Costanzo, *infra* note 49.

16. *See* Blanck & Martinis, *supra* note 5, at 27.

17. *See* TEX. GOV'T CODE ANN. § 5301.02446 (West 2009) (expired 2013) (establishing a volunteer supported decision-making advocate pilot program for persons with intellectual disabilities and persons with other cognitive disabilities).

18. *Supported Decision Making Program*, ADMIN. CMTY. LIVING, https://acl.gov/programs/consumer-control/supported-decision-making-program (last modified July 2, 2021).

19. *See* NAT'L RES. CTR. FOR SUPPORTED DECISION MAKING, http://www.supporteddecisionmaking.org/ **Error! Hyperlink reference not valid.**(last visited Mar. 12, 2022); *see also* Blanck & Martinis, *supra* note 5, at 33.

20. The states included Delaware, Florida, Georgia, Indiana, Maine, Minnesota, Mississippi, Nevada, New York, North Carolina, Oregon, South Carolina, Tennessee, and Wisconsin. *See* NAT'L RES. CTR. FOR SUPPORTED DECISION MAKING, *supra* note 19.

examine the relationship between SDM and self-determination,[21] the latter of which has been linked to better life outcomes through decades of research.[22]

Also, in 2014, the National Conference of Commissioners on Uniform Laws started the process of revising its model law, the 1997 Uniform Guardianship and Protective Proceedings Act, to incorporate recommendations from the third National Guardianship Summit.[23] That initiative would yield further ammunition to community advocates seeking to reform law and court practices to recognize SDM.[24] Approved in July 2017, the revised model law, now called the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (UGCOPAA),[25] formally recognizes SDM and requires its consideration as a less-restrictive option before courts order a guardianship, conservatorship, or other protective arrangement.[26] In so doing, the UGCOPAA shifts away from its

21. *See* QUALITY TR. FOR INDIVIDUALS WITH DISABILITIES, THE NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING (NRC-SDM): SUMMARY EVALUATION REPORT 2 (2020) (on file with Syracuse Law Review); Karrie A. Shogren et al., *Development of the Supported Decision Making Inventory System*, 55 INTELL. AND DEVELOPMENTAL DISABILITIES 432, 433–38 (2017).

22. *See, e.g.*, Yves Lachapelle et al., *The Relationship Between Quality of Life and Self-Determination: An International Study*, 49 J. INTELL. DISABILITY RSCH. 740, 743 (2005); Michael Wehmeyer & Michelle Schwartz, *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 EXCEPTIONAL CHILD. 245, 250 (1997); Michael L. Wehmeyer & Susan B. Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination*, 38 EDUC. AND TRAINING IN DEVELOPMENTAL DISABILITIES 131, 139 (2003); Ishita Khemka, et al., *Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*, 110 AM. J. ON MENTAL RETARDATION 193, 200–02 (2005); Brian P. O'Connor & Robert J. Vallerand, *The Relative Effects of Actual and Experienced Autonomy on Motivation in Nursing Home Residents*, 13 CAN. J. ON AGING 528, 536–37 (1994); Laurie E. Powers et al., *My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education*, 25 CHILD. AND YOUTH SERVS. REV. 2179, 2185–86 (2012); Karrie A. Shogren et al., *Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities*, 48 J. SPECIAL EDUC. 256, 262–65 (2013).

23. *See* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT, Prefatory Note (UNIF. L. COMM'N 2017) ("The [2017] act is the result of the work of the drafting committee, which was charged with revising the UGPPA to implement recommendations of the Third National Guardianship Summit (NGS) held in 2011.").

24. *See* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT, Prefatory Note, at 2.

25. *See id.*

26. *See id.* at § 102(31) (defining "Supported decision making" as "assistance from one or more persons of an individual's choosing in understanding the nature

predecessor's use of the term "incapacity" to justify the court ordering such arrangements.[27] It requires that a court instead find, by clear and convincing evidence, that the individual "is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making." [28] As one of its Comments states:

> Rather than being asked to assign a status (e.g., 'incapacitated' or 'has capacity') to the individual, the court is called upon to make particularized findings about the adult's individual needs in light of what the adult can and cannot do. This change is also consistent with the act's avoidance of the term 'incapacitated person,' which has been criticized as unnecessarily stigmatizing.[29]

The finalization of the UGCOPAA was followed closely by a resolution from the American Bar Association in August 2017 that urged U.S. state, territorial, and tribal legislatures to amend their guardianship statutes to require that SDM "be identified and fully considered as a less restrictive alternative, before guardianship is imposed" and be considered as a grounds for termination of a guardianship and restoration of rights.[30] This resolution, coupled with the influence that prior versions of the model law have had in many states, signals there is the promise of more state law reform recognizing SDM in the coming years.

In one way or another, many state legislatures are already well underway in doing so. As of March 2022, at least forty-one states and the District of Columbia have introduced one or more pieces of legislation specifically referring to SDM, and at least thirty-two of

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."); *id.* at § 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.").

27. *Compare id., with* UNIFORM GUARDIANSHIP & PROTECTIVE PROC. ACT *passim* (UNIF. L. COMM'N 1997).

28. *See* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT §§ 301(a)(1), 301(a)(1)(A), 401(b)(1)(A), 411(b)(1), 502(a)(1), 503(a)(1)(A) (UNIF. L. COMM'N 2017).

29. *Id.* at § 301 cmt.

30. *ABA Urges Supported Decision Making as Less-Restrictive Alternative to Guardianship,* AM. BAR ASS'N, (Aug. 1, 2017), https://www.americanbar.org/groups/law_aging/publications/bifocal/vol_38/issue-6—august-2017-/aba-urges-supported-decision-making-as-less-restrictive-alternat/ [hereinafter *ABA Urges Supported Decision Making*].**Error! Hyperlink reference not valid.**

those states and the District of Columbia have passed them.[31] The way in which SDM has been codified in state laws has varied from formally recognizing it within legal documents (usually referred to as "SDM agreements," which can be used to enforce the decision-makers' right to use supporters with third parties), in the context of special education for students who have reached the age of majority or are engaged in post-secondary transition planning, in areas of medical decision-making involving non-discriminatory access to organ transplantation, and in judicial deliberations required prior to the appointment of a guardian or conservator, among others.[32]

Specific reference to SDM has also already been making its way into judicial deliberations, orders, and decisions by state courts in guardianship proceedings. At least thirteen states,[33] as well as the

31. As of March 2022, the states who have introduced legislation referencing SDM include Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, Texas, Utah, Virginia, Washington, West Virginia, Wisconsin, and Wyoming, as well as the District of Columbia. Those that have enacted such legislation include Alaska, Arizona, Arkansas, Colorado, District of Columbia, Delaware, Florida, Illinois, Indiana, Kansas, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, Texas, Virginia, Washington, West Virginia, Wisconsin, and Wyoming. *See In Your State*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, http://www.supporteddecisionmaking.org/states (last visited Mar. 29, 2022) (listing state legislation and statutes referencing supported decision-making by state). *See also* QUALITY TR. FOR INDIVIDUALS WITH DISABILITIES, *supra* note 21, at 11.

32. *See* Tina M. Campanella & Morgan K. Whitlatch, *Supported Decision-Making: U.S. Status and Trends*, 32 IMPACT 1, 1 (2019) (noting the variety of ways in which the term SDM has been codified in state laws).

33. These states include Alaska, Florida, Georgia, Indiana, Kentucky, Massachusetts, Maine, Minnesota, Nevada, New York, Pennsylvania, Virginia, and Vermont. *See In re* Guardianship of Michael Lincoln, Case No. 56 2014 GA 000041PPXXXX, slip op. at 4 (Fla. Cir. Ct. 19th Cir. Oct. 13, 2016); *see also In re* John Francis McCarty, Est. No. 225013, slip op. at 1-2 (Ga. Fulton County Prob. Ct. Sept. 16, 2018); *see also* John McCarty, *Supported Decision Making and Guardianship Termination*, SELF ADVOCACY RES. & TECH. ASSISTANCE CTR. (May 13, 2020), https://selfadvocacyinfo.org/resource/supported-decision-making-and-guardianship-termination/; *see also In re* Guardianship of Jamie Lavonne Beck, No. 89D02-1805-GU-000044 (Ind. Wayne Cty. Super. Ct. No. 2 Jun. 13, 2018); *see also A Kentucky First: Woman Wins Her Rights in Courts Using SDM*, EXCEPTIONAL FAM. KY, 2017, 14, 15; *see also Meet Cory*, NAT'L RES. CTR. FOR SUPPORTED DECISION MAKING, https://supporteddecisions.org/stories-of-supported-decision-making/corys-story/ (last visited Apr. 1, 2021); *see also In Re* Joshua Damian Strong, No. 2002-0082 (Me. Knox Cty. Prob. Ct. Jun. 6, 2018); *In re* [Redacted], No. 70-1995-07327 (Minn. Scott Cty. Dist. Ct. Apr. 16, 2019); *see also In re*

District of Columbia,[34] have court orders and decisions terminating or refusing to order guardianship because of SDM, and many of them occurred without a change first being made to state law.[35]

The fact that court recognition of SDM need not necessarily be predicated by legislative change is supported by the ABA August 2017 resolution, which, while urging state legislative change, simultaneously asked courts to proceed in considering SDM as less restrictive alternative to guardianship and, along with other decision-making supports, as a possible ground for terminating a guardianship, if it would meet the individual's needs.[36]

SDM also has been endorsed by other influential associations, national organizations, and federal agencies and advisory boards.[37] Of particular relevance is the work of the National Council on Disability, which, in March 2018, issued its first of two reports on guardianship and alternatives that examined guardianship and alternatives through the lens of U.S. laws and federal policy impacting people with disabilities, including older adults with disabilities.[38] As NCD stated in that report:

Guardianship of [Redacted], No. PR03-00264 (Nev. Washoe Cty. 2d Dist. Ct. Sep. 11, 2017);*see also Matter of Sean O.*, 2016 NYLJ EXIS 3647, at 18 (N.Y. Sur. Ct., Suffolk County); *In re* Michelle M., 2016 N.Y. Misc. LEXIS 2719, at *18 (N.Y. Sur. Ct. Jul. 22, 2016); *see also In re* Hytham M.G., 2016 N.Y. Misc. LEXIS 2722, at *19–21 (N.Y. Sur. Ct. Apr. 14, 2016); *In re* Dameris L., 956 N.Y.S.2d 848, 853 (N.Y. Sur. Ct. 2012); *Matter of Capurso*, 63 Misc. 3d 725, at *725 (N.Y. Sur. Ct, Wetchester County, March. 26, 2019); *see also In re* Peery, 727 A.2d 539, 541 (Pa. 1999); Ross v. Hatch, No. CWF120000426P-03, 2013 Va. Cir. LEXIS 413, at *1, *6-*7 (Va. Cir. Ct. Aug. 2, 2013*)*; *see also* In re C.B., Stipulation to Dismiss Guardianship (Vt. Super. Ct. Orleans Unit April 11, 2017). *But see* Jenica Cassidy, *Restoration of Rights in the Termination of Adult Guardianship*, 23 ELDER L.J. 83, 119 (noting that, as early as 1891, state courts in the US have "hinted at the (then-unnamed) concept" of SDM as an alternative to guardianship).

34. *See In re* Ryan Herbert King, No. 2003 INT 249 (D.C. Super. Ct. Oct. 6, 2016).

35. *Compare* supra note 33 to supra note 31.

36. AM. BAR ASS'N, 113 RESOLUTION: ADOPTED BY THE HOUSE OF DELEGATES (Adopted Aug. 14–15 2017), https://www.americanbar.org/content/dam/aba/directories/policy/annual-2017/2017-am-113.pdf.

37. *See* Campanella & Whitlatch, *supra* note 32 at 1 (noting SDM's recognition by the National Guardianship Association, the American Bar Association Commission on Law and Aging, the Arc of the United States and the American Association on Intellectual and Developmental Disabilities in 2016, the U.S. Department of Education's Office of Special Education and Rehabilitation Services, the U.S. Social Security Advisory Board, the U.S. Senate Special Committee on Aging, and the National Council on Disability).

38. *See* NAT'L COUNCIL ON DISABILITY, *supra note* 9, at 15. For NCD's second report on guardianship and alternatives, see NAT'L COUNCIL ON DISABILITY,

> [G]uardianship must be understood as a disability policy issue worthy of examination, reflection, and reform . . . . Regardless of whether one is a young adult with a congenital developmental disability subject to guardianship because the court determined he or she lacked the ability to make decisions him or herself, or whether one is in his or her 80s and the court believes that Alzheimer's disease has advanced to the point where he or she can no longer make decisions for his or herself, the reason to impose guardianship is disability in both instances.[39]

In making its many recommendations for reform to the U.S. President, Congress, and a host of federal agencies,[40] NCD expressly recognized that, although guardianship is created by state law, it raises "fundamental questions concerning federal civil rights and constitutional due process" that are worthy of examination and intervention at the national level.[41] Among its findings, NCD saw the value of promoting SDM, concluding that it furthers the important goals of federal policy, including people's right to accommodations, and community integration under the Americans with Disabilities Act and the person-centered planning goals of Medicaid and Home and Community Based Services programs, among others.[42] It also recognized that, on a practical level, SDM has gained more headway as an alternative to guardianship for people with intellectual and developmental disabilities, as opposed to older adults with cognitive impairments and people with psychiatric disabilities,[43] and its recommendations included the funding of more SDM pilots that would test SDM models for those latter populations.[44]

B. Potential for Older Populations

It is widely accepted that older people are one of the main groups likely to become subject to guardianship.[45] The reasons are multiple. Incidence of disabilities, including those related to mobility impairments, hearing and vision difficulties, independent living

TURNING RIGHTS INTO REALITY: HOW GUARDIANSHIP AND ALTERNATIVES IMPACT THE AUTONOMY OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 1–2 (2019) [hereinafter TURNING RIGHTS INTO REALITY].

39. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 9, at 41.
40. *See id.* at 161–67.
41. *Id.* at 27.
42. *See id.* at 132.
43. *See id.* at 133.
44. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 9, at 137.
45. *See id.* at 69.

difficulties and cognitive difficulty—rises with age.[46] Other factors such as diminishing support networks, increased interaction with health care and other service systems, holes in the social safety net, family disputes over an older person's financial or personal choices, and elder abuse and exploitation also play a role.[47] In addition, all of these factors are filtered through the lens of ageism, which can result in a societal presumption that older persons are less capable than they actually are.[48]

Notwithstanding the proliferation of SDM discussion, practice and legislation, most of the focus has remained on younger persons with intellectual and developmental disabilities.[49] There are a number of reasons for this, including the historic origins of SDM in the independent living movement and the focus of pilot projects on persons with IDD.[50] In addition, there are the challenges we describe, *infra*: an orientation toward protection over rights in the elder service system; rates of isolation and dwindling family support; concerns about undue influence and exploitation; and skepticism about the worthwhileness of using SDM by persons with dementia if further progressive decline is inevitable.[51]

Nonetheless, it has been recognized that SDM can be an alternative to guardianship for all adults, not just persons with IDD.[52]

46. WAN HE & LUKE J. LARSEN, U.S. CENSUS BUREAU, OLDER AMERICANS WITH A DISABILITY: 2008-2012, 2–3 (2014), https://www2.census.gov/library/publications/2014/acs/acs-29.pdf.

