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## Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making

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# LEGAL CAPACITY FOR ALL: INCLUDING OLDER PERSONS IN THE SHIFT FROM ADULT GUARDIANSHIP TO SUPPORTED DECISION-MAKING

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## INTRODUCTION

Adult guardianship is the state law process by which a court appoints a surrogate to make decisions for an adult who is deemed “incapacitated,” frequently by virtue of intellectual disability, mental

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illness, or cognitive impairment.<sup>1</sup> Once an individual is under guardianship, she loses her rights to make basic decisions about her life, including where she lives, how to spend her money, and whether to consent to health care.<sup>2</sup> For the last several decades, guardianship has been the subject of continual calls for reform, often spurred by revelations of guardian malfeasance and other abuses in the system.<sup>3</sup>

Recent developments in international human rights law and disability rights advocacy, however, pose a more fundamental challenge to the institution. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD),<sup>4</sup> with its declaration that everyone, regardless of mental disability or cognitive impairment, is entitled to make decisions and have those decisions recognized under the law, offers no less than a promise to end adult guardianship as we know it.<sup>5</sup>

Under Article 12, governments may not deprive individuals of their “legal capacity,” or right to make decisions and have those decisions recognized, on the grounds of disability or impaired decision-making skills.<sup>6</sup> Instead, cognitive and other mental disabilities trigger a right to “support” in decision-making.<sup>7</sup> This support can take the form of

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1. See UNIFORM GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT § 102(5) (UNIF. LAW COMM’N 1997) (defining “incapacitated person”). See *infra* note 26 and accompanying text for a discussion of who becomes subject to guardianship.

2. See *id.* §§ 315(a)(2),(4) (guardian may consent to health care, choose place of residence) and 410(a)(2) (conservator may make any financial decision person could have made). The UGPPA and a number of states differentiate between a “conservator,” who is given power over a person’s financial matters, and a “guardian,” who is given power over health care and personal decisions. For purposes of this Article, I will refer to systems in which a surrogate is appointed to make financial and/or personal decisions collectively as guardianship.

3. See *infra* notes 48–50, 83–84 and accompanying text.

4. G.A. Res. 61/106, art. 12, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006).

5. *Id.*

6. G.A. Res. 61/106, *supra* note 4, § 2; see also Comm. on the Rights of Persons with Disabilities, General Comment No. 1, art. 12, ¶ 13, 15, U.N. Doc CRPD/C/GC/1 (Apr. 11, 2014) (hereinafter “CRPD General Comment”) (explaining difference between legal capacity and mental capacity and reiterating that Article 12 does not permit the deprivation of legal decision-making rights on the grounds that an individual’s decision-making skills are impaired).

Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.

*Id.*

7. See G.A. Res. 61/106, *supra* note 4, § 3.

accessible formats or technological assistance in communication.<sup>8</sup> Or it can take the form of “supported decision-making” arrangements, in which “supporters” assist individuals with decision-making in relationships of trust.<sup>9</sup> In whatever form, the support is an appropriate accommodation that enables the individual to enjoy the right to legal capacity.<sup>10</sup>

The United States signed, but, somewhat notoriously, has not ratified the CRPD.<sup>11</sup> Nonetheless, the concept of “supported decision-making” has generated significant excitement among disability rights advocates. The federal Department of Health and Human Services’ Administration for Community Living, which promotes independent living for persons with disabilities and older adults, has endorsed the concept and funded a national resource center on the topic.<sup>12</sup> Pilot projects to provide supported decision-making services continue to spring up around the country.<sup>13</sup>

But as proponents of supported decision-making have made significant inroads in persuading the disability rights community that guardianships should be supplanted by this more rights-based alternative, questions persist about how it could and should work in practice. Nina Kohn and others have pointed to a dearth of empirical data on how supported decision-making actually functions to support

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8. CRPD General Comment, *supra* note 6, ¶ 17.

9. *Id.* ¶ 29 (describing supported decision-making regimes).

10. For a full discussion of support as a reasonable accommodation required under U.S. law by the Americans with Disabilities Act, see Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision-making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010).

11. See Rosalind S. Helderma, *Senate Rejects Treaty to Protect Disabled Around the World*, WASH. POST, Dec. 4, 2012.

12. Aaron Bishop & Edwin Walker, *Preserving the Right to Self-Determination: Supported Decision-Making*, ACL BLOG, [http://www.acl.gov/NewsRoom/blog/2015/2015\\_01\\_28.aspx](http://www.acl.gov/NewsRoom/blog/2015/2015_01_28.aspx) [<https://perma.cc/6TP8-WXFW>].