47. *See* 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, 153 (2021); 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) (analyzing context for sample of guardianship petitions brought against older adults).

48. *See* Diller & Salzman, *supra* note 47, at 151; Jennifer Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J. L. & PSYCHIATRY 350, 361 (2010).

49. *See* L. COMM'N ONT., LEGAL CAPACITY, DECISION-MAKING AND GUARDIANSHIP: FINAL REPORT 97 (2017) (rounding up literature on pilot projects to date which then focused on persons with intellectual disabilities and to lesser extent included persons with psychosocial disabilities); Cathy Costanzo et al., *Supported Decision-Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 97 (2022) (in this volume for a discussion of pilot projects in the IDD context).

50. *See* 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, 520–23 (2016).

51. *See* text accompanying *infra* notes 96–115.

52. *See e.g.*, UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 102 (13) (UNIF. L. COMM'N 2017) (supported

In the aging context specifically, the U.S. Senate's Special Committee on Aging, after a yearlong investigation into guardianship, recommended that states promote SDM among other less restrictive alternatives.[53] The AARP, the nation's leading advocacy organization for older adults, has also endorsed efforts to pass state SDM legislation.[54] There is no particular reason why an effective alternative to guardianship in one context cannot be effective in another.

And it will be even more important in coming years, as the population of older adults rises, to consider how SDM can be used in the aging context. According to the Administration for Community Living, there were 52.4 million persons sixty-five and older in the U.S. in 2018, a thirty-five percent increase from a decade prior, and that number is expected to go up to 94.7 million by 2060.[55] The number of persons eighty-five and older is also rising significantly—reaching 6.5 million in 2018 and expected to reach 14.4 million in 2040.[56] The number of persons living with dementia, a common (though not the only) contributing cause for guardianship for older persons, is also rising with the growth in older population. According to the Alzheimer's Association, "an estimated 6.2 million Americans aged sixty-five and older are living with Alzheimer's dementia in 2021" and "the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050."[57]

In assessing the potential for older populations who might otherwise be at risk of guardianship, it is important to consider in more detail the myriad reasons why older people become subject to guardianships. It is often assumed that a dementia diagnosis is the main factor in guardianships over older adults.[58] But recent

decision-making included as a potential less restrictive alternative for all guardianships).

53. U.S. SENATE SPECIAL COMM. ON AGING, ENSURING TRUST: STRENGTHENING STATE EFFORTS TO OVERHAUL THE GUARDIANSHIP PROCESS AND PROTECT OLDER AMERICANS 23 (2018).

54. Elaine Ryan, *3 Ways to Improve Adult Guardianship and Fight Elder Abuse*, AARP BLOGS (June 7, 2018), https://blog.aarp.org/where-we-stand/3-ways-to-improve-adult-guardianship-and-fight-elder-abuse.

55. *See* ADMIN. FOR CMTY. LIVING ET AL., 2019 PROFILE OF OLDER AMERICANS 3 (2020).

56. *See id.* at 4.

57. ALZHEIMER'S ASS'N, 2021 ALZHEIMER'S DISEASE FACTS AND FIGURES 19–23 (2021).

58. For example, popular press accounts explaining guardianship often refer to it as a mechanism meant for older people with dementia. *See, e.g.*, Liz Day et al., *Britney Spears Quietly Pushed for Years to End Her Conservatorship*, N.Y. TIMES (June 22, 2021), https://www.nytimes.com/2021/06/22/arts/music/britney-spears-

guardianship case file reviews reveal a more complex story. In one of the most systematic attempts to gather data in recent years, the Brookdale Center for Healthy Aging reviewed more than 2,400 case files made under New York's Article 81 adult guardianship law.[59] Because New York has a separate guardianship statute that applies exclusively to persons with IDD, the Article 81 cohort generally includes few persons with IDD; almost sixty percent of persons under guardianship in the files reviewed were older adults.[60] Dementia was listed as a reason in forty-one percent of cases, and psychiatric disability in twenty percent of cases, and a number of other conditions, such as stroke, substance use, traumatic brain injury and others, were noted as well.[61] A file review of cases under Indiana's generally applicable adult guardianship law also revealed that guardianships were associated with a range of impairments; dementia was mentioned in 25.8 percent of filings, cognitive/intellectual impairment in twenty-two percent and severe mental illness in 10.5 percent.[62] Stroke-related conditions were described in 5.4 percent and a general category of "conditions associated with old age" comprised 1.4 percent.[63]

When dementia is mentioned in guardianship filings, as when it is diagnosed, it can mean a variety of things.[64] Dementia is "a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with . . . daily life"[65] and can have a variety of causes. Those include Alzheimer's disease, the most common cause of dementia, but also vascular dementia, Lewy body dementia and frontotemporal dementia, all of which cause progressive cognitive decline.[66] Dementia can also be present as a symptom or mistakenly

conservatorship.html; Laurel Wamsley, *Britney Spears is Under Conservatorship. Here's How That's Supposed to Work*, NPR (June 24, 2021), https://www.npr.org/2021/06/24/1009726455/britney-spears-conservatorship-how-thats-supposed-to-work.**Error! Hyperlink reference not valid.**

59. *See* Jean Callahan et al, *Guardianship Proceedings in New York State: Findings and Recommendations*, 37 BIFOCAL A.B.A COMM. ON L. & AGING 83, 84–85 (2016).

60. *See id.*

61. *See id.*

62. *See* Michael J. Jenuwine, *The State of Adult Guardianship in Indiana: An Empirical Perspective*, *in* WHO'S OVERSEEING THE OVERSEERS? A REPORT ON THE STATE OF ADULT GUARDIANSHIP IN INDIANA 37, 46 (2012).

63. *Id.*

64. *See Dementia: Symptoms and Causes*, MAYO CLINIC, https://www.mayoclinic.org/diseases-conditions/symptoms-causes/syc-20352013 (last visited Mar. 12, 2022).

65. *Id.*

66. *See id.*

diagnosed when a person experiences dehydration, infection, metabolic problems, nutritional deficiencies, and side effects of medication—all conditions that may be reversible with treatment.[67] In addition, even for those with Alzheimer's disease, the severity of cognitive impairment depends on the stage of the disease.[68] The early stage of mild cognitive impairment, which may precede Alzheimer's but can also be diagnosed for other reasons, can be expected to last for an average of eighty-four months with mild dementia expected to last for twenty-four months after that.[69] Moderate dementia is expected to last an additional eighteen months on average before progressing to moderately severe dementia, defined as when a person needs help putting on clothes and eventually bathing and toileting, and then severe dementia.[70] When someone has mild cognitive impairment or mild dementia, their functional capacity can also fluctuate from day to day and even from hour to hour; changes in setting and surroundings can also result in varied levels of cognition.[71] In addition, some types of decisions may require more support than others; for example, managing finances may need more support than decisions about where to live and whether to consent to particular medical treatment.[72] Thus, when a guardianship petition is brought for reasons of "dementia," dementia should be recognized as only the beginning of a description that warrants further inquiry and not the end.[73]

67. *See id.*

68. *See Alzheimer's Functional Assessment Staging Test*, MED. CARE CORP., https://www.mccare.com/pdf/fast.pdf (last visited Mar. 12, 2022).

69. *See id.*

70. *See id.*

71. On fluctuation, see Manuel Trachsel et al., *Cognitive Fluctuations as a Challenge for the Assessment of Decision-Making Capacity in Patients with Dementia*, 30 AM. J. ALZHEIMER'S DISEASE & OTHER DEMENTIAS 360, 360–62 (2015); on changes in setting and surroundings affecting cognition, see Linda F. Smith, *Representing the Elderly Client and Addressing the Question of Competence*, 14 J. CONTEMP. L. 61, 66–67 (1988); Theresa S. Wied et al., *The Human Right to Make One's Own Choices – Implications for Supported Decision-Making in Persons with Dementia*, 24 EUR. PSYCH. 146, 152 (2019) (metareview of articles on medical decision-making).

72. *See* Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decision-Making*, 79 MD. L. REV. 257, 269–70 (2020); Eric Widera et al., *Finances in the Older Patient with Cognitive Impairment*, 305 JAMA 698, 699 (2011) ("Although medical decision-making is primarily a verbally mediated activity occurring at discrete points in time, financial capacity involves a range of knowledge, performance, and judgment skills that are exercised on an ongoing basis.").

73. *See* Wright, *supra* note 72, at 279; AM. BAR ASS'N COMM'N ON L. & AGING & AM. PSYCH. ASS'N, ASSESSMENT OF OLDER ADULTS WITH DIMINISHED CAPACITY: A HANDBOOK FOR PSYCHOLOGISTS 25–26 (2008).

As Megan Wright has summarized in a recent article, "persons with dementia may retain decision-making abilities for years after a dementia diagnosis."[74] But medical personnel, legal professionals and service providers often presume incapacity based on the diagnosis alone, without performing further analysis or engaging in a process to support the person to make decisions.[75] Providing supports and accommodations takes time, effort and patience; as a result, many systems take shortcuts and turn to surrogate decision-making in order to bypass that process.[76]

The availability and recognition of SDM for older persons has a number of potential benefits regardless of diagnosis. Capacity determinations, already highly variable and subjective, can be adjusted to consider whether the older person can, with support, appreciate and understand the consequences of a decision.[77] The legal recognition of decisions made pursuant to SDM agreements can reduce third-party demands that older people be placed under guardianship in order to obtain services or enter contracts.[78] And to the extent that guardianship over older adults is used as a proxy to provide intensive case management and social services, the availability of SDM in conjunction with other supportive services could be an effective alternative.[79]

As with younger persons with IDD who use SDM, older persons stand to benefit by having control over their decisions, which, for many older persons potentially subject to guardianship, is something

74. Wright, *supra* note 72, at 273.

75. *See id.* at 269 n.60.

76. *See id.* at 266, 269–70.

77. *See* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 301(a)(1)(A) (UNIF. L. COMM'N 2017) (standard for appointing a guardian requires court to consider whether the respondent is "unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making").

78. *See* Diller, *supra* note 50 at 530–33. For a discussion of the tensions between the contractual doctrine of incapacity and the anti-discrimination provisions applicable to public accommodations under the Americans with Disabilities Act, see Sean M. Scott, *Contractual Incapacity and the Americans with Disabilities Act*, 124 DICK. L. REV. 253, 257 (2020).

79. PAM TEASTER ET AL., INCAPACITATED, INDIGENT, AND ALONE: MEETING GUARDIANSHIP AND DECISION SUPPORT NEEDS IN NEW YORK 29 (The Guardianship Project ed., 2018) [hereinafter INCAPACITATED, INDIGENT, AND ALONE] (quoting New York City judge as saying, "[a] number of people in New York City could avoid guardianship if services were available beforehand. There should be more attention to preventing guardianship. More aggressive case management and supported decision making.").

they have exercised their whole life. Older persons want to retain control.[80] A recent survey of older persons regarding how they would want to make decisions if they developed dementia finds support for "continuing the push toward a SDM model rather than the traditional 'surrogate decision-making' model" and that older persons wanted control over "more 'personal' decisions on their own for longer as compared to less personal decisions."[81] Studies have also shown that "persons with dementia prefer to be actively involved in decisions that affect their lives."[82] In other contexts, social scientists have found that retaining control and involvement in decisions about one's life correlates with improved outcomes.[83] Conversely, being labeled as incapacitated or incompetent can stigmatize the individual, result in learned helplessness, and accelerate any decline.[84]

As with other groups who may benefit from SDM, the potential for older persons is an important means of facilitating the right to legal capacity. SDM is a means, not an end.[85] It is a means of permitting persons to exercise their human right to legal capacity: to make decisions and have those recognized under the law.[86] This right for older people, as for younger individuals with disabilities, has long been abrogated notwithstanding universal human rights principles that

80. James Toomey, *Understanding the Perspective of Seniors on Dementia and Decision-Making*, 12 AJOB EMPIRICAL BIOETHICS 101, 108–09 (2021).

81. *Id.* at 102, 108.

82. *See* Wright, *supra* note 72, at 261.

83. *See generally* Glen, *supra* note 13, at 98 (discussing the shifting paradigm of guardianship control to the "promotion of greater autonomy for the incapacitated person."). *See also* Nina A. Kohn, *Elder Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1, n.4 (2006) (gathering studies). *See also* AM. BAR ASS'N, PRACTICAL TOOL FOR LAWYERS: STEPS IN SUPPORTING DECISION-MAKING 9 (2016) ("[M]aintaining opportunity for choice and control is an important component of mental health; and that loss of ability—or perceived ability—to control events can lead to or exacerbate physical or emotional illness.").

84. *See* Bruce J. Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health Law*, 1 PSYCH. PUB. POL'Y & L. 6, 14–15 (1995); AM. BAR ASS'N, PRACTICAL TOOL FOR LAWYERS: STEPS IN SUPPORTING DECISION-MAKING 9 (2016) (noting that concerning accelerating decline, "complete loss of status as an adult member of society could in effect act as a self-fulfilling prophecy, intensifying any disability an older person may have").

85. *See* Kristin Booth Glen, *Introducing A "New" Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 9 (2018).

86. *See* Convention on the Rts. of Persons with Disabilities, on Its Eleventh Session, U.N. General Comment No.1, Art. 12 ¶ 8 at 2 (May 19, 2014).

require it to be respected.[87] The UN Committee on the Rights of Persons with Disabilities' General Comment on Article 12 maintained that the CRPD prohibits guardianship altogether;[88] others question that conclusion.[89] But whatever one's position on the CRPD, it is hard to dispute that significant numbers of older people have suffered deprivations of rights through the inappropriate appointment of guardians, the imposition of overly broad guardianships, and a failure to monitor and supervise guardianships.[90] Periodic guardianship scandals have demonstrated that older people have been deprived of their rights in shameful ways that have gone unchecked.[91] In these instances, the safeguards built into existing guardianship law have not been sufficient to prevent the deprivations of rights and ensure that guardianship is performing a beneficial function. In light of these institutional failures, additional alternatives to guardianship that can preserve the right to legal capacity for older people are surely worth exploring and developing.

The right to legal capacity is not just important for ensuring that older persons can make decisions but also for ensuring respect for their

87. *See* Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and Its Implications for the Rights of Elderly People Under International Law*, 25 GA. ST. U. L. REV. 527, 559–64 (2009).

88. *See* Convention on the Rts. of Persons with Disabilities, on Its Eleventh Session, U.N. General Comment No.1, Art. 12 ¶ 7 at 2 (May 19, 2014).

89. *See* Terry Carney, *Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?*, 4 LAWS 37, 41 n.3 (2015) (noting interpretive reservations of Australia and Canada).

90. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 9, at 88–89; U.S. GOV'T ACCOUNTABILITY OFF., GAO-17-33 ELDER ABUSE: THE EXTENT OF ABUSE BY GUARDIANS IS UNKNOWN, BUT SOME MEASURES EXIST TO HELP PROTECT OLDER ADULTS 19 (2016); U.S. H.R. SPECIAL COMM. ON AGING, ABUSE OF POWER: EXPLOITATION OF OLDER AMERICANS BY GUARDIANS AND OTHERS THEY TRUST 4, 7 (2018) (written testimony of David Slayton, Administrative Director, Office of Court Administration, Executive Director Texas Judicial Council).

91. *See, e.g.*, Rachel Aviv, *How the Elderly Lose Their Rights*, NEW YORKER (Oct. 2, 2017), https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights; Monivette Cordeiro & Jeff Weiner, *Florida Guardian Rebecca Fierle Improperly Billed AdventHealth Nearly $4 Million, Report Says*, ORLANDO SENTINEL (Sept. 12, 2019, 5:02 PM), https://www.orlandosentinel.com/news/florida/guardians/os-ne-rebecca-fierle-adventhealth-payments-20190912-ajkua7c6qzg7vg2u3xeezum2wu-story.html; Monivette Cordeiro, *Man Died After Orlando Legal Guardian Filed 'Do Not Resuscitate' Order Against His Wishes, Investigation Finds*, ORLANDO SENTINEL (July 15, 2019, 7:38 AM), https://www.orlandosentinel.com/news/florida/guardians/os-ne-rebecca-fierle-adventhealth-payments-20190912-ajkua7c6qzg7vg2u3xeezum2wu-story.html.

personhood under the law.[92] It is no coincidence that guardianship has been termed a "civil death," in that the person under guardianship ceases to be a holder of rights under the law.[93] This has implications not just for the legal recognition of a particular decision the person may make but also for how the law and society view the person under guardianship more generally. As the COVID-19 crisis laid bare, rampant ageism persists and plays out in policy debates in both obvious and subtle ways—from choices about rationing treatment and the woefully inadequate efforts to stop the spread of COVID-19 in nursing homes to discussions of the crisis's toll that devalue the significance of deaths of older persons.[94] Depriving an older person of their personhood under the law sends a powerful message about their value in society.

II. CONTEXT & CHALLENGES FOR OLDER POPULATIONS

There are a number of challenges to expanding the availability of SDM for older persons. Some of these, such as the significant time and resources (financial and otherwise) that it can take to engage in SDM, have been identified by Costanzo, Glen, and Krieger.[95] Others are unique in the way they play out for older people; we focus on those challenges here.

A. Orientation Toward Protection, Not Rights, in the Elder Service System

One of the most significant challenges stems from the institutional mindsets of the legal, health care, and social service systems. "Ageism," in the form of negative stereotypes about capabilities and social marginalization, is well-documented as occurring throughout these spheres.[96] But a particular manifestation of ageism—the paternalism that overrides decisions made by older persons in the name of guarding against risk—is an especially

92. United Nations Convention on the Rights of Persons with Disabilities and Optional Protocols, art. 12, §1. On guardianship and personhood, see Gerard Quinn & Abigail Rekas-Rosalbo, *Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability*, 56 IRISH JURIST 286, 296 (2016). *See generally* Ellionoir Flynn & Anna Arstein-Kerslake, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, 10 INT'L J. L. CONTEXT 81 (2014) (examining use of legal capacity to regulate personhood).

93. Quinn & Rekas-Rosalbo, *supra* note 92, at 286–87.

94. *See, e.g.*, Sara Fraser et al., Commentary, *Ageism and Covid-19: What Does Our Society's Response Say About Us?*, 49 AGE & AGEING 692, 693 (2020).

95. *See* Costanzo et al., *supra* note 49, at 55–60.

96. *See* Whitton, *infra* note 191, at 456–57.

challenging obstacle to expanding SDM as an alternative to guardianship.[97] This risk-aversion tendency plays out with special force in those parts of these service systems that intersect with guardianship. While much public policy has been oriented toward promoting independent living and autonomy for older persons—including significant parts of the Older Americans Act, which has among its stated objectives "[f]reedom, independence, and the free exercise of individual initiative in planning and managing their own lives"[98]—the parts of the elder service system that intersect with guardianship often are more centrally focused on protection than promotion of autonomy.[99]

One part of the social services system that is often closely connected to guardianship practice is the adult protective services divisions of local and state government.[100] Adult protective services can include case management but also more aggressive interventions into the lives of older adults, including psychiatric evaluations, seeking court orders to gain access to a residence, involuntary financial management, and, finally, petitions for guardianship.[101] Adult protective services departments also often oversee or run local public guardian programs.[102] The statutory mandate of these departments is primarily to investigate and protect from abuse, neglect, and exploitation.[103] While many departments may seek to promote client rights and use the least restrictive means of

97. *See* Whitton, *infra* note 191, at 472.

98. 42 U.S.C. § 3001(10) (2010).

99. *See generally* Whitton, *infra* note 191, at 472.

100. *See* Callahan et al., *supra* note 59 at 85 (in Brookdale's study, the county, via the local Department of Social Services or Adult Protective Services, accounted for 22% of petitioners in guardianship proceedings).

101. See, *e.g.*, N.Y. SOC. SERV. LAW § 473(1) (McKinney 2021).

102. *See e.g.* N.Y. MENTAL HYG. LAW § 81.06(a)(6) (McKinney 2021); PAM B. TEASTER ET AL., PUBLIC GUARDIANSHIP AFTER 25 YEARS: IN THE BEST INTEREST OF INCAPACITATED PEOPLE? 27–28 (2007) [hereinafter PUBLIC GUARDIANSHIP AFTER 25 YEARS].

103. *See* 42 U.S.C. § 1397j(2) (2010) (defining adult protective services as "such services provided to adults as the Secretary may specify and includes services such as— (A) receiving reports of adult abuse, neglect, or exploitation; (B) investigating the reports described in subparagraph (A); (C) case planning, monitoring, evaluation, and other case work and services; and (D) providing, arranging for, or facilitating the provision of medical, social service, economic, legal, housing, law enforcement, or other protective, emergency, or support services"). In contrast, the Developmental Disabilities Act's purposes include protection but also promotion of integration and inclusion and providing support so that individuals can make informed choices about their lives. *See* 42 U.S.C. § 15001(a)(16) (2010).

intervention, the nature of the work is such that the focus is inevitably more on protection than promoting the rights of the individual.[104] This is not to say that protective services are only provided to older people; in a number of states, any adult with a mental or physical impairment may be deemed eligible due to inability to manage resources or carry out the activities of daily living or other factors.[105] But to the extent that these departments are the ones that interact with the courts with regard to a certain subset of guardianships, it is noteworthy that their statutory mission is focused on protection, not promoting independence,[106] and, therefore, significant culture change may be needed for these systems to embrace SDM.

Then there is the well-documented tendency of pockets of the health care system to overmedicate, overtreat, and override patient wishes so as to reduce risks and further institutional prerogatives.[107] Health care institutions such as hospitals and nursing homes are frequent players in guardianship. For example, hospitals may petition for guardianship as part of discharge planning for a patient whom the hospital deems ready to leave but incapable of going home.[108] That same patient may be capable of returning home safely with adequate

104. The focus becomes clear when contrasted with another "protection," namely the protection and advocacy programs that serve persons with developmental disabilities, mental illness, traumatic brain injury, and other disabilities, which have as their core statutory mandate not just protection but also advocacy of the rights of persons receiving their services. *See* 42 U.S.C. § 15043 (2010) (Protection and Advocacy for Persons with Developmental Disabilities); 42 U.S.C. § 10801(b)(1) (2010) (Protection and Advocacy for Individuals with Mental Illness; 29 U.S.C. § 794e (2021) (Protection and Advocacy for Individual Rights); 42 U.S.C.S. § 300d–53 (LexisNexis 2021) (Protection and Advocacy for Persons with Traumatic Brain Injury).

105. For a round-up of state APS eligibility requirements, see AM. BAR ASS'N COMM'N ON LAW & AGING, THRESHOLD ELIGIBILITY REQUIREMENTS FOR ADULT PROTECTIVE SERVICES 1 (2020).

106. *See* 42 U.S.C § 1397j(2) (2010).

107. *See* Alberto B. Lopez & Fredrick E. Vars, *Wrongful Living*, 104 IOWA L. REV. 1921, 1925 (2019) ("a physician may overlook whether or not the patient wants to avoid increasingly invasive treatments" and at end of life, "[p]atients are 'objectified' in a state of 'custodial dehumanization' where patient autonomy is an afterthought."). This idea that a patient's wishes can be overridden is embedded in many state advance directives laws, which permit providers to refuse to comply with a patient's wishes for reasons of conscience, ethical or moral grounds, or in some cases, for any reason. *See also* Monica Sethi, *A Patient's Right to Direct Own Health Care* vs. *a Physician's Right to Decline to Provide Treatment*, 29 BIFOCAL 21, 22 (2007).

108. Jennifer Moye, et. al., *Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice* 2 (June 2017) (unpublished manuscript, available on the HEC FORUM); s*ee* Rosenberg, *supra* note 47, at 342.

supports that are difficult to obtain. Nursing homes, frequent petitioners in guardianships and also the places where many older people under guardianship reside, either when their guardianships are commenced or after being moved there by their guardians, have been the focus of much advocacy to push them toward a more person-centered model of providing care. [109] Yet, despite these efforts to effect "culture change," much has stayed the same operationally within many institutions and much "nursing home care thwarts resident autonomy and decision-making."[110]

Finally, within the legal system itself, aging rights do not stand on quite the same footing, either domestically or internationally, as disability rights. There is no international human rights treaty specific to older persons and, as Arlene Kanter has written, "as we review the international and regional instruments that have been enacted to enhance the rights of elderly people, as a group, the majority seem to perpetuate the view of older people as in need of protection, not as rights-holders."[111] The same theme holds in domestic law. Notwithstanding the prevalence of age discrimination in multiple aspects of public life, age is not a suspect classification subject to heightened scrutiny nor is there a comprehensive statutory regime to protect against it.[112] Many older people can benefit from the protections of the ADA to the extent that they suffer discrimination due to age-related disabilities,[113] but they may not identify as persons with disabilities after not having had that identity for most of their lives.[114] Though the aging and disability categories may overlap in that

109. On nursing homes as petitioners, see Nina Bernstein, *To Collect Debts, Nursing Homes Are Seizing Control Over Patients*, N.Y. TIMES (Jan. 25, 2015), https://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html; *see also* Callahan et. al., *supra* note 59, at 85 (nursing homes 15% of petitioners and "[a] t the time of the petition 31% of AIPs were residing in skilled nursing homes . . . and 11% were in a hospital."). On advocacy for person-centered care in nursing homes, see Laci Cornelison, *The Culture Change Movement in Long-Term Care: Is Person-Centered Care a Possibility for the Looming Age Wave?*, 12 NAELA J. 121, 124 (2016)

110. *Id.*

111. Kanter, *supra* note 87, at 538.

112. *See, e.g.* Mass. Bd. Ret. v. Murgia, 427 U.S. 307, 312 (1976); Kimel v. Fla. Bd. Regents, 528 U.S. 62, 83 (2000). The major federal anti-discrimination law devoted to age is the increasingly limited Age Discrimination in Employment Act; the Age Discrimination Act of 1975, which prohibits age discrimination in federally funded programs, is quite limited in scope. *See* 42 U.S.C. § 6102 (1975).

113. *See generally* Kevin M. Cremin, *Regarding Age as a Disability: Conceptualizing Age Discrimination at Work as (Mis)perception of Disability Discrimination*, 39 CARDOZO L. REV. 439, 466–67 (2017).

114. *Id.* at 450–51.

older persons at risk of guardianship are likely persons with age-related disabilities, without a broader elder rights framework baked into the legal system, notwithstanding language in many guardianship statutes about preserving rights to the greatest extent possible, it is easy for practice to perpetuate a paternalistic model focused more on avoidance of risk and the prerogatives of than on preserving autonomy.[115]

These are broad characterizations, of course. But to the extent that these systems all play a role in guardianship practice and would have to embrace to some degree the model of SDM in order for it to take root, these paternalistic tendencies pose a challenge.

B. Overlap of Decision-Making Support Needs with Social Safety Net Needs

If SDM is to be used as an alternative to guardianship for older persons, then the question of why an older person might be under guardianship or at risk of guardianship arises. And here the answer is multidimensional, and not just a product of that person's decision-making ability or challenges. Most state statutes provide that guardianship may only be imposed when an individual faces personal or financial harm due to an inability to make or communicate decisions or when a need for assistance, care or supervision is demonstrated.[116] Many people with cognitive impairments may need support with decision-making; yet guardianship is not considered as a necessary protection until a crisis arises that threatens to harm the individual.[117] The availability of SDM will not on its own solve the other personal and financial crises that prompt guardianship petitions to be filed.

Some older adults become subject to guardianships not specifically because of decision-making impairments but because of poverty, threats of homelessness, and related economic and social challenges.[118] Some of these individuals may not need SDM in order to make decisions but may need significant social safety net support

115. *Cf.* Nina Kohn, *A Civil Rights Approach to Elder Law*, *in* BEYOND ELDER LAW 19 (Israel Doron & Ann M. Soden eds., 2012).

116. *See* AM. BAR ASS'N COMM'N ON LAW & AGING, CAPACITY DEFINITION & INITIATION OF GUARDIANSHIP PROCEEDINGS (Aug. 2020), www.americanbar.org/content/dam/aba/administrative/law_aging/chartcapacityandinitiation.pdf; UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT §§ 301, 401 (UNIF. L. COMM'N 2017).

117. *See* Rosenberg, *supra* note 47, at 326–27.

118. *See* INCAPACITATED, INDIGENT, AND ALONE, *supra* note 79, at 25; Rosenberg, *supra* note 47, at 32.

to obtain benefits and housing. For example, in its practice, the Bet Tzedek clinic, has removed guardianships from four individuals in recent years who were not found incapacitated but rather consented to a guardianship brought on by a social services department concerned about their looming eviction.[119] The guardianships persisted long after the evictions, and while the guardianships may have delayed the evictions initially, the individuals ended up in an adult home, assisted living or other institutional setting while under guardianship, indicating that the guardianship was not able to solve the underlying root problem of a lack of housing.[120]

For others, SDM, in conjunction with other supports and accommodations, may be the less restrictive alternative that could prevent guardianship or permit the older person to terminate a guardianship.[121] But SDM alone will not be sufficient in these cases. Just as guardianship is a transfer of legal decision-making rights to a surrogate and not a package of services, SDM can accommodate cognitive impairments by supporting the decision-making process, but it cannot alone provide other social and economic supports that the individual may need. For example, an older person may benefit from SDM to assist with gathering information about and filling out housing applications but the support with those documents will not produce an affordable apartment or assist the older person in moving to the top of a long waitlist.[122] Similarly, when an older person needs support in the form of intense case management to obtain public benefits, SDM may help with some aspects of that process but it is not a substitute for an advocate's assistance to navigate the intricacies of Medicaid

119. The sources and details related to the cases mentioned here have not been independently verified by *Syracuse Law Review*. In light of confidentiality, further identifying information concerning the practice of Cardozo's Bet Tzedek clinic may be obtained by contacting the authors directly.

120. *Id.*

121. UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT, Prefatory Note 1 (UNIF. L. COMM'N 2017) ("[UGCOPAA] recognizes the role of, and encourages the use of, less restrictive alternatives, including supported decision-making and single-issue court orders instead of guardianship and conservatorship.").