13. See, e.g., *Funding Announcement: Supported Decision-Making*, N.Y. STATE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL, [http://www.ddpc.ny.gov/sites/default/files/Supported%20Decision%20Making%20RFP%20Final%20Electronic%20Version\\_0.pdf](http://www.ddpc.ny.gov/sites/default/files/Supported%20Decision%20Making%20RFP%20Final%20Electronic%20Version_0.pdf) [<https://perma.cc/3KH2-2F9R>] (announcing availability of funds to launch a supported decision-making pilot project); see also *The Arc of San Angelo: Volunteer-Supported Decision-Making*, TEX. DEP’T OF AGING & DISABILITY SERVS., <http://www.tcdd.texas.gov/projects/grants-completed-projects/the-arc-of-san-angelo/> [<http://perma.cc/LT95-BCQ9>] (describing pilot project run by the Arc of San Angelo, with funding from the Texas Council for Developmental Disabilities); *Pilot Project*, CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/> [<https://perma.cc/L5A3-L5KV>] (describing supported decision-making pilot run by Center for Public Representation and Nonotuck Resource Associates in Northampton, Massachusetts).

the normative and ethical arguments for it.<sup>14</sup> Advocates are beginning to address those critiques by developing assessment tools for emerging pilot projects.<sup>15</sup>

Perhaps the most significant hurdle in shifting opinion toward supported decision-making is developing an argument for it that addresses the particular concerns of a significant, and likely growing, segment of those under guardianships: older persons, many of whom have cognitive impairments such as dementia. Older persons are believed to comprise a majority of the persons under guardianships<sup>16</sup> but, to date, their particular concerns have not been a central part of the legal capacity discussion. Supported decision-making has its roots in the disability rights movement.<sup>17</sup> Mental health consumers have also embraced the concept as a means of preserving their rights to make decisions about medical treatment and their lives.<sup>18</sup>

However, if supported decision-making is to take hold and supplant guardianship, attention must be paid to older persons and the particular ways that they might benefit from the shift. The legal model cannot change unless it makes sense to, and offers improvements for, the majority of people subject to it. Indeed, the aging of the population and the increase in Alzheimer's disease and dementia threaten to place a greater amount of older persons at risk of guardianship. The Alzheimer's Association predicts that the

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14. See generally Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111 (2013) (arguing that little is known about how supported decision-making works in practice and proposing an empirical research agenda).

15. See, e.g., HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH, PILOT EVALUATION YEAR 1 REPORT (2015), [http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1\\_HSRI-2015.pdf](http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf) [<https://perma.cc/ZCP8-MDTS>].

16. See ERICA F. WOOD, A.B.A., STATE LEVEL ADULT GUARDIANSHIP DATA: AN EXPLORATORY SURVEY 11–14 (2006), <http://www.ncea.aoa.gov/Resources/Publication/docs/GuardianshipData.pdf> [<https://perma.cc/P748-UB7A>] (summarizing limited empirical data that is available on guardianship).

17. See GUARDIANSHIP SUMMIT, BEYOND GUARDIANSHIP: SUPPORTED DECISION-MAKING BY INDIVIDUALS WITH INTELLECTUAL DISABILITIES 1–2 (2011), [http://nlrc.acl.gov/Legal\\_Issues/Guardianship/docs/kris\\_glen\\_paper\\_final\\_10-12.pdf](http://nlrc.acl.gov/Legal_Issues/Guardianship/docs/kris_glen_paper_final_10-12.pdf) [<https://perma.cc/V3QS-CDQE>] (finding that the CRPD, which utilizes supported decision-making, was a consequence of “activism and participation by the disability rights movement”).

18. See TINA MINKOWITZ, WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY, LEGAL CAPACITY AS RIGHT, PRINCIPLE AND PARADIGM: SUBMISSION TO THE COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES IN RESPONSE TO ITS CALL FOR PAPERS ON THEORETICAL AND PRACTICAL IMPLEMENTATION OF ARTICLE 12 (2011), [http://www.wnusp.net/documents/2012/WNUSP\\_Article12\\_Submission.doc](http://www.wnusp.net/documents/2012/WNUSP_Article12_Submission.doc) [<https://perma.cc/RH45-76JV>].

annual number of new cases of Alzheimer's and other dementias is expected to double by 2050.<sup>19</sup> Supported decision-making and/or other alternatives must be attractive and viable options if, for them, guardianship is to be supplanted, or at least minimized in its use. Without that embrace by older adult advocates, the movement toward supported decision-making is likely to stall or leave out a large portion of the population potentially subject to guardianship.<sup>20</sup>

This Article argues that the paradigm shift away from guardianship to a right to legal capacity can and should apply to older persons who would otherwise be at risk of guardianship. But, in order for it to take root, the theoretical underpinnings of the right to legal capacity should be expanded to more fully encompass the experience of older persons who would otherwise be at risk of guardianship. Proponents also need to grapple with legitimate hesitations and objections concerning potential for abuse, as well as practicability. This Article attempts to fill in those gaps by offering a normative argument for supported decision-making rooted in the particular concerns of older adults facing the loss of their rights. It then suggests a number of contexts in which a shift away from guardianship for older persons may be achieved most readily.