122. For a discussion of the affordable housing crisis facing older persons, see JOINT CTR. FOR HOUS. STUD. OF HARV. UNIV., HOUSING AMERICA'S OLDER ADULTS: MEETING THE NEEDS OF AN AGING POPULATION 21 (2014) ("In 2011, 3.9 million households aged sixty-two and over without children had very low incomes (at or below 50 percent of area median), a common eligibility threshold for programs targeting the 'elderly.' Of these, only 1.4 million (36 percent) benefited from rental assistance. A large majority (58 percent) of very low-income households aged sixty-two and over without assistance face either excessive housing costs, live in severely inadequate units, or both. . . .").

eligibility, to take one example.[123] Or, when an older person has been subject to abuse or financial exploitation, the use of SDM may ensure that a trusted supporter can assist the older person in the future, but it may not on its own remedy the abuse suffered previously (though guardianship may not either).[124]

C. Lack of Recognition of SDM by Third Parties

In addition, without clear statutory guidance on third-party recognition of SDM arrangements, older people using support will continue to face the challenge of having their decisions made with support recognized by third parties. Just as younger persons with disabilities are pushed toward guardianship as a result of service providers telling families that guardianship is necessary because the individual's decisions will not be given legal recognition,[125] so too do older people face guardianships spurred by a "gatekeeper" demanding it in order to provide a service or recognize a decision.[126] In these instances, health care, social service and financial institutions reject the decisions of the older person and/or inform a family member attempting to support the individual that she must obtain guardianship in order to do so.[127]

These demands may emanate from unfounded assumptions about capacity. They may also be rooted in fear of liability--fear that if it were later found that the individual lacked the mental capacity to provide informed consent or agree to a transaction, the other party could be liable.[128] More widespread training on how older persons can be supported to make decisions can ameliorate this barrier. If, for

123. *See Medicaid*, NAELA, www.naela.org/Web/Consumers_Tab/Consumers_Library/Consumer_Brochures/Elder_Law_and_Special_Needs_Law_Topics/Medicaid.aspx (last visited Mar. 13, 2022) ("Because [Medicaid] is so complex, Elder Law attorneys are a particularly appropriate source of advice.").

124. *See* Diller & Salzman, *supra* note 47 at 181.

125. A number of scholars and advocates have written about this "school to guardianship" pipeline. *See, e.g.*, Arlene S. Kanter, *Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act*, 8 J. INT'L AGING L. & POL'Y 1, 3 (2015).

126. Diller, *supra* note 50 at 530–31.

127. *Id.* at 531.

128. *See* Kevin De Sabbata, *Dementia, Treatment Decisions, and the UN Convention on the Rights of Persons with Disabilities. A New Framework for Old Problems*, 11 FRONTIERS PSYCHIATRY 1, 9 (2020) (describing European efforts to change professional standards for obtaining informed consent to encompass supported decision-making for persons with dementia so that medical professionals will not fear liability).

example, medical professional standards required not just capacity assessments but a series of standard interventions to ensure that older patients received necessary supports to make decisions, the incentive structure would change.[129] Legislative reform can also reduce this barrier by providing third parties clear guidance on when they will be immunized from liability for accepting a decision made with support under a particular SDM agreement or process.[130]

D. Isolation and Tightening of Circle of Support

SDM for older persons faces an additional challenge in that most models to date have presumed pre-existing supporters in the form of trusted family or friends whom decision-makers may choose to support them.[131] For many older people, it is precisely because they do not have anyone in their lives who can serve as a consistent and reliable source of support that they may be at risk of guardianship.[132] For example, the lack of support may make advance planning more challenging because they do not have a trusted person to designate in an advance directive.[133] In our practice experience, we have observed that it is often those who do not have trusted family or friends in their lives who find themselves subject to guardianship, especially public guardianship.[134]

Age is correlated with increased social isolation, defined as "having few social relationships or infrequent social contact with others."[135] According to a National Academies of Sciences report,

129. *Id.* (describing issuance of guidelines by German medical associations for how to support people with dementia in making choices about health care).

130. The various state statutes on supported decision-making do this. *See, e.g.*, TEX. EST. CODE ANN. § 1357.101 (West 2021).

131. *See* Rachel Mattingly Phillips, *Model Language for Supported Decision-Making Statutes*, 98 WASH. UNIV. L. REV. 615, 629 (2020). This assumption is embedded in the various state statutes that have recognized supported decision-making agreements. *See id.* at 628. The statutes typically permit an individual to designate another person as their supporter but do not provide a mechanism for those who have no one to designate. *See id.*

132. NAOMI KARP & ERICA WOOD, AM. BAR ASS'N COMM'N ON L. & AGING, INCAPACITATED AND ALONE: HEALTH CARE DECISION-MAKING FOR THE UNBEFRIENDED ELDERLY, 1 (2003), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2003_Unbefriended_Elderly_Health_Care_Descision-Making7-11-03.pdf.

133. *Id.* at 7.

134. *See* INCAPACITATED, INDIGENT, AND ALONE, *supra* note 79, at 22 ("One judge we interviewed pointed out that a lot of people have no one and have outlived their children and relatives.").

135. NAT'L ACAD. OF SCIS, ENG'G & MED., SOCIAL ISOLATION AND LONELINESS IN OLDER ADULTS: OPPORTUNITIES FOR THE HEALTH CARE SYSTEM 1 (Nat'l Acad. Press 2020).

"[a]pproximately one-quarter (24 percent) of community-dwelling Americans aged 65 and older are considered to be socially isolated, and a significant proportion of adults in the United States report feeling lonely."[136] Social isolation and loneliness among older persons can arise due to a number of factors, including outliving one's spouse, relatives and friends; incidents of vision, hearing, mobility, and other impairments that may make social interaction more difficult; living alone; the loss of professional relationships due to retirement and geographic location.[137] Then there are lifelong "loners," who had existed at the margins of society for much of their lives.[138] They might have continued their somewhat isolated lives without drawing attention from the legal, healthcare and social service systems but for the development of significant health care needs, which prompted medical institutions to search for persons to engage in the decision-making process.

The SDM work in the U.S. to date has often presumed that a decision-maker already has trusted family and others among whom they can choose to provide support. This approach is reflected in the state statutes on SDM Agreements, described *supra*, which presume that individuals have supporters to name in their agreements.[139] Similarly, while more state statutes have required SDM to be considered as a less restrictive alternative before guardianship may be imposed, it appears that courts have not yet interpreted those provisions to mandate that the state provide those supports or resources for those who do not have preexisting supports.[140] For older people in particular, this approach may have limitations as trusted family and friends pass away, or are no longer available, or as emergent needs arise for persons who may never have had a circle of trusted individuals in their lives.[141]

136. *Id.*

137. *Id.* at 63–89.

138. KARP & WOOD, *supra* note 132 at 15.

139. For a summary of the statutes to date, see generally Phillips, *supra* note 131 at 628 (describing state statutes that presume individuals have trusted individuals to name as supporters).

140. *See* KARP & WOOD, *supra* note 132 at 27. This leads to situations in which a person who may need support with financial or health care management but who has no preexisting supporters may only be able to obtain assistance if they lose their rights and have a guardian appointed. Many guardianships might be avoided if there were more robust publicly funded alternatives providing support, not just the public guardianship programs.

141. *Id.* at 15.

A lack of preexisting supporters raises several challenges. First, the model for providing support may have to adjust to accommodate new persons in the life of the decision-maker, and not those who have known the person for a long time and already gained their trust.[142] Second, if persons who need support cannot rely upon close relatives and friends, then it becomes necessary to consider the development of a cadre of paid supporters — and the significant questions about whether funds for paid support should be provided publicly and/or be supplemented by the person being supported, if that person can afford it.[143] There is also the possibility of creating volunteer programs, which might be less costly but would nonetheless require funds for training and supervision in order to ensure that volunteers perform their supporter function properly.

So far, SDM has largely been presented as a potential resource-saving alternative to guardianship, a measure that can keep people with significant needs out of the courts.[144] But in order to ensure that it is actually a viable option for older persons without an existing network, public funding will be necessary.[145] That funding would likely result in savings elsewhere in the guardianship and/or elder service systems, but further study would be necessary to demonstrate how, where, and how much.

E. Impact of COVID-19 Pandemic

The COVID-19 pandemic added another layer of challenges to implementing SDM, providing the most recent example of how a public health crisis can further exacerbate isolation experienced by older adults.[146] It brought to the fore discriminatory hospital visitor bans that failed to allow for required reasonable accommodations for patients with disabilities who need in-person supporters while hospitalized in order to ensure the equal access to health care to which they are entitled under federal law.[147] A patient with a disability—including older adults who have experienced strokes or have or other

142. *Id.* at 32.

143. *See* PUBLIC GUARDIANSHIP AFTER 25 YEARS, *supra* note 102 at 48.

144. Eliana J. Theodorou, Note, *Supported Decision Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973, 994–95 (2018).

145. KARP & WOOD, *supra* note 132, at 26.

146. *Id.*

147. Letter from Bob Joondeph, Dir., Disability Rts. Conn. et al., to Roger Severino, Dir., Off. for Civ. Rts., 3 (May 4, 2020), https://www.centerforpublicrep.org/wp-content/uploads/2020/05/CT-OCR-visitor-policy-cmplt-FINAL-5.4.20-.pdf (federal complaint alleging illegal discrimination concerning COVID-19 hospital visitation policies).

neurological or psychiatric conditions—may require an in-person supporter to ensure effective communication, informed consent through SDM, and/or physical and behavioral support while in the hospital. These bans have prompted federal complaints to be filed with the U.S. Department Health and Human Services' Office for Civil Rights (OCR).[148] One such high profile complaint came out of Connecticut and highlighted the experience of "G.S.," an older adult in her early seventies who had experienced a frontal lobe aneurism and several strokes that resulted in aphasia and severe short-term memory loss.[149] G.S. required family members to remain at the hospital with her in order to facilitate communication between her and the hospital staff.[150] The complaint described that process in a way that clearly linked it to G.S.'s ability to use SDM. It stated:

> Over the years, family members have developed sophisticated individualized means of communicating with G.S. including modeling words, simplifying and chunking information, making direct eye contact and recognizing when G.S. is experiencing fever, fatigue, pain, and discomfort through various non-verbal cues. Through these communication techniques, G.S. has been able to understand the treatment being offered to her and been provided with the opportunity to make informed decisions concerning her care.[151]

The Complaint argued that, by failing to ensure that people like G.S. had reasonable access to supporters while in the hospital, the State of Connecticut was violating its responsibility under Title II of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.[152] On June 9, 2020, the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) announced it resolved both this complaint and an accompanying one against the hospital.[153] Community advocates argue that these resolutions and the new Connecticut policy represent OCR expectations for how states and hospitals nationwide can safeguard public health while following federal law requirements

148. *Id.* at 2.
149. *Id.* at 3.
150. *Id.*
151. *Id.* at 3–4.
152. Joondeph et al., *supra* note 147, at 8.
153. *See* Press Release, U.S. Dep't Health & Hum. Servs., OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19 (June 9, 2020), https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html.

to reasonably accommodate patients with disabilities who need access to their supporters while hospitalized.[154]

However, even after the June 2020 OCR resolutions, the struggle for enforcement of reasonable accommodations in decision-making for older hospital patients with disabilities in different jurisdictions continued, as states were uneven in their implementation.[155] It also included advocacy in nursing facility settings.[156] In response to such pressure, in September 2020, the Centers for Medicare and Medicaid Services (CMS) issued revised nursing facility visitation guidance that recognized "that physical separation from family and other loved ones has taken a physical and emotional toll on residents"[157] and clarified that each facility must comply with federal disability rights law, including Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, including allowing entry of supporters to facilitate communication under certain circumstances.[158] Elder justice advocates continued to push for state implementation of this CMS guidance and further reforms, so that nursing facility residents had access to the "essential support persons" they needed to combat the damaging toll of isolation during the COVID-19 pandemic.[159] With

154. Memorandum from The Arc et al., Evaluation Framework for Hospital Visitor Policies 1 (Oct. 2020) https://secureservercdn.net/166.62.108.22/izh.66f.myftpupload.com/wp-content/uploads/2020/10/FINAL-Disability-Org-Guidance-on-COVID-19-Hospital-Visitation-Policies-updated-100720.pdf.

155. *See, e.g.*, Press Release, Disability Rts. DC, HHS OCR Achieves Resolution of Federal Complaint Challenging MedStar Health's Visitation Policies and Discriminatory Denial of Equal Access to Medical Care During COVID-19 Pandemic 1 (Feb. 16, 2021), www.uls-dc.org/media/1238/medstar-hhs-ocr-resolution-press-release-final-021621.pdf (announcing resolution of complaint to remedy MedStar Health's denial of access to in-person support for William King, a 73-year old man with communication-related disabilities) (CommunicationFIRST, the Center for Public Representation, The Arc of the United States, the Autistic Self Advocacy Network, the Civil Rights Education, and Enforcement Center, Quality Trust for Individuals with Disabilities, and the Washington Lawyers' Committee joined the federal disability discrimination complaint); Dominique Maria Bonessi, *MedStar Health Changes COVID-19 Protocols Following Disabilities Discrimination Complaint*, DCIST (Feb. 19, 2021, 1:46 PM), https://dcist.com/story/21/02/19/medstar-health-covid-19-protocols-disabilities-discrimination-complaint/.

156. Memorandum from U.S. Dep't Health & Hum. Servs. Ctrs. for Medicare & Medicaid Servs., Nursing Home Visitation–COVID-19, 1 (Sept. 17, 2020), https://cms.gov/files/documents/qso-20-39-nh.pdf.

157. *Id.* at 2.

158. *Id.* at 6.

159. *See* Letter from The Nat'l Consumer Voice for Quality Long-Term Care, to Elizabeth Richter, Acting Adm'r, Ctrs. for Medicare & Medicaid, 1 (Mar. 3, 2021).

the rise in vaccination rates of residents and staff in nursing facilities and the reduced weekly COVID-19 infection rates, CMS again updated its guidance in November 2021 to allow more liberal visitation, including indoor visits, "at all times for all residents," with "very limited and rare exceptions" and with an emphasis on infection prevention practices.[160] But the prior restrictions and isolation took a heavy toll. According to an Associated Press report, besides COVID-19 deaths, 40,000 more people than usual died in US nursing facilities in 2020, many from neglect and isolation.[161]

F. Risk of Financial Exploitation and Undue Influence

Perhaps the most frequent concern voiced about SDM for older persons is that it will become a tool for abuse or exploitation, especially with regard to the older person's finances.[162] This concern is legitimate and important, given estimates that at least 3.5 million adults experienced elder financial abuse in 2017.[163] One of the most ambitious studies of elder financial exploitation prevalence found that 4.7 percent of older persons surveyed reported having experienced

160. Memorandum from U.S. Dep't Health & Hum. Servs. Ctrs. For Medicare & Medicaid Servs., Nursing Home Visitation – COVID-19 (Revised) (Nov. 12, 2021, revised Mar. 10, 2022) https://www.cms.gov/files/document/qso-20-39-nh-revised.pdf.

161. *See* Emily Paulin, *Feds Drop Most COVID-19 Restricts on Nursing Home Visits,* AARP (Nov. 15, 2021), https://www.aarp.org/caregiving/nursing-homes/info-2021/coronavirus-nursing-home-restrictions.html (citing Matt Sedensky & Bernard Condon, *Not Just COVID: Nursing Home Neglect Deaths Surge in Shadows*, AP NEWS (Nov. 19, 2020), https://apnews.com/article/pandemics-us-news-coronavirus-pandemic-daac7f011bcf08747184bd851a1e1b8e).