Part I describes guardianship and its limitations, even after the most recent wave of reform, which emphasized some preservation of autonomy for those with impaired decision-making abilities. Part II traces the emergence of the right to "legal capacity" and the development of supported decision-making as a replacement for guardianships in the intellectual disability community. Part III compares the concerns of older adults at risk of guardianship to those of persons with intellectual disabilities and describes the ways in which their interests and concerns with regard to legal capacity overlap and diverge. Part IV sketches out a normative justification for preserving the legal capacity of older adults. Finally, Part V

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19. ALZHEIMER'S ASS'N, 2015 ALZHEIMER'S DISEASE FACTS AND FIGURES 20 (2015) [http://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](http://www.alz.org/facts/downloads/facts_figures_2015.pdf) [<https://perma.cc/9QAG-NX9H>].

20. Advocates for the rights of older persons also have a separate, but related, interest in sorting out a position on questions of legal capacity in advance of further efforts to arrive at an international human rights treaty on the rights of older persons. See G.A. Res. 65/18, U.N. Doc. A/RES/65/182, ¶ 28 (Dec. 21, 2010) (establishing working group to consider the feasibility of additional instruments to protect the human rights of older persons). See generally Israel Doron & Itai Apter, *The Debate Around the Need for an International Convention on the Rights of Older Persons*, 50 GERONTOLOGIST 586, 587 (2010). Legal capacity is not the primary focus of such efforts but could prove to be a stumbling block should there be incoherence around the principles that would apply.

discusses the practicability of moving toward a supported decision-making model. It identifies ways in which the availability of a supported decision-making model can offer tangible benefits and identifies areas where further thinking is needed.

## I. ADULT GUARDIANSHIP AFTER RECENT REFORMS

In order to understand what supported decision-making and the right to legal capacity<sup>21</sup> can offer older persons, as well as the backdrop of what they might replace, it is first necessary to consider the current state of guardianship law and practice. This part describes the basic process of guardianship, and then discusses the most recent round of reforms that began nearly thirty years ago in the wake of media accounts of widespread exploitation and abuse in guardianship. It then concludes that reforms have only been a limited success in that practice has not conformed to legal changes that were supposed to preserve autonomy for persons under guardianship.

### A. The Mechanism of Guardianship

Adult guardianship is a state law process, often occurring in probate court. It is the legal system's response to an adult who is or becomes mentally "incapacitated" and is deemed unable to make legally binding decisions.<sup>22</sup> Most definitions of incapacity require two findings: (1) the individual is at risk of harm because of an inability to provide for personal or financial needs; and (2) the individual lacks the cognitive ability to understand and appreciate decisions.<sup>23</sup> The central premise of guardianship is that the law will protect the person by appointing a surrogate to protect her from either her bad decisions

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21. Supported decision-making is one means by which an individual may avoid guardianship and avoid being stripped of her right to legal capacity. However, it is important to recognize that legal capacity can be taken away from individuals through means other than guardianship and that the right to legal capacity is broader than a right to supported decision-making. *See generally* CRPD General Comment, *supra* note 6, ¶ 7.

22. *See, e.g.*, N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2016).

23. For example, the Uniform Guardianship & Protective Proceedings Act defines incapacity with respect to managing property as "an impairment in the ability to receive and evaluate information or make decisions, even with the use of appropriate technological assistance." UNIFORM GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 401(2)(a) (UNIF. LAW. COMM'N 1997). New York's Article 81 guardianship statute defines an incapacitated person as one "likely to suffer harm because: 1. the person is unable to provide for personal needs and/or property management; and 2. the person cannot adequately understand and appreciate the nature and consequences of such inability." N.Y. MENTAL HYG. LAW § 81.02(b) (McKinney 2016).

or her inability to make decisions.<sup>24</sup> Guardianship removes the legal right of the incapacitated person to make decisions and vests that right with a surrogate. The person under guardianship ceases to be “a legal actor” whose decisions receive legal recognition.<sup>25</sup>

Guardianships have typically affected three main groups: (1) older adults with cognitive impairments, such as dementia and, to a lesser extent, those living with stroke-related conditions; (2) persons with intellectual disabilities; and (3) persons with psychosocial disabilities.<sup>26</sup> In recent years, as more attention has been brought to traumatic brain injury, that too has been counted as an impairment giving rise to guardianship.<sup>27</sup> Of course, an individual may fall into not just one but also two or three of these categories at the same time or over the course of a lifetime. Under many guardianship regimes, particularly now that many states use a functional assessment approach to incapacity determinations, the individual’s particular diagnosis or condition is not supposed to be determinative; what is supposed to matter is the functional ability to make decisions.<sup>28</sup>

The removal of decision-making power is a significant deprivation of individual rights.<sup>29</sup> Once under guardianship, persons may lose the right to choose where they live,<sup>30</sup> how they spend their money,<sup>31</sup> with

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24. See *In re Guardianship of Hedin*, 528 N.W.2d 567, 571–73 (Iowa 1995) (describing history of guardianship as protective mechanism). Various schemes talk of persons under guardianship as “protected persons.” See, e.g., UGPPA § 401 (creating “protective proceedings” for individuals’ property). The guardian, in turn, is deemed to provide “protection.” *Id.* § 318.

25. Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 119 (2012).

26. See *id.* at 93 n.1. The condition that shows up in the most guardianship filings is dementia. See, e.g., MICHAEL J. JENUWINE, THE STATE OF ADULT GUARDIANSHIP IN INDIANA: AN EMPIRICAL PERSPECTIVE 46, *in* INDIANA ADULT GUARDIANSHIP STATE TASK FORCE, WHO’S OVERSEEING THE OVERSEERS? A REPORT ON THE STATE OF ADULT GUARDIANSHIP IN INDIANA (2012), <http://www.in.gov/judiciary/admin/files/ad-guard-2012-full-report.pdf> [<https://perma.cc/JDS6-GR3F>]. In the study of Indiana filings, dementia was mentioned in 25.8% of filings, compared to 22% for cognitive/intellectual impairment and 10.5% for severe mental illness. *Id.* Stroke-related conditions were described in 5.4% and a general category of “conditions associated with old age” comprised 1.4%. *Id.*

27. See JENUWINE, *supra* note 26, at 62.

28. See UNIFORM GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT prefatory note (characterizing 1997 revision to uniform guardianship law as requiring a functional analysis).

29. See *In re Guardianship of Hedin*, 528 N.W.2d 567, 575 (Iowa 1995) (“Guardianship involves such a significant loss of liberty that we now hold that the ward is entitled to the full panoply of procedural due process rights comparable to those present in involuntary civil commitment proceedings.”).

30. N.Y. MENTAL HYG. LAW § 81.22(a)(9) (McKinney 2010).

31. N.Y. MENTAL HYG. LAW § 81.21(a) (McKinney 2015).



whom they spend their time, and with whom they have relationships.<sup>32</sup> They cannot enter contracts, authorize the disclosure of their medical records, or make health care decisions.<sup>33</sup> Thus, commentators have said that the person under a guardianship is reduced to “the status of a child”<sup>34</sup> with the loss of the basic civil rights that adults enjoy. The late Congressman Claude Pepper famously put it another way: “[t]he typical ward has fewer rights than the typical convicted felon.”<sup>35</sup> Others have described guardianship as a “civil death.”<sup>36</sup>

Why does the law permit such an incursion? On the theoretical level, the justification is *parens patriae*, the ancient power of the state to protect those who are thought not able to protect themselves.<sup>37</sup> Historically, the king and his representatives exercised this power to wrest control over property.<sup>38</sup> The common law, and later “lunacy” statutes, continued this practice in the United States, and the law further evolved to embrace a general principle that the state has an obligation to protect those deemed unable to care for themselves.<sup>39</sup>

Whereas the theoretical justification for guardianship is the state’s protective power, in practice guardianships over older adults typically are sought when a relative, friend, or health care institution believes one of two situations has arisen: (1) some legally binding decision needs to be made and the person is thought not able to make it; or (2) the person is making decisions thought to be irrational and/or harmful to themselves. In the first circumstance, guardianships become necessary due to the barriers imposed by two other doctrines that involve cognitive tests: informed consent for medical decisions and contractual capacity, both of which demand that decision-makers be

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32. *Id.* § 81.22(2); see also *Hedin*, 528 N.W.2d 567 (challenging guardianship brought by man whose guardian limited his time with his girlfriend and forbade him from marrying her).

33. N.Y. MENTAL HYG. LAW §§ 81.21, 81.22.

34. *Hedin*, 528 N.W.2d at 572 (quoting Sheryl Dicker, *Guardianship: Overcoming the Last Hurdle to Civil Rights for the Mentally Disabled*, U. ARK. LITTLE ROCK L. REV. 485, 485 (1981)).

35. *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace: Hearing Before the H. Select Comm. on Aging*, 100th Cong. 8 (1987) (statement of Claude Pepper, Chairman of H. Select Comm. On Aging).

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

37. See Margaret K. Krasik, *The Lights of Science and Experience: Historical Perspectives on Legal Attitudes Toward the Role of Medical Expertise in Guardianship of the Elderly*, 33 AM. J. LEGAL HIST. 201, 203 (1989).

38. *Id.* at 204.