162. *See, e.g.*, ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT 26 (2016), https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-SDM-HSRI-Evaluation-Year-2-Report-2016.pdf.

163. CONSUMER FIN. PROT. BUREAU: OFF. FIN. PROT. FOR OLDER AM., SUSPICIOUS ACTIVITY REPORTS ON ELDER FINANCIAL EXPLOITATION: ISSUES AND TRENDS 12 (2019), https://files.consumerfinance.gov/f/documents/cfpbsuspicious-activity-reports-elder-financial-exploitatation_report.pdf (applying a conservative prevalence rate of 5.2 percent to the number of adults sixty and older in 2017). As the CFPB noted, data is incomplete due to underreporting, and there is a wide range in the estimates of the prevalence of elder financial exploitation as well as the total financial losses associated with it. *Id.* at 23. A recent New York study gleaned prevalence rates from a survey of more than 4,000 older New Yorkers and found that 41 out of 1000 reported "major financial exploitation" defined as "theft of money or property, using items without permission, impersonation to get access, forcing or misleading to get items such as money, bank cards, accounts, power of attorney." LIFESPAN OF GREATER ROCHESTER, INC. ET AL., UNDER THE RADAR: NEW YORK STATE ELDER ABUSE PREVALENCE STUDY 3 (2011), www.ocfs.state.ny.us/main/reports/Under%20the%20Radar%2005%2012%2011%20final%20report.pdf.

elder financial exploitation.[164] Limitations in managing instrumental activities of daily living and activities of daily living are risk factors that make one more susceptible.[165] Dementia has also been found to be a risk factor.[166] Given the prevalence of financial exploitation through means such as wills, powers of attorney, deed theft, abuse of ATM and credit cards, and others, there has been concern about whether SDM could provide yet one more means that an abuser could use to take advantage of an older person with a cognitive or other impairment.

Elder financial exploitation occurs in a variety of contexts with perpetrators ranging from family caretakers to off-shore telephone scam artists.[167] It can occur to people in the community exercising full control over their financial and personal affairs, and it can occur under guardianship when unscrupulous guardians evade court scrutiny or operate in court systems that do not actively monitor guardianships.[168] While the incidents that gain the most attention tend to involve exploitation of the rich and famous, such as Brooke Astor, the data show that older persons living in poverty are more likely to experience elder financial exploitation than their wealthier counterparts.[169]

There is not any systematic data yet on abuse or exploitation with SDM arrangements nor is there reason to believe that SDM will subject an older person to abuse more so than any other mechanism. In the Center for Public Representation's Nonotuck pilot project, an independent evaluation concluded that participants "did not experience abuse, neglect or financial exploitation as a consequence of SDM."[170] As participants in the ABA Commission on Law and Aging's convening on SDM across the age spectrum noted:

164. Janey C. Peterson et al., *Financial Exploitation of Older Adults: A Population-Based Prevalence Study*. 12 J. OF GEN. INTERNAL MED. 1615, 1618 (2014).

165. *See id.* at 1621.

166. *Research, Statistics, and Data*, NAT'L CTR. ON ELDER ABUSE, https://ncea.acl.gov/About-Us/What-We-Do/Research/Statistics-and-Data.aspx (last visited Mar. 13, 2022).

167. U.S. GOV'T ACCOUNTABILITY OFF., GAO-13-110 ELDER JUSTICE: NATIONAL STRATEGY NEEDED TO EFFECTIVELY COMBAT ELDER FINANCIAL EXPLOITATION 1 (2012), https://www.gao.gov/assets/660/650074.pdf.

168. *Id.*; *see* NAT'L COUNCIL ON DISABILITY, *supra* note 9, at 70–71, 103–04.

169. Peterson et al., *supra* note 164, at 1618. Poverty may make one more likely to fall into guardianship as well. *See* Callahan et al., *supra* note 59, at 84. In the Brookdale Center's analysis of the New York guardianship system that applies mostly to older adults, fifty-five percent of the persons over whom guardianship was sought "had annual incomes of less than $20,000." *Id.* at 85.

170. PELL & MULKERN, *supra* note 162 at 5.

> [w]hile in theory the range of decision support mechanisms are neither a cause nor a solution to abuse, neglect, or financial exploitation, all agreed that any decision support, from a supported decision-making agreement to a power of attorney or joint bank account, or guardianship, poses a risk of abuse, neglect, and exploitation."[171]

It is important to note that in contrast to a power of attorney, under which an agent may be able to make a surrogate decision for the principal without her knowledge or involvement, SDM agreements specifically provide that the supporter may not make decisions for the principal or decision-maker but rather may only assist in gathering and understanding information and in communicating decisions.[172]

State SDM agreement statutes have included provisions designed to address the possibility of abuse in a variety of ways. Some require certain thresholds for entering the agreements, such as ensuring it be voluntarily and without undue influence or coercion,[173] and/or requiring that the decision-maker understand the nature and effect of the SDM agreement.[174] Statutes have required formalities of execution such as notarization or witnessing, permitted the agreements to be terminated at any time, and barred those with conflicts of interests[175] or certain background or criminal histories[176] from serving as supporters. SDM agreement statutes have included provisions stating that a third-party presented with an agreement who suspects abuse

171. AM. BAR ASS'N COMM'N ON LAW & AGING, SUPPORTED DECISION-MAKING ACROSS THE AGE SPECTRUM 7 (March 2020), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-supporting-decision-making-final-report.pdf.

172. *See* WIS. STAT. § 52.10(2) (2021) ("A supporter is not a surrogate decision maker for the adult with a functional impairment and does not have the authority to sign legal documents on behalf of the adult with a functional impairment or bind the adult with a functional impairment to a legal agreement.").

173. *See* Supported decision-making Agreements, DEL. CODE ANN. tit. 16, § 9405A (2021); Authorizing and Witnessing of Supported Decision-making Agreement, TEX. EST. CODE. ANN. § 1357.055 (West 2021).

174. ALASKA STAT. § 13.56.010 (2021).

175. *See*, e.g., TEX. EST. CODE ANN. § 1357.055 (West 2021); ALASKA STAT. § 13.56.040 (2021) (document may be either signed by two witnesses or notarized); DEL. CODE ANN. tit. 16, § 9405A (enabling principal to revoke a SDM Agreement at any time by providing written notice to the other parties to the SDMA); ALASKA STAT. § 13.56.020 (2021) (barring service providers from serving as supporters).

176. *See* D.C. CODE § 7-2132(b) (2021) (prohibiting an individual from being a formal supporter under an SDMA if they have been found by a governmental agency to have abused, neglected, or exploited the supported person or inflicted harm upon a child, elderly individual or person with a disability or have been convicted of certain criminal offenses).

either is mandated or permitted to make a report to state registries and/or adult protective services agencies.[177] In response to advocacy by the real estate, probate, and trust section of the State Bar, Texas imposed an explicit fiduciary duty upon supporters by statute.[178] Many advocates have opposed including such measures in light of their potential to deter supporters from entering SDM agreements and the differences between the roles played by voluntary supporters, and those in fiduciary roles.[179] As of March 2022, U.S. SDM statutes have also not included monitoring provisions found in the British Columbia Representation Agreement Act, which spurred the development of the SDM model around the world.[180] Under that statute, a monitor is required under certain circumstances in which a representative is appointed to support the decision-maker with routine financial matters.[181]

There has been no evidence to date of any particular correlation between SDM and the potential abuse of older adults, but it has not been studied explicitly, to the authors' knowledge, in the U.S. Without data and experience, many elder law practitioners may be skeptical and reluctant to add this tool to the range of advance planning options they provide their clients.[182]

G. Progressive Nature of Cognitive Decline

The particular nature of support that a person with dementia or other cognitive impairments may need to make decisions has not been systematically studied or piloted. Much of the literature on SDM by persons with IDD talks about learning to make decisions over time and how it is a skill that can be developed.[183] The pilots that have occurred in the U.S. and most of those done internationally have presumed this as part of their model.[184] For older persons, who may have made

177. *See* TEX. EST. CODE ANN. § 1357.102 (West 2021); WIS. STAT. §52.32(1) (West 2021).

178. *See* Theodorou, *supra* note 144, at 1003–04.

179. Theodorou, *supra* note 144, at 1004 n.194.

180. *See* Representation Agreement Act, R.S.B.C. 1996, C. 405 § 20 (Can.).

181. *Id*.

182. *See generally* Nina A. Kohn, *Legislating Supported Decision-Making*, 58 HARV. J. LEGIS. 314 (2021). For an example of a critique of existing supported decision-making statutes, partly on the ground that they could subject the decision-maker to exploitation,*see id*. at 335-37.

183. *See generally id.* at 322.

184. *See, e.g.*,Kristin Booth Glen, *Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot* Project, 13 ALBANY GOV'T L. REV. 94, 109-11, 119 (2020).

decisions their whole life, the process of educating supporters, and decision-makers about their respective roles in the arrangement may be somewhat different.

Yet many of the core activities and modalities of providing support may be similar. A number of longstanding strategies for legal and medical professionals have been documented in the literature.[185] These include changes to the environment such as providing extra time and introducing each decision slowly, ensuring a quiet and uncluttered environment in which to make a decision, and creating a supportive environment by "making suggestions, establishing a plan, forming strategies together, enabling a dialogue to develop rather than simply providing information" and making sure the person had a chance to be heard.[186] Additional supports aimed at promoting understanding by the person with dementia include "defining a decision topic and discussing goals," "using simple and clear language," using "visual illustrations and props, reminders, streamlining options" and "using a question-answer pattern" to check understanding.[187]

The progressive nature of Alzheimer's and other dementia has prompted some critics of SDM to say that SDM is inappropriate for persons with dementia.[188] Others have noted that SDM may be used during early stages of dementia but that it will soon be replaced by forms of substitute decision-making as cognitive impairment progresses.[189] For some, there is a sense that SDM is just not worth the trouble since eventually the individual may later need a guardian.[190] This sense is similar to the reasons that judges and lawyers do not explore limited guardianship orders for older people—in the words of Linda S. Whitton, "they believe the elderly ward's condition will most likely deteriorate, thus requiring a rehearing and

185. *See* Linda F. Smith, *Representing the Elderly Client and Addressing the Question of Competence*, 14 J. CONTEMP. L. 61, 61 (1988); Wied et al., *supra* note 71, at 149–52 (metareview of articles on medical decision-making).

186. *Id.* at 152–53.

187. *Id.* at 153.

188. Margaret Isabel Hall, *Dementia, Autonomy and Guardianship for the Old*, *in* THE L. & ETHICS OF DEMENTIA 346 (Charles Foster, et al ed., 2014); Margaret Isabel Hall, *Situating Dementia in the Experience of Old Age: Reconstructing Legal Response*, 66 INT'L J. L. & PSYCHIATRY 1, 2 (2019).

189. KRISTA JAMES & LAURA WATTS, L. COMM'N OF ONT., UNDERSTANDING THE LIVED EXPERIENCES OF SUPPORTED DECISION-MAKING IN CANADA 52 (2014), https://collections.ola.org/mon/28004/326452.pdf.

190. *Id.* at 51.

more time investment on the part of the attorney and court, as well as financial expenditure on the part of the client."[191]

It is important to recognize that dementia's trajectory is unpredictable and cognitive ability may be uneven or fluctuate for a long period of time.[192] Moreover, SDM need not be viable forever in order for it to have some value in an older person's life. If SDM is a stopgap measure that preserves autonomy for some period of time in conjunction with planning for the future through traditional advance directives such as powers of attorney and health care proxies, or if SDM works for some time but court approval is needed later for a single transaction or protective arrangement, or even if a limited guardianship is imposed, it still has been an important tool for that individual.[193] SDM may not have been a path toward lifelong independence, as it can be for a younger individual with IDD, but no less importantly, it may have permitted the older person to extend control over their life during what may be limited time left.[194] In addition, the process of using SDM for some period of time can ensure that if substituted decision-making needs to be used later either through a power of attorney or, when one has not been executed, a limited guardianship, the surrogate decision-maker will have much more knowledge of what the person's will, and preferences are because there will be a recent history of eliciting them.

For persons who progress to advanced dementia, when impairments are such that their present will and preferences can no longer be determined in one or more areas of decision-making, more

191. Linda S. Whitton, *Ageism: Paternalism and Prejudice*, 46 DEPAUL L. REV. 453, 481 (1997). Whitton termed this approach "advocacy nihilism," a legal analogue to the well-documented "therapeutic nihilism" that the medical profession employs toward older people believed to be in decline. *Id.*

192. Kathleen Van Dyk et al., *Assessing Fluctuating Cognition in Dementia Diagnosis: Interrater Reliability of* the Clinician Assessment of Fluctuation, AM. J. ALZHEIMER'S DISEASE & OTHER DEMENTIAS 137, 137 (2015), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4758876/.

193. 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). The Australian scholar Terry Carney has described another approach, "Stepped Care" Legal Toolkits, in which the state, rather than consider a binary alternative of supported decision-making versus guardianship, 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. *Id.*

194. *Cf.* Bruce Jennings, *Freedom Fading: On Dementia, Best Interests, and Public Safety*, 35 GA. L. REV. 593, 610 (2001).

work needs to be done to contemplate how to retain legal personhood while providing the practical decision-making support they may need. Michael Bach and Lana Kerzner have posited a promising model of "facilitated decision-making," in which an agent under a power of attorney or a facilitator appointed by a court facilitate the making of decisions based on knowledge of what the person previously expressed to be their wishes.[195] This model is similar to the model articulated by the Cognitive Decline Partnership Center in Australia, which we describe below.[196] Only if it is impossible to discern past will and preferences may a facilitator use a "best interests" standard to make decisions.[197] This insistence on making an effort to uncover past will and preferences differs from the way the substituted judgment standard is often practiced, and still appears in a number of state guardianship statutes that place best interest on equal footing with the person's wishes, notwithstanding improved language on guardian decision-making duties in the UCGOPAA.[198]

There are two other ways in which a facilitated decision-making model differs from current U.S. guardianship practice. Facilitated decision-making status does not reflect a permanent judgment about

195. MICHAEL BACH & LANA KERZNER, L. COMM'N OF ONT., A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 91–94 (2010) https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf.

196. See infra note 214 and accompanying text.

197. UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 313 (UNIF. L. COMM'N 2017). Some see this concept as similar to that contained in the UGCOPAA, which requires the guardian to "make the decision the guardian reasonably believes the adult would make if the adult were able unless doing so would unreasonably harm or endanger the welfare or personal or financial interests of the adult," considering "the adult's previous or current directions, preferences, opinions, values, and actions, to the extent actually known or reasonably ascertainable by the guardian." *Id.* at § 313(d). If the guardian "cannot reasonably determine the decision the adult probably would make" or "reasonably believes the decision . . . would unreasonably harm or endanger the welfare or personal or financial interests of the adult, the guardian shall act in accordance with the best interest of the adult." *Id.* at § 313(d). Similarly, National Guardianship Association standards of practice 7.II provides that the guardian "shall identify and advocate for the person's goals, needs, and preferences" and only use best interest "when the person's goals and preferences cannot be ascertained." NAT'L GUARDIANSHIP ASSOC., STANDARDS OF PRACTICE 9 (4th ed. 2013). These provisions are important steps forward toward implementing the will and preferences of the person. It is unclear how much effort courts will actually require to ascertain the person's wishes, especially for more routine decisions, in order to find that the reasonably feasible standard was met.