39. See Salzman, *supra* note 10, at 164.

able to understand and appreciate the consequences of their decisions and be able to communicate a decision.<sup>40</sup> The inability to pass the “understand and appreciate” threshold is what drives many older people into guardianships, because third parties demand a legally cognizable actor to make health care decisions, engage in banking transactions, enter a residential lease, or engage in other real estate and financial transactions.<sup>41</sup> If the person has the resources and inclination to execute an advance directive, such as a power of attorney or health care proxy, before experiencing significant cognitive decline, the law typically looks to the agent in those documents to make decisions.<sup>42</sup> However, in the absence of such documents, or in situations when the named agents cannot act or could abuse their powers, a need for guardianship may arise.<sup>43</sup>

In the second circumstance, a family member, government social services agency, health care institution, or other concerned party believes that an individual is at risk of financial or physical harm because of impaired decision-making ability. A concerned person or agency may petition the court to take away a person’s decision-making rights to stop or remedy financial or other abuse.<sup>44</sup> Or, one family member may believe that another family member is not caring

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40. On informed consent, see *In re Conroy*, 486 A.2d 1209, 1222, 1241 (N.J. 1985) (patient must be able to understand information conveyed, evaluate options, and communicate a decision). On capacity to contract, see RESTATEMENT (SECOND) CONTRACTS § 15(1) (AM. LAW INST. 1981) (providing that contract is voidable “if by reason of mental illness or defect . . . he is unable to understand in a reasonable manner the nature and consequences of the transaction” or “he is unable to act in a reasonable manner . . . and the other party has reason to know of his condition”). See also *Ortelere v. Teacher’s Retirement Bd.*, 250 N.E.2d 460, 464 (N.Y. 1969) (party must be able to make a rational judgment about the transaction). It is also black-letter law that each party to a contract manifest her assent to the transaction. RESTATEMENT (SECOND) CONTRACTS § 17(1) (AM. LAW INST. 1981).

41. See YOTAM TOLUB, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES, ALTERNATIVES TO GUARDIANSHIP IN FINANCIAL AFFAIRS 14 (Noga Kadman & Maya Johnston eds., Debbie Cohen trans.), <http://bizchut.org.il/en/wp-content/uploads/2014/12/Alternative-to-Guardianship-report.pdf> [<https://perma.cc/8ABP-8FTP>].

42. See, e.g., *In re May Far C.*, 877 N.Y.S.2d 367, 368 (N.Y. App. Div. 2009); *In re Matter of Isadora R.*, 773 N.Y.S.2d 96 (N.Y. App. Div. 2004).

43. See, e.g., *In re Nora McL.C.*, 764 N.Y.S.2d 128, 129 (N.Y. App. Div. 2003) (affirming appointment of independent guardian where niece had abused power of attorney).

44. See *infra* notes 150–51 (third parties can petition the court for guardianship); PowerPoint: Jean Callahan & Raquel Romanick, Brookdale Center for Healthy Aging, Understanding Guardianship in New York State, Slide 17 (Nov. 2015) (unpublished presentation) (on file with author) (financial abuse mentioned as reason for guardianship in 12% of petitions reviewed in a sample of New York state guardianship cases).

properly for the person, and use a guardianship as a form of an adult custody battle.<sup>45</sup> Or, the person may live in objectionable, hoarding conditions that the petitioner seeks to remedy through a guardianship.<sup>46</sup>

Should the guardianship function as intended—with the surrogate acting responsibly and in keeping with the individual’s wishes, it could be a useful tool for maximizing her welfare while promoting her preferences. Indeed, the National Guardianship Association, the leading professional group in the field, promotes as one of its standards of practice that the guardian shall “identify and advocate for the person’s goals, needs and preferences.”<sup>47</sup> However, as is described in Section I.B, many guardianships are not that ideal, efforts to improve the system have been only a partial success, and, even at their best, guardianship still deprives the person of basic human rights.

### B. Recent Reform Efforts

Concern about abuse within the guardianship system prompted a major wave of reform, starting in the late 1980s.<sup>48</sup> These reforms were spurred by a major Associated Press exposé that portrayed a lawless system, under which older adults were summarily stripped of their rights, and then frequently subjected to exploitation by guardians whose actions went unchecked by the courts.<sup>49</sup> In the wake of the AP’s report, which termed the guardianship system a “national disgrace,” reformers succeeded in overhauling the guardianship statutes in eighteen states between the late-1980s and late-1990s.<sup>50</sup>

Much of the impetus for guardianship reform came from the legal community, with the American Bar Association playing a critical

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45. See *In re Camoia*, No. 100250/2012, 2015 WL 4877675 (N.Y. Sup. Ct. 2015).

46. See Callahan & Romanick, *supra* note 44, at Slide 17 (hoarding mentioned in three percent of guardianship petitions reviewed in sample).

47. NAT’L GUARDIANSHIP ASS’N, STANDARDS OF PRACTICE 6 (4th ed. 2013), [http://www.guardianship.org/documents/Standards\\_of\\_Practice.pdf](http://www.guardianship.org/documents/Standards_of_Practice.pdf) [<https://perma.cc/BB3X-ZSYH>].

48. See Glen, *supra* note 25, at 108–10.

49. See *id.* 109; Fred Bayles & Scott McCartney, *Guardians of the Elderly: An Ailing System Part II: Many Elderly Never Get Their Day in Court*, ASSOCIATED PRESS (Sept. 20, 1987, 11:50 PM), <http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-II-Many-Elderly-Never-Get-Their-Day-In-Court/id-8ea94c1c992fd97e7eea7fe72a924f73> [<https://perma.cc/5YRP-7FQK>].

50. See A. Frank Johns, *Ten Years After: Where is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?*, 7 ELDER L.J. 33, 79 & n.398 (1999) (summarizing changes in state guardianship laws).

role.<sup>51</sup> These reformers were leery of guardianships,<sup>52</sup> and sought to limit their role significantly, especially when guardianships were brought to further a third party's interest, or when less restrictive alternatives would suffice.<sup>53</sup> But for the most part, these reformers stopped short of calling for the abolition of guardianship. Few challenged the fundamental premise of guardianships—that the solution to an adult's impaired decision-making is to wrest away her legal right to make decisions and deposit it into the hands of a surrogate.<sup>54</sup> Thus, the debates largely took place around how an improved guardianship process should work, what had to be proven to appoint a guardian, how the courts should monitor the activities of the surrogate, and how extensive the guardian's powers should be.<sup>55</sup>

Reformers succeeded in changing the standard for determining whether to appoint a guardian from a diagnostic-based, medical declaration of incompetency to a functional assessment of the person's ability to make decisions.<sup>56</sup> They also imported due process into guardianship proceedings and mandated that an individual's rights could not be taken away without a hearing, often with a right to counsel.<sup>57</sup> They further imposed reporting obligations on guardians

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51. See Glen, *supra* note 25, at 108–09; see also AMERICAN BAR ASSOCIATION, *GUARDIANSHIP: AN AGENDA FOR REFORM, RECOMMENDATIONS OF THE NATIONAL GUARDIANSHIP SYMPOSIUM AND POLICY OF THE AMERICAN BAR ASSOCIATION* iii (1989) [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2011/2011\\_aging\\_gship\\_agda\\_refrm.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_gship_agda_refrm.authcheckdam.pdf) [https://perma.cc/V2ZW-6A8N] [hereinafter *GUARDIANSHIP: AN AGENDA FOR REFORM*].

52. See Lawrence A. Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 31 *STETSON L. REV.* 735, 740 (2002) (describing attitude of suspicion and antagonism toward guardianship).

53. See *GUARDIANSHIP: AN AGENDA FOR REFORM*, *supra* note 51, at 3.

54. See Glen, *supra* note 25, at 119 (noting that the most recent guardianship reforms pushed for a mode of guardian decision-making in which the person's preferences would be adhered to but still transfer the decision-making right to the guardian).

55. See *generally id.* at 108–19 (breaking these reforms of the last thirty years into two rounds: the first addressing procedural protections and the move toward a functional, as opposed to medical, assessment of incapacity, and the second addressing the advent of substitute decision-making—making decisions for the person based on what she would have decided as opposed to using the more paternalistic best interests rubric).

56. See N.Y. MENTAL HYG. LAW § 81.02(c) (McKinney 2016) (describing functional assessment in determining whether person is incapacitated); see also Phillip B. Tor & Bruce D. Sales, *A Social Science Perspective on the Law of Guardianship: Directions for Improving the Process and Practice*, 18 *LAW & PSYCHOL. REV.* 1, 7 (1994).

57. See Tor & Sales, *supra* note 56, at 3.

so that courts could monitor how guardians performed after their appointments.<sup>58</sup>

Reformers also embraced the concept of “least restrictive alternative,” which had emerged in constitutional litigation involving involuntary commitment of persons with mental illness.<sup>59</sup> First, revised statutes sought to end “plenary” guardianship, which grants a guardian virtually unfettered decision-making authority over all aspects of a person’s life.<sup>60</sup> Instead, reformed guardianship statutes require that courts tailor guardianship so that the guardian is given only those powers necessary to meet the person’s needs.<sup>61</sup> The person under guardianship is supposed to retain decision-making powers over other aspects of their lives not specifically designated to the guardian’s control.<sup>62</sup> These ambitious aims are reflected in the “findings and purpose” language of New York’s primary adult guardianship law, which reads more like a declaration of individual rights than the preface to a statutory scheme that authorizes surrogate decision-making:

The legislature finds that it is desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention which assists them in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable. The legislature declares that it is the purpose of this act to promote the public welfare by establishing a guardianship system which is appropriate to satisfy either personal or property management needs of an incapacitated person in a manner tailored to the individual needs of that person, which takes in account the personal wishes, preferences and desires of the person, and which affords the person the greatest amount of independence and self-determination and participation in all the decisions affecting such person’s life.<sup>63</sup>

The other way in which the least restrictive alternative concept was applied to guardianships involved codifying the notion that

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58. Tor & Sales, *supra* note 56, at 30.

59. See Glen, *supra* note 25, at 108 & n.67; see also Michael L. Perlin, “*Their Promises of Paradise*”: Will Olmstead v. L.C. Resuscitate the Constitutional “Least Restrictive Alternative” Principle in Mental Disability Law?, 37 HOUS. L. REV. 999, 1010–17 (2000).