198. Lawrence A. Frolik & Linda S. Whitton, *The UPC Substituted Judgment/Best Interest Standard for Guardian Decisions: A Proposal for Reform*, 45 UNIV. MICH. J. L. REFORM 739, 744 (2012).

the person's cognitive status, and there is a continuing obligation of the state to attempt to discern the person's will and preferences and/or to engage them in decision-making.[199] Finally and most significantly, under this model, the person has not been deprived of their legal capacity and remains a person under the law who holds rights.[200] This model offers promise and should be studied and evaluated when pilot projects serving persons with dementia get under way.

III. LESSONS LEARNED FROM AUSTRALIA, ISRAEL, AND DOMESTIC RESTORATION OF RIGHTS CASES FOR OLDER ADULTS

As Costanzo, Glen & Krieger discuss, there have been a number of promising projects piloting different SDM models directly with people with IDD and psychosocial disabilities.[201] Admittedly, some of the people with disabilities participating in them have also fit into the older adult demographic. However, we are not aware of domestic pilots that have been specifically aimed to recruit primarily older adults with dementia or cognitive decline who do not have another concurrent disability. While the same is largely true in the international context,[202] lessons can be learned from the examination of key projects in Australia and Israel, as well as from the authors' experience as practitioners in restoration-of-rights proceedings.

A. Australia's Cognitive Decline Partnership Center

In a project spanning over three years (March 2016 to June 2019), the National Health and Medical Research Council (NHMRC) Cognitive Decline Partnership Center (CDPC) funded a multi-disciplinary investigation team to explore community attitudes, policy, and law connected with SDM and dementia across New South Wales, South Australia, and Western Australia.[203] The project's objectives included examining relevant legislation, case law, tribunal hearings and care provider organizational policies; interviewing

199. BACH & KERZNER, *supra* note 195 at 92.

200. *Id.*

201. *See generally* Costanzo et al., *supra* note 49.

202. L. COMM'N ONT., *supra* note 49 at 416, n.105 (rounding up literature on pilot projects to date which then focused on persons with intellectual disabilities and to lesser extent included persons with psychosocial disabilities).

203. *See* NHMRC COGNITIVE DECLINE P'SHIP CTR., SUPPORTED DECISION-MAKING IN DEMENTIA CARE: FINAL PROJECT REPORT 5 (2019), https://cdpc.sydney.edu.au/wp-content/uploads/2019/07/CDPC_Supported_Decision-Making_Final_Project_Report.pdf.

persons with dementia and their family members, supporters, and care partners; interviewing and surveying professionals in the healthcare and legal sectors; establishing SDM "interest groups" in each of the target states to collaborate with the research team; and developing an SDM training program for supporters of people with dementia.[204]

Among the project participants was Theresa Flavin, who lives with dementia. In a 2020 article in the publication *Dementia,* Ms. Flavin powerfully articulates what is at stake for people with dementia:

> Every human being on Earth has a right to self-determination . . . Contrast this with what the common understanding of decision making is when a person has a label of dementia. We come back to the compassionate and gentle guidance to a predetermined decision made in our best interest. This is frankly rather insulting and offensive. . . . Taking away a person's choices, however well-intentioned and for whatever reason, silences you. It robs you of your identity and sense of self.[205]

She describes the inability to "contribute to [her] own existence" as making her feel like the "walking dead; physically here using resources, but irrelevant."[206]

The CDPC project identified strategies for keeping people with dementia involved in decision-making[207] – many of which, in the co-authors' experience, parallel strategies employed in supporting people with other types of disabilities. These included permitting extra time, identifying the right time of day and environment for decision-making, repeating or reinforcing information, communicating through multiple senses (auditory and visual), using prompts and communication aids, translating jargon, simplifying abstract concepts, presenting fewer options, breaking down decisions, knowing the person well and understanding their wishes, keeping other family members involved, and managing, but not eliminating, risks.[208]

204. *Id.* at 8.

205. Theresa Flavin, *Supported Decision-Making for People Living with Dementia*, 19 DEMENTIA 95, 96 (2020).

206. *Id.*

207. *See* NHMRC COGNITIVE DECLINE P'SHIP CTR., *supra* note 203, at 14.

208. *Id.*

While concluding that "no single type of [SDM] will be suitable for all people living with dementia,"[209] the investigator team has proposed a "spectrum model," where there are a range of levels and types of support provided to the person over time, depending on the situation, complexity of the decision being made, and the nature and level of the person's cognitive impairment.[210] Regardless of the stage of dementia or type of support required, this model is governed by certain "prevailing principles" that include always considering a person's ascertainable will and preferences; presuming decision-making ability and assessing it in a time- and decision-specific way that is geared towards understanding the person's need for support; and tailoring supportive interventions to the person with dementia, and the "relational decision-making unit" in way that is proportionate, least restrictive of the person's freedoms, addresses potential sources of undue influence, and maintains or develops the person's existing informal support networks.[211]

The spectrum model includes a role for "supporters" and "representatives" who ensure that the person's will, preferences, and human rights direct decisions about their lives.[212] Under this model, "representative" decision-making (used as a last resort, when the person's will and preference cannot be elicited or would place the person or others at "manifest and unreasonable risk of harm") is not synonymous with the "best interest" standard of decision-making. [213] Rather, it means balancing what is known of the person's current will and preferences with the person's historical wishes and decisions and overarching human rights, including safety and social inclusion.[214] This model also contemplates: (1) a formal framework for SDM, where SDM agreements clarify the supporter's role, the process for sharing personal information, the ongoing mentorship and oversight of supporters, and the way in which the supporter and representative roles can exist together; (2) development of a professional SDM facilitator role, ideally established early in the course of the illness, to provide mentorship, oversight, and advocacy for the SDM arrangements; (3) advocacy, education and community development

209. Craig Sinclair et al., *"A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making*, 16 J. BIOETHICAL INQUIRY 587, 605 (2019).

210. *Id.* at 601.

211. *Id.* at 601–04.

212. *Id.* at 603.

213. *Id.* at 601.

214. Sinclair et al., *supra* note 209, at 601.

to address social and contextual barriers, including social isolation and exclusion, attitudinal hurdles, and opposition from family and service providers.[215]

While not specifically piloted with older adults with dementia in Australia, the "spectrum model" of SDM may be a promising model to test in the United States for participants with dementia who have close family relationships upon which they can draw upon.[216] While widespread use of the model's professional SDM facilitator would likely require significant resources and funding,[217] costs could be initially contained and better assessed by limiting the number of participants during the pilot. As indicated by the CDPC investigators, there will be a necessary educational component for people with dementia, their supporters, and third parties, including service providers, that would also be needed.[218] The dementia-specific, person-centered training package and consumer guidebook that were developed and piloted by CDPC during its three-year project could serve as a model to springboard such as training initiative.[219]

B. Israel's SDM Project

In the wake of the CRPD, Israel is one of the countries that has revised its guardianship laws to attempt to comply with the mandates

215. *Id.* at 602.

216. Among the acknowledged limitations of the CDPC study, the investigator team noted that its participants were limited to those in close family relationships (spouse/partner and parent/child), rather than people whose support networks include more distant family, friends, or neighbor-based relationships or people who lacked any close relationships. The team called for future research to address the experiences of the latter groups, who it considered "arguably more vulnerable." *Id.* at 604.

217. *See id*. "Given the complexity of this role, the intensity of facilitation or mentorship that might be required, the likely requirement for acute responses to after-hours 'crises,' and the projected increase in the population of people living with dementia, such a role would require significant resources and funding. In some jurisdictions this has been addressed through the development of a cohort of volunteers." *Id.*

218. NHMRC P'SHIP CTR. FOR DEALING WITH COGNITIVE AND RELATED FUNCTIONAL DECLINE IN OLDER PEOPLE, CLINICAL PRACTICE GUIDELINES AND PRINCIPLES OF CARE FOR PEOPLE WITH DEMENTIA 10 (2016) https://www.clinicalguidelines.gov.au/portal/2503/clinical-practice-guidelines-and-principles-care-people-dementia.

219. *See, e.g.,* CRAIG SINCLAIR ET AL., SUPPORTING DECISION-MAKING: A GUIDE FOR PEOPLE LIVING WITH DEMENTIA, FAMILY MEMBERS, AND CARERS 3 (2018), https://cdpc.sydney.edu.au/wpcontent/uploads/2019/06/SDM_Handbook_Online_Consumers-ReducedSize.pdf [hereinafter SINCLAIR ET AL., SUPPORTING DECISION-MAKING].

of Article 12.[220] In 2016, Israel enacted a major revision of its guardianship law that legislatively authorized SDM and durable powers of attorney (which had previously not been recognized) as less restrictive alternatives to guardianship.[221] In addition, the SDM law, which went into effect in 2018, limited the use of plenary guardianships and now permits guardianship in "only those cases in which guardians are necessary to prevent harm to the person in question and when no less restrictive alternative is available."[222] Israel's recognition of SDM differs in one critical respect from the statutes that have been enacted in the U.S.: in Israel, the appointment of a supporter is done primarily by a court instead of by private agreement or arrangement.[223]

A significant judicial decision issued just before the new SDM law was enacted influenced the legislative reforms.[224] In that case, a widow in her 70s who had Alzheimer's disease faced a guardianship proceeding.[225] A medical report identified concern about her ability to manage her financial affairs.[226] The woman was deeply opposed to having a guardian and repeatedly expressed that she had a close friend whom she trusted to manage her finances.[227] She was able to engage in other activities of daily living, such as managing her household and cooking, independently.[228] Her attorneys were able to persuade the social services office and ultimately the judge that a SDM arrangement with the close friend would better preserve the older woman's autonomy while ensuring that she had necessary support.[229]

At the time of the decision in April 2015, Israel did not yet have a provision for durable powers of attorney (DPOA). Had such an option existed, her attorneys would have advised SDM plus a DPOA

220. Arlene S. Kanter & Yotam Tolub, *The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law for People with Disabilities in Israel and Beyond*, 39 CARDOZO L. REV. 557, 558–59 (2017).

221. *Id.* at 580, 590.

222. *Id.*

223. *See id*. at 563.

224. *See* Michael (Mickey) Schindler & Meytal Segal-Reich, *Supported Decision-Making for Older Persons in Israel: The 2015 Precedent and the Following 2016 Regulation*, 10 ELDER L. REV. 1, 10–15 (2016).

225. *See id.* at 11–12.

226. *See id.* at 11.

227. *See id.*

228. *See id.* at 11.

229. *See* Schindler & Segal-Reich, *supra* note 224, at 12. The client was represented by Dr. Michael (Mickey) Schindler, among others. Schindler is now the director of MARVA-Law, Welfare and Empowerment.

for when her condition deteriorated; as that was not an option at the time, the woman used SDM for some time and then when her condition became severe, had a guardian appointed.[230] When interviewed about the case, Dr. Michael (Mickey) Schindler, one of her attorneys, said that the ultimate need to appoint a guardian did not diminish the value of using the SDM arrangement initially.[231] SDM permitted this client to retain autonomy and control for longer than she otherwise would have at a point in her life when her limited time meant each moment of autonomy was more meaningful.[232]

It is estimated that, as of September 2021, about 700 court orders have issued in response to applications for the appointment of a supporter since the law went into effect and that of that amount, about one-quarter pertain to older persons.[233] In cases involving Alzheimer's disease or other dementias, it is common for a judge to make the appointment of the supporter temporary, from 6 months to a year, and then revisit the arrangement later.[234] In addition, in some SDM cases, the judge may require further court approval for certain significant transactions, such as those involving real estate and business deals.[235]

In order to assess how the new law is working in practice and to identify best practices, the Ministry of Justice is sponsoring a pilot project, just getting under way as of the fall of 2021, run by MARVA-Law, Welfare and Empowerment ("MARVA"), an NGO that provides legal representation and advocacy for older people and persons with disabilities, along with the organizations, JJDC Israel, and Mosaica Center for Conflict Resolution.[236] The goal is to set up SDM for 80

230. *See* Zoom Interview with Michael (Mickey) Schindler, Dir., MARVA-Law, Welfare & Empowerment (Jan. 13, 2021) (verification on file with *Syracuse Law Review*).

231. *See id.*

232. *See id.*

233. *See* Zoom Interview with Ornit Dan, Off., Isr. Ministry of Just. (Jan. 26, 2021) (verification on file with *Syracuse Law Review*); Email from Michael (Mickey) Schindler to Rebekah Diller (Sept. 26, 2021) (on file with *Syracuse Law Review*)

234. *See* Zoom Interview with Ornit Dan, Off., Isr. Ministry of Just. (Jan. 26, 2021).

235. *See id.*

236. *See* ISR. MINISTRY JUST., https://www.gov.il/en/departments/agor_ministry_of_justice/govil-landing-page (last visited Mar. 13, 2022); MARVA, https://www.marva.org.il/en/ (last visited Mar. 13, 2022); MOSAICA CTR. FOR CONFLICT RESOL., https://mosaica.org.il/en/ (last visited Mar. 13, 2022).

people spanning across age and type of disability.[237] Some of those served by the pilot will use SDM as an alternative to guardianship with court approval.[238] The pilot will also assist a subset of individuals in executing SDM agreements outside of the court process in order to develop a better set of criteria for when the non-court-supervised process is appropriate.[239]

The Israeli approach also differs from what has been attempted so far in the U.S. in that there is a more proactive effort to create a pool of supporters for persons who do not have family or close friends already in their lives who can serve in this role. The law provides for paid supporters, who must complete an approved training course and cannot be those who are already serving as paid guardians.[240] During the years 2020 to 2021 the Guardian General office within the Ministry of Justice initiated seven courses in which about 100 paid supporters were trained.[241] The pilot will also be training a cadre of volunteers for those without preexisting sources of support—to date, the project has recruited and trained about fifty supporting volunteers.[242]

C. Domestic Restoration-of-Rights Cases for Older Adults

In 2017, the ABA Commission on Law and Aging, in conjunction with the Virginia Tech Center for Gerontology, published a study and recommendations relating to guardianship termination, referred here as "restoration of rights."[243] The project conducted legal research on restoration of rights in each state, court file research, and an interdisciplinary round table to develop related recommendations.[244] As part of the court file research, the project asked each of four participating sites in Minnesota, Washington, Illinois, and Kentucky,

237. *See* Zoom Interview with Ornit Dan, Official, Isr. Ministry of Just. (Jan. 26, 2021).

238. *See id.*

239. *See id.*

240. *See id.*

241. Email from Michael (Mickey) Schindler, Dir., MARVA-Law, Welfare & Empowerment to author (Sept. 26, 2021) (on file with *Syracuse Law Review*).

242. *See* Zoom Interview with Ornit Dan, Official, Isr. Ministry of Just. (Jan. 26, 2021).

243. ERICA WOOD ET AL., RESTORATION OF RIGHTS IN ADULT GUARDIANSHIP: RESEARCH AND RECOMMENDATIONS 6 (2017), https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf [hereinafter WOOD ET AL., RESTORATION OF RIGHTS].

244. *See id.* at 6–7.

to identify cases from August 2012 to August 2015 that resulted in restoration of rights. [245]

Although the limitations in the data set restricts broad analysis or interpretation, the research does offer some evidence that, compared to other populations within the data set, older adults appear less likely to have their rights restored.[246] Of the cases identified, only a small percentage (approximately 21% or about one-fifth of the cases) involved people sixty years or older. Mental illness was the most common trigger for the original guardianship appointment, accounting for about 33%, or one-third of the cases.[247] Dementia is the named trigger in less than 5%, or one-twentieth of the restoration cases,[248] although it may have been an unidentified co-occurring condition in a greater percentage of cases. In almost 43% of the cases, the individual had no counsel.[249] While the court had appointed a lawyer in almost 47% of the cases, almost half of those served in the role of guardian ad litem, tasked with acting in the person's best interests, rather than to zealously represent the person's expressed wishes.[250] Moreover, the project concluded that, while each state statute sets out a process by which people subject to guardianship can have their rights restored, that process appears to be infrequently used, possibly due to a lack of awareness that it exists.[251]

From 2016 through 2021, the Bet Tzedek clinic at Cardozo School of Law, in which one of the co-authors teaches, brought motions to restore the rights of five persons under guardianship in New York City.[252] All of the clients were placed under guardianship as a result of petitions filed by the local department of social services. All of the guardianships were prompted by pending evictions or other housing crises yet continued on long after those initial crises were over. These cases demonstrate that guardianships need not be for life and that important autonomy interests can be vindicated through restorations.

245. *See id.* at 6. This study examined court files in Minnesota and Washington and public guardianship files in Illinois and Washington.

246. *See id.* at 7.

247. *See id.*

248. *See* WOOD ET AL., RESTORATION OF RIGHTS, *supra* note 243, at 7.

249. *See id.* at 8.

250. *See id.* at 12.

251. *See id.* at 10.

252. The sources and details related to the cases mentioned here have not been independently verified by *Syracuse Law Review*. In light of confidentiality, further identifying information concerning the practice of the Cardozo Bet Tzedek clinic may be obtained by contacting the authors directly.

In one case, a 67-year-old widow had consented to a guardianship when facing eviction because she was told it was the only way she could continue to live with her adult son, a person with a disability who already had a guardian through New York City's equivalent of a public guardian program.[253] Instead of getting the help she had hoped for, she and her son were placed in a homeless shelter for eighteen months before eventually being moved to an apartment by their guardian. By the time she sought assistance from the Bet Tzedek clinic, her son had passed away and her guardian had moved her to a restrictive assisted living facility where facility staff limited her ability to come and go as she pleased. Though she complained to the facility and to her guardian about wanting to leave, it was only when her sister came and got her that she was able to move out and into her sister's apartment. After the clinic brought a motion, her rights were restored. Had there been sufficient alternative community supports available for this client from the beginning, she never would have been under guardianship.

In another case, a 67-year-old man had been under guardianship for about a year, after a fall left him with a broken neck and a pending eviction due to the inability to pay rent.[254] He had consented to the guardianship due to the crisis in his life at the time.[255] After recovering from the fall, he brought a motion to terminate his guardianship, which was highly contested by his guardian.[256] After an evidentiary hearing, the motion was granted.[257] He was especially adamant about having control over his finances again, as he had had for his whole life, and did not need substantial ongoing support once his crisis passed.[258]

Another illustrative case study can be found in a 2018 guardianship termination proceeding that was introduced at the beginning of this article.[259] "Dolores" was represented by Quality Trust for Individuals with Disabilities' Jenny Hatch Justice Project, under the former leadership of this article's other co-author.[260] There

253. *See* N.Y. SOC. SERV. LAW § 473-d (McKinney 2021). In New York City, when a guardianship petition is initiated by the Department of Social Services, courts may appoint a non-profit agency operating as a "community guardian" program through a contract with the city.

254. *See* Banks v. Richard A., 100 N.Y.S.3d 818, 819 (Sup. Ct. 2019).

255. *See id.*

256. *See id.* at 823.

257. *See id.* at 824.

258. *See id.* at 823.

259. *See* Vargas, *supra* note 2.

260. *See id.*

are several takeaways from Dolores' case that may inform future efforts to advance SDM with older populations at risk of diminishing capacity. Like many older adults, the composition of Dolores's support network was becoming more professionalized over time. Apart from a limited pool of trusted family members, Dolores had a mixture of service and community-based supporters in her life, including attorneys from local legal service organizations, case managers from an aging service program, and local church leadership. This case hinged on further bolstering that pre-existing network by connecting Dolores to additional supports and services, including a local program that assists older adults with memory loss to budget and manage their own finances, as well encouraging her to use bank services for direct payment of her rent each month. The budgeting program Dolores enrolled in also had a "step up" feature in which, should her ability to manage her own financial affairs diminish, she could be transitioned into a professional representative payee program. In addition, to further allay judicial concerns and reduce the risk of having to return to court in the future, advance planning proved critical, including the development of an advance directive and springing power of attorney following the termination of the guardianship.

Dolores's case also brings to the fore key challenges older adults can face in seeking to have their rights restored under their particular state's law. For example, in the District of Columbia, guardians can only be appointed if the court finds that the individual for whom a guardian is sought is "incapacitated" and the appointment is necessary as a means of providing for that person's continuing care.[261] Similarly, in most cases where a conservator is appointed, the court also must find that the person is "incapacitated."[262] Therefore, under D.C. law and court practice, by agreeing to the appointment of a guardian and conservator, Dolores was, in effect, consenting to a finding of her own incapacity – an internally inconsistent concept, at best. When Dolores decided that she did not want a guardian and conservator anymore, she

261. D.C. CODE § 21-2044(b) (2021); D.C. CODE § 21-2011(11) (2021) (defining "incapacitated individual" as "an adult whose ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that he or she lacks the capacity to manage all or some of his or her financial resources or to meet all or some essential requirements for his or her physical health, safety, habilitation, or therapeutic needs without court-ordered assistance or the appointment of a guardian or conservator").

262. D.C. CODE § 21-2051(b) (2021) (finding of incapacity is required unless the individual has disappeared, is being detained by a foreign power, or is being held hostage by someone other than a foreign power).

could not withdraw that consent.[263] Rather, she had to demonstrate that she was no longer incapacitated,[264] and doing so took time, resources, and zealous representation to which other older adults might not have access.

Dolores's case also brings into sharp relief the question of whether state legislative change is beneficial in persuading judicial systems to recognize SDM as a viable alternative to guardianship for older populations. Admittedly, at the time of Dolores's guardianship termination, the District of Columbia was one of the jurisdictions in which SDM had already been recognized in at least one court order without a change in state statute. In October 2016, Ryan King, who was in his thirties and lived with developmental disabilities, became the first person in D.C. to have his guardianship terminated by a court order that expressly recognized SDM. [265] Dolores's case may well have proceeded in a similar fashion, even absent state law change, given the supporting expert evidence already on the record in the case. However, in May 2018, just a month before Dolores's final hearing, D.C. became the fourth jurisdiction in the United States to statutorily recognize SDM agreements.[266] Thus, that new law was able to be featured prominently in counsel's final briefing to the court. The ability to cite a codified definition of SDM arguably added legitimacy to a term with which the judge had little to no familiarity prior to presiding over the case.[267] It also may have helped counteract any

263. *See* D.C. CODE § 21-2048 (2021) (providing that guardianship only terminates "upon the death of the guardian or ward, the determination of incapacity of the guardian, or the removal or resignation of the guardian").

264. *See* D.C. CODE § 21-2049(b) (2021) (providing that the person under guardianship or any person interested in the welfare of that person may petition for an order that the person is no longer incapacitated and for termination of the guardianship).

265. *See* Quality Tr. for Individuals with Disabilities & Burton Blatt Inst., *Freedom for Ryan King*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING (Dec. 12, 2016), www.supporteddecisionmaking.org/impact-stories/freedom-ryan-king; *In re: Ryan Herbert King,* 2003-INT-249 (D.C. Super. Ct. Oct 6, 2016), www.supporteddecisionmaking.org/sites/default/files/ryan-king-order.pdf; Susie J. King, *Our Journey of Supported Decision-Making for Ryan*, UNIV. MINN. INST. ON CMTY. INTEGRATION, https://publications.ici.umn.edu/impact/32-1/our-journey-of-supported-decision-making-for-ryan (last visited Sep. 9, 2021).

266. *See* D.C. CODE § 7-2133(a) (2021).

267. It is noteworthy that, despite counsel's citations to other resources on SDM and Mr. King's court order, the only citation included in the court's final order is the citation to DC's SDM law. *See* Super. Ct. of D.C. Prob. Div., *Order*, SUPPORTED DECISION MAKING, 2 (June 2018), https://supporteddecisionmaking.org/sites/default/final-order-dc-062018.pdf (identifying information redacted because the subject is a ward); *In re: Ryan Herbert King,* 2003-INT-249 (D.C. Super. Ct. Oct 6, 2016).

institutional ageism that could have influenced the result. It is unknown whether or not the outcome would have been different absent the state law change. None of this to say that legal arguments for SDM cannot still be successfully made in court using alternative methods, *e.g.*, a framework that recognizes SDM as a reasonable accommodation or modification on the basis of disability under state and federal law. Rather, it suggests the benefits of using a multi-model advocacy strategy to advance SDM that includes not only judicial system education and litigation, but also legislative reform.

IV. NEXT STEPS: RECOMMENDATIONS FOR REFORM

Based on the above analysis, we offer the following recommendations[268] for making SDM more accessible to older adults, including persons living with dementia, living in the United States.

A. Place SDM More Squarely on the Agenda of Aging Rights Groups

SDM is seen as a key part of the disability rights agenda whereas it has not been as front and center for groups focused on aging rights, though that is changing.[269] Groups such as the AARP have participated in advocacy to adopt state statutes recognizing SDM agreements, [270] among other initiatives, and the ABA Commission on Law & Aging has done significant work to promote SDM. [271] Other groups that have sought to advance SDM through training and educational initiatives[272] have included the National Resource Center

268. This article was prepared as a background paper to inform the deliberations of delegates at the Fourth National Guardianship Summit, organized by the National Guardianship Network and held in May 2021. This summit resulted in 22 final recommendations, some of which were directly relevant to this article. *See generally Fourth National Guardianship Summit Standards & Recommendations*, 72 SYRACUSE L. REV. 29, 30–40 (2022).

269. BACH & KERZNER, *supra* note 195 at 37 ("Supported decision-making, so important to people with intellectual disabilities and their advocacy organizations, is not on the radar of older adults.").

270. *See* Theodorou, *supra* note 144, at 999–1000.

271. *See Guardianship and Supported Decision-Making*, AM. BAR A SS'N COMM'N ON L. & AGING, https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practise/ (last visited Mar. 13, 2022) (listing resources and reports on supported decision-making).

272. *See Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 32 (Recommendation 2.1).

for Supported Decision-Making,[273] Justice in Aging,[274] and the National Center on Law and Elder Rights.[275] Further engaging groups such as ADvancing States (formerly the National Association of States United for Aging and Disability)[276] and the National Association of Area Agencies on Aging will be a key component to making this recommendation a reality. SDM fits with the Older Americans Act's goals of promoting independence and "the free exercise of individual initiative in planning and managing their own lives."[277] More firmly identifying SDM as an aging rights issue will help ensure it is more widely considered as a viable alternative for older persons at risk of guardianship.

B. Fund Research and Pilots on Use of SDM Models by Older Adults

More research is needed to determine the effectiveness of various approaches to SDM for older adults with dementia and diminishing capacity and ways to overcome barriers related to social isolation, risks of abuse or exploitation, cost, and the lack of community education.[278] This will mean funding demographically and geographically diverse domestic pilots specifically focusing on the

273. *See generally Supported Decision-Making Symposium: Taking Stock and Forging Ahead* (June 10–11, 2019), NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, http://www.supporteddecisionmaking.org/sites/default/files/docs/events/sdm-2019-dc-agenda.pdf; *Webpage on Webinar/Conferences*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, http://www.supporteddecisionmaking.org/events (last visited Mar. 14, 2022).

274. *See generally Webinar: Legal Basics: Supported Decision-Making* (July 11, 2017), JUST. AGING, https://justiceinaging.org/webinar-legal-basics-supported-decision-making/.

275. *See* ERICA WOOD & DARI POGACH, GUARDIANSHIP TERMINATION AND RESTORATION OF RIGHTS (Aug. 2018), https://ncler.acl.gov/Files/Guardianship-Termination-Restoration-of-Rights.aspx.

276. *See About ADvancing States*, ADVANCING STATES, http://www.advancingstates.org/about-advancing-states (last visited Mar. 14, 2022) (Advancing States has already offered a webinar on supported decision-making, which the authors conducted in February 2020).

277. 42 U.S.C. § 3001 (2012).

278. *See* AM. BAR ASS'N COMM'N ON L. & AGING, SUPPORTED DECISION MAKING ACROSS THE AGE SPECTRUM 8–9 (March 2020), www.americanbar.org/content/dam/aba/administrative/law_aging/2020-supporting-decision-making-final-report.pdf (highlighting the need for more research and consensus on a research agenda); *Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 32, 34–36, 38–39 (Recommendations 2.1, 3.4, 5.2, 5.3 highlighting need for broad community education on less restrictive alternatives to guardianship, including supported decision-making).

needs and various support networks of this older population.[279] The pilots should also be conducted across various living arrangements, including the community, assisted living facilities, and nursing homes. Possible avenues with which to pursue research funding include advocating for SDM to be placed on the agenda of the Advisory Council on Alzheimer's Research, Care, and Services, which was established by the National Alzheimer's Project Act to advise the Secretary of the U.S. Department of Health and Human Services and Congress on priority actions to not only treat and prevent the condition, but also to improve care for people with Alzheimer's disease and related dementias and expand support for their caregivers.[280] Each year the Advisory Council develops recommendations relating to clinical care, long-term services and supports, and research, which in turn inform the annual updates to the National Plan to Address Alzheimer's Disease, as well as Congressional legislation and appropriations.[281] Another avenue may be to link studies on decision-making to the grant and funding priorities of the National Institute on Aging.[282] During the COVID-19 epidemic, issues related to medical consent of older adults and people with disabilities have come to the forefront during national dialogues associated with vaccine distribution and may demonstrate an opportunity to push for funding for studies testing various decisional models, like SDM.[283] In addition, ACL should not only continue funding initiatives to promote SDM across the life span[284] and alternatives to guardianship for transition-age youth with intellectual

279. *See Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 33 (Recommendation 2.2 is recommending promotion and expansion of sustainable and funded pilot projects targeting diverse populations, including older adults).

280. *See NAPA—Nat'l Alzheimer's Project Act*, OFF. ASSISTANT SEC'Y FOR PLAN. & EVAL., U.S. DEP'T OF HEALTH & HUM. SERVS. (last visited Mar. 14, 2022), https://aspe.hhs.gov/national-alzheimers-project-act.

281. *See The Nat'l Plan to Address Alzheimer's Disease: Are we on Track to 2025?: Hearing Before the Special Comm. on Aging*, 113th Cong. 4 (2013) (statement of Bill Nelson, Florida, Chairman).