60. See Frolik, *supra* note 52, at 735 n.4, 740–41.

61. See, e.g., Frolik, *supra* note 52, at 735 n.4.

62. See, e.g., N.Y. MENTAL HYG. LAW § 81.29(a) (McKinney 2010) (stating that person under guardianship retains all powers and rights except those granted to the guardian).

63. N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2016).

guardianships are a means of last resort.<sup>64</sup> Even if a person is deemed “incapacitated,” courts are supposed to reject a guardianship when the person has in place sufficient alternatives, such as a power of attorney or other resources, to meet their needs.<sup>65</sup>

In addition, as the statutory language above suggests, there was some effort to change the standard for decision-making by guardians from a historical “best interests” standard to one that took into account the wishes, preferences, and desires of the person—what has been termed “substituted judgment.”<sup>66</sup> Kristin Booth Glen has described this as a separate, later phase of the most recent reform movement, “intended to maximize the incapacitated person’s dignity and autonomy.”<sup>67</sup> In their study of decision-making standards for guardians, Linda Whitton and Lawrence Frolik found that eighteen jurisdictions have some resemblance of the “substituted judgment” language in their guardianship statutes, but that fourteen of those also have “best interests” language as well.<sup>68</sup>

On paper, these reforms were significant. In practice, however, they can be judged as a limited success. As Lawrence Frolik has argued, despite the significant changes in guardianship law, the culture and practice remain largely unchanged.<sup>69</sup> There is limited empirical data about guardianship in general, but the few in-depth studies of state court files demonstrate that these reforms have, in large part, not been implemented as intended. First, even though statutes require consideration of less restrictive alternatives and demand a high threshold for a finding of incapacity, guardianship petitions are rarely denied and proceedings are often pro forma and procedurally flawed, with persons alleged to be incapacitated

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64. See, e.g., N.Y. MENTAL HYG. LAW §§ 81.02 (a)(2) (McKinney 2016) (stating that guardianships should only be appointed if necessary), 81.03(e) (McKinney 2004) (requiring courts to assess other “available resources” such as powers of attorney, health care proxies, and representative payees, when assessing whether a person needs a guardian).

65. See N.Y. MENTAL HYG. LAW §§ 81.02(a)(2), 81.03(e); see also *In re May Far C.*, 61 A.D.3d 680, 668 (N.Y. App. Div. 2009); *In re Isadora R.*, 773 N.Y.S.2d 96 (N.Y. App. Div. 2004).

66. See Glen, *supra* note 25, at 98-99.

67. *Id.* at 119.

68. Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491, 1499 (2012).

69. Lawrence A. Frolik, *Guardianship Reform: When the Best Is the Enemy of the Good*, 9 STAN. L. & POL’Y REV. 347, 348 (1998) (“But the rock of guardianship culture and practice still stands, and stands mainly unchanged.”).

frequently appearing without counsel in some states.<sup>70</sup> It is also quite common for guardians to be appointed for an indefinite duration, as opposed to a limited time necessary to resolve whatever crisis prompted the guardianship.<sup>71</sup>

Second, notwithstanding the statutory thumb on the scale toward limiting the powers granted to guardians (and thereby taken away from the individual), courts continue to grant broad plenary powers to guardians in the majority of cases.<sup>72</sup> Courts favor wholesale grants of power to guardians because they fear the burden of hearing future applications from guardians every time a new need arises that might warrant an expansion of the guardian's powers.<sup>73</sup> Thus, plenary guardianships are overwhelmingly the norm.<sup>74</sup> For example, a recent study reviewed all guardianship filings in 2008 in certain Indiana courts and found that limited guardianships were granted in *less than one percent* of the cases.<sup>75</sup>

Third, while it appears that substituted judgment standards have had some effect, it remains unclear how much success they have had on making sure that a guardian effectuates the person's wishes. In a survey of guardians, Whitton and Frolik found that the presence of substituted judgment language in statutes correlated with more conversations by guardians with the individuals regarding their preferences in health care and other decisions.<sup>76</sup> The survey also found that guardians continued to take into consideration what they believed to be in the individuals' best interests when making decisions

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70. Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 199 (2007) (summarizing a 1994 study showing most hearings are very brief, most respondents are not represented, and evidence presented is limited); JENUWINE, *supra* note 26, at 44 (stating that in 97.6% of cases reviewed in an Indiana study, persons alleged to be incapacitated were unrepresented by counsel); WOOD, *supra* note 16, at 12 (finding that 64% of guardianships were granted before an attorney was appointed and 92% were granted before a court investigator's report).

71. See Callahan & Romanick, *supra* note 44, at Slide 7 (finding that of 1636 guardianship petitions that had been fully adjudicated, 972 resulted in permanent guardianship).

72. See Salzman, *supra* note 10, at 245 n.51 (2010) (citing studies that found limited guardianships in 0% to 7% of cases and 13% of cases); see also Teaster et al., *supra* note 70, at 219, 234; Frolik, *supra* note 52, at 740–44 (explaining that courts prefer, and often invoke, plenary guardianship, despite the option for limited guardianship because of its advantages).

73. See Frolik, *supra* note 52, at 741–44.

74. See Teaster et al., *supra* note 70, at 219, 234.

75. See JENUWINE, *supra* note 26, at 49.

76. See Whitton & Frolik, *supra* note 68, at 1534.

on their behalf.<sup>77</sup> There is scant case law in which persons under guardianship challenge guardian decision-making for not taking account of their wishes, likely because of how difficult it is for persons under guardianship to obtain legal assistance to challenge decisions by their guardians.<sup>78</sup>

Fourth, studies have shown that guardianship monitoring in many states ranges from non-existent to deeply flawed and reports of guardianship abuse persist.<sup>79</sup> In a report on a survey of judges and court personnel, the National Center for State Courts quoted a number of respondents as stating that their courts did not have the resources to adequately monitor guardianships.<sup>80</sup> With regard to checking on the personal well-being of the person under guardianship, as opposed to checking on the accounting of finances, the Center concluded that “[f]ew courts regularly monitor the condition of the incapacitated person.”<sup>81</sup> Such findings have also appeared on the state level. For example, a recent study of guardianships in Pennsylvania reports that seventy-five percent of clerks in the courts that handle guardianships do not monitor whether the guardian submits the initial inventory—an accounting of assets that the person possesses at the beginning of a guardianship—and sixty-nine percent of clerks do not monitor whether the guardian submits annual reports.<sup>82</sup> A 2010 Government Accountability Office (GAO) report “identified hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the

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77. Whitton & Frolik, *supra* note 68, at 1534.

78. See Jenica Cassidy, *Restoration of Rights in the Termination of Adult Guardianship*, 23 ELDER L.J. 83, 102 (2015) (describing the difficulties persons under guardianship have in finding, retaining, and affording counsel, especially because they are no longer in control of their money, to pursue restoration of their rights).

79. See BRENDA K. UEKERT, CENTER FOR ELDERS AND THE COURTS, ADULT GUARDIANSHIP COURT DATA AND ISSUES: RESULTS FROM AN ONLINE SURVEY 5 (2010), [http://www.guardianship.org/reports/Guardianship\\_Survey\\_Report.pdf](http://www.guardianship.org/reports/Guardianship_Survey_Report.pdf) [https://perma.cc/DG8P-M75N]; GUARDIANSHIP MONITORING COMMITTEE, GUARDIANSHIP MONITORING COMMITTEE FINDINGS AND RECOMMENDATIONS 118 (2014), <http://www.pacourts.us/assets/files/page-543/file-4022.pdf?cb=1444534377573> [https://perma.cc/5748-B6WL]; U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-10-1046, GUARDIANSHIPS: CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS 27 (2010) [hereinafter GAO-10-1046].

80. See UEKERT, *supra* note 79, at 24–25; see also Arian Campos-Flores & Ashby Jones, *Abuses Plague System of Legal Guardians for Adults*, WALL ST. J. (Oct. 30, 2015, 1:18 PM), <http://www.wsj.com/articles/abuse-plagues-system-of-legal-guardians-for-adults-1446225524> [https://perma.cc/U7RF-8YQD] (providing examples of abuse and the lack of oversight for guardians).

81. See UEKERT, *supra* note 79, at 5.

82. See GUARDIANSHIP MONITORING COMMITTEE, *supra* note 79, at 118, 138.



District of Columbia between 1990 and 2010.”<sup>83</sup> A steady drumbeat of press reports from around the country has confirmed that these deficiencies persist and point to a lack of monitoring and enforcement by court systems.<sup>84</sup>

To be sure, this account has focused on the shortcomings, not the cases in which guardians assisted a vulnerable individual by providing needed services and care.<sup>85</sup> It has also not focused on describing the many substantial efforts afoot to improve matters and to make sure that the guardianship system functions as intended.<sup>86</sup> Or the many times that court monitors have caught guardians who have attempted to cheat the persons whom they are supposed to be protecting.<sup>87</sup> But, as a systemic matter, it is hard to conclude that the reformed guardianship regimes have delivered on their promises of enhanced autonomy and accountability.

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83. GAO-10-1046, *supra* note 79. To cite just one example, the GAO recounted a New York case in which the guardian misappropriated at least \$327,000 to herself, family, and friends from an eighty-two-year-old retired judge—all while presiding over the decrease of his estate from several million dollars to almost nothing. *Id.* at 13.

84. *See, e.g.*, Campos-Flores Jones, *supra* note 80; Colton Lochhead, *Clark County's Private Guardians May Protect—or Just Steal and Abuse*, LAS VEGAS REVIEW-JOURNAL (Apr. 13, 2015, 10:38 AM), <http://www.reviewjournal.com/news/las-vegas/clark-county-s-private-guardians-may-protect-or-just-steal-and-abuse> [<https://perma.cc/Q9GK-LZNV>]; Shannon Mullen, *Investigation: Betrayal