282. *See Grants & Funding*, NAT'L INST. ON AGING, U.S. DEP'T OF HEALTH & HUM. SERVS., (last visited Mar. 14, 2022), https://www.nia.nih.gov/research/grants-funding.

283. *See* Helen Lynne Turnham et al., *Consent in the Time of COVID-19*, J. MED. ETHICS 565, 565 (2020), https://jme.bmj.com/content/medethics/46/9/565.full.pdf.

284. *See New Funding Opportunity: Supported Decision Making Across the Lifespan Planning Grant*, ADMIN. FOR CMTY. LIVING (July 1, 2019), https://acl.gov/news-and-events/announcements/new-funding-opportunity-supported-decision-making-across-lifespan.

and developmental disabilities,[285] but also SDM projects specifically focused on older populations, including those with dementia and related conditions.[286]

C. Integrate SDM into Advance Planning

In terms of formal recognition of SDM, there are currently inconsistent legal structures across states. For example, some states have SDM agreement legislation;[287] most do not. While not a perfect solution, one way to seek to document or enforce such arrangements is through incorporating SDM principles into existing advance planning documents, such as durable powers of attorney for health care, health care proxies, and other powers of attorney. Such legal forms can be modified to appoint a legal agent to act for the person under certain circumstances, such as incapacity, and also set forth the SDM framework for the agent to follow before and after such circumstances occur.[288] Specific examples exist for how to do so.[289]

285. *See Alternatives to Guardianship Youth Resource Center*, ADMIN. FOR CMTY. LIVING, https://acl.gov/grants/supported-decision-making-across-lifespan-planning-grant-0 (last modified Sept. 21, 2020); The Center on Youth Voice, Youth Choice, https://youth-voice.org/the-center (last visited March 29, 2022).

286. *See Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 33 (Recommendation 2.2 is recommending promotion and expansion of sustainable and funded pilot projects targeting diverse populations, including older adults).

287. *See* ALASKA STAT. §§ 13.56.010–13.56.195 (2021); COLO. REV. STAT. ANN. §§ 15-14-801–15-14-806 (2021), D.C. CODE §§ 7-2131–7-2134 (2021); DEL. CODE ANN. Tit. 16, §§ 9401A-9410A (2021); 755 ILCS 9/1–99 (West 2022), IND. CODE ANN. §§ 29-3-14-1–29-3-14-13 (LexisNexis 2021); LA. STAT. ANN. §§ 13:4261.101–13:4261.302 (2021); NEV. REV. STAT. ANN. §§ 162C.010–162C.330 (LexisNexis 2021); N.H. REV. STAT. § 464-D:1 (2021); N.D. CENT. CODE §§ 30.1-36-01–30.1-36-08 (2021); 42 R.I. GEN. LAWS ANN. §§ 42-66.13-1–42-66.13-10 (2021); TEX. EST. CODE ANN. §§ 1357.00–1357.102 (West 2021); WASH. REV. CODE ANN. §§ 11.130.700–11.130.755 (West 2021) (effective Jan. 1, 2022); WIS. STAT. ANN. §§ 52.01–52.32 (West 2021); *See also* MO. REV. STAT § 475.075(13)(4) (West 2021) (requiring courts to consider whether a person's needs may be met by less restrictive alternatives, including "Supported Decision-Making Agreements," before appointing a guardian or conservator).

288. *See* David Godfrey, *Legal Basics: Supported Decision-Making*, NAT'L CTR. ON L. & ELDER RTS. 3 (July 2017), https://ncler.acl.gov/pdf/Legal-Basics-Supported-Decision-Making1.pdf.

289. *See* David Godfrey & Morgan Whitlatch, *Defining Supported Decision Making – SDM in Advance Care Planning, in* SUPPORTED DECISION-MAKING AS AN ALTERNATIVE TO GUARDIANSHIP 6 (2017), https://www.washoecourts.com/OtherDocs/AdultGuardianship/SDMASurveys/November28SDMAPresentationMaterials.pdf (describing provisions to include in a power of attorney for health care that would instruct the health care surrogate to include keep the principal informed, include the principal in the decision-making process, and to base

For example, before DC's SDM Agreement law went into effect in May 2018, Quality Trust for Individuals with Disabilities developed a springing DC Durable Power of Attorney for Health Care with Special Provisions for Supported Decision-Making.[290] With the expanded push for early diagnosis of dementia comes an increased opportunity to conduct legal planning before the person's ability to execute such documents further declines.

D. Combine SDM and Other Social Supports

SDM can be used as an accommodation for older adults in their decisions including concerning health care, finances, benefits, and living arrangements.[291] But by itself, it cannot ensure that the older person has access to health care, sufficient funds to survive, all the government benefits to which they are entitled or an accessible, affordable home. Without a sufficient social safety net and social services support for struggling older persons, SDM will be of limited use. It needs to be thought of as part of a package of supportive services that older persons can access to meet basic needs.

E. Proactively Build Safeguards in SDM Agreements

As discussed above, state statutes have attempted to address the potential for exploitation in a variety of ways.[292] More data and analysis are required before we can reach conclusions about the extent of the risk of exploitation under SDM and whether these measures are effective in guarding against exploitation without producing unintended consequences that limit the use of agreements. In addition, pilots and other programs promoting SDM should continue to encourage the use of more than one supporter, which can be effective in deterring abuse by ensuring there are extra eyes on the

decisions on what the surrogate thinks the principal would do if he/she/they were able to make the choice).

290. *See District of Columbia Durable Power of Attorney for Health Care with Special Provisions for Supported Decision-Making*, QUALITY TR. FOR INDIVIDUALS WITH DISABILITIES (May 1, 2016), http://supporteddecisionmaking.org/sites/default/files/Durable-Power-of-Attorney-for-Health-Care-with-Special-Provisions-for-Supported-Decision-Making_0.pdf.

291. *See Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 34 (Recommendation 2.4 is recommending the U.S. Department of Justice and other federal and state agencies recognize supported decision-making can be a reasonable accommodation under the American with Disabilities Act of 1990, as amended).

292. *See supra* notes 173-181 and accompanying text.

relationship.[293] For persons without robust preexisting networks, promoting the development of multiple supporter relationships will be especially important.

F. Develop Support Resources for Those Who Do Not Have Pre-existing Networks of Supporters

As more pilots are launched,[294] we will need to test different models for people with dwindling support networks, who may not have friends or family to serve as supporters. These include piloting programs to train and provide volunteer supporters or to provide infrastructure to form peer support networks. In addition, we will need to explore the concept of professional, paid supporters. While this may be controversial in some quarters, it may be impossible to provide SDM to a significant number of older persons who might benefit from it without developing a funding source and model for paid support.

G. Make Restoration of Rights More Attainable for Older Persons Under Guardianship

Restoration petitions may perform an especially important role in the guardianships of older persons, many if not most of which are imposed for indefinite duration on the theory that further decline is inevitable. But with support, many older persons may be able to have their guardianships terminated, especially when the guardianship was prompted by a health or economic crisis that has subsided. In order to make restorations possible in the older adult context, there need to be more legal offices able to take such cases. One way of broadening the availability of legal representation would be to expand funding through Title III-B of the Older Americans Act, which already authorizes grants to be spent on representing persons who are under guardianship.[295] In addition, Protection and Advocacy organizations, which have increasingly prioritized restoration cases, play an important role.[296] There also should be a ready means for an individual to seek restoration on her own through an informal communication rather than a formal petition; many persons under guardianship are not

293. *See Stripped of Funds,* 24 U. PA. J. L. & SOC. CHANGE 149, 184.

294. *See id.*

295. *See* 42 U.S.C. § 3030d(a)(6)(B)(ii) (2012) (explaining even persons under guardianship who may have funds may qualify based on social need); 42 U.S.C. § 3002(33) (2012) (stating legal assistance may be provided to persons "with economic or social needs").

296. *See* WOOD ET AL., RESTORATION OF RIGHTS, *supra* note 243, at 51-52.

aware that they even have this option.[297] Forms in clerks' offices and simplified procedures to bring a restoration proceeding should be explored. Guardians should be required to promote the restoration of rights by including plans for restoration in initial plans and bringing motions before the court when guardianship is no longer needed; the burden should not fall only on the person under guardianship to bring restoration matters to the court's attention.[298] In addition, judicial education on restorations as an emerging issue can perform a helpful role in changing attitudes within the court system.[299]

H. Promote State Legislative Reform to Formally Recognize SDM

At a minimum, state legislatures should amend their statutes to recognize SDM as a less-restrictive option to be fully considered by courts before guardianship is imposed and as a possible ground for court termination of guardianship, consistent with the UGCOPAA and the ABA's 2017 Resolution.[300] However, more is needed to ensure that third-parties other than courts — such as health care and service providers and banks — honor the right of older adults with dementia and other cognitive disabilities are reasonably accommodated in decision-making. That is one reason for state legislatures to consider

297. The new UGCOPAA provision requiring a notice of rights to seek termination, among other things, within 30 days after the appointment of a guardian or conservator addresses this problem. *See* UNIF. GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT § 311(b) (UNIF. L. COMM'N 2017); *id.* at § 412(b).

298. Under the UGCOPAA, guardians shall "to the extent reasonably feasible, encourage the adult to participate in decisions, act on the adult's own behalf, and develop or regain the capacity to manage the adult's personal affairs" and must provide in annual reports "a recommendation as to the need for continued guardianship and any recommended change in the scope of the guardianship." *Id.* at § 313(b); *see id.* at § 317(b)(13). In addition, the guardian's initial plan must identify "goals for the adult, including any goal related to the restoration of the adult's rights, and how the guardian anticipates achieving those goals." *Id.* at § 316(a)(5). This recommendation encompasses these provisions and goes one step further to require that guardians commence restoration proceedings in appropriate cases.

299. *See Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 31–32 (Recommendation 1.3 is recommending, among other reforms, that courts and lawyers be trained on the rights restoration process).

300. *See id.* at 33–34 (Recommendation 2.3 is recommending statutes, court rules, policies, and processes in every state require courts to consider supported decision-making as one of the alternatives to guardianship at appointment and periodically thereafter); *id.* at 34–35 (Recommendation 3.1 is recommending states adopt and implement the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act).

going farther than the UGCOPAA by statutorily recognizing and creating enforceability mechanisms for SDM agreements, to place such formal legal arrangements on equally footing with more commonly used tools, such as powers of attorney.

I. Firmly Connect SDM to the American with Disabilities Act

As recommended by the National Council on Disability,[301] the Department of Justice should issue guidance to states, including Adult Protective Service agencies and courts that handle adult guardianship proceedings, on their legal obligations pursuant to the Americans with Disabilities Act (ADA).[302] Such guidance should clarify not only that the ADA is applicable to state guardianship proceedings, but also that the need for assistance with activities of daily living and/or making one's own decisions is not equivalent to incapacity and that guardianship should be sought and ordered only after less restrictive options have been exhausted.

J. Create Funding Streams for Promoting Judicial Reform and Diversion from Guardianship Systems

As recommended by the American Bar Association[303] and the National Council on Disability,[304] Congress should invest in a Guardianship Court Improvement Program for adult guardianship.[305] Such a program can play an important role in bolstering court due process protections, including ensuring access to zealous representation for people in guardianship or who are facing guardianship proceedings and a clear process for terminating unnecessary or overbroad guardianship.[306] Investment in the development of state court infrastructure for comprehensive and

301. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 9, at 19.

302. *See id. See also Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 34 (Recommendation 2.4 is recommending the Department of Justice and other federal and state agencies recognize that SDM can be a reasonable accommodation or modification under the Americans with Disabilities Act of 1990, as amended).

303. *See* AM. BAR ASS'N, 105 RESOLUTION: ADOPTED BY THE HOUSE OF DELEGATES 1 (Aug. 3–4, 2020), https://www.americanbar.org/content/dam/aba/directories/policy/annual-2020/105-annual-2020.pdf.

304. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 9, at 22.

305. *See Fourth National Guardianship Summit Standards & Recommendations*, *supra* note 268, at 39–40 (Recommendations 6.1, 6.2, and 6.3 are recommending Congress establish and fund a Guardianship Court Improvement Program).

306. *See id.* at 39–40.

detailed data collection about guardianship in the United States is also critically needed. [307]

However, merely investing in state judicial systems is not, in and of itself, enough to effectuate meaningful and lasting change. Such singular investment could serve only to legitimize a prevailing model that systemically deprives people, including older adults, of their decision-making rights.[308] Instead, policymakers should simultaneously and equally prioritize investment in strategies that encourage states, territories, and service systems to divert their constituents away from guardianship systems and towards less-restrictive options, including SDM.[309] Such strategies will not only benefit older adults whose rights are being unnecessarily curtailed, but also the court systems that are currently overburdened with unnecessary guardianship petitions and proceedings.[310] Such steps should include creating and funding federal grants and other financial incentives to states and territories to encourage them to support guardianship diversion programs,[311] alternatives-to-guardianship training initiatives,[312] and innovative and far-reaching SDM projects[313] – all spearheaded primarily by non-profit organizations located outside the court system. In addition, there should be federal investment in a long-term national technical assistance center to promote SDM models and to provide states and territories with the

[321] *See id.* at 36 (Recommendation 4.1 is recommending the state's highest court require ongoing collection of timely guardianship data); *see also id.* at 39 (Recommendation 6.1 is recommending Congress establish a Guardianship Court Improvement Program that effectuates consistent and meaningful data collection).

308. *See, e.g.*, supra note 143.

309. *Cf. id.* at 35 (Recommendation 3.3 is recommending that every state should have a guardianship diversion program that includes, among other things, education and facilitation of the use of powers of attorney, health care consent statues, and supported decision-making).

310. For example, since legislation that would formally recognize supported decision-making was introduced in Wisconsin, the annual number of petitions to courts for guardianship decreased by almost 20 percent. *See* WSAW-TV, Guardianship requests decline as knowledge of alternative legal option grows (Aug. 9, 2021), available at https://www.wsaw.com/2021/08/10/guardianship-requests-decline-knowledge-alternative-legal-optiongrows/.

311. *See supra* note 309.

312. *See id*. at 35–36 (Recommendation 3.4 is recommending states provide accessible, practical, and tailored trainings to individuals and entitles, including judges and lawyers, on supported decision-making and other less restrictive alternatives to guardianship).

313. *See id.* at 33 (Recommendation 2.2 is recommending governments and organizations promote and expand sustainable funded SDM projects targeting diverse populations).

support and technical assistance they need to advance them successfully.[314]

314. *See* Cathy Costanzo, *Congressional Testimony of the Center for Public Representation*, at 4, https://www.centerforpublicrep.org/wp-content/uploads/National-CPRJudciaryTestimony.final_.pdf (October 4, 2021) (written testimony submitted to the U.S. Senate Judiciary Subcommittee on the Constitution for its September 28, 2021 hearing on "Toxic Conservatorships: The Need for Reform"); *see also* U.S. Committee on the Judiciary, Subcommittee on the Constitution, "Toxic Conservatorships: the Need for Reform" (Sept. 28, 2021), https://www.judiciary.senate.gov/meetings/toxic-conservatorships-the-need-for-reform (recording and written testimony of live witnesses at hearing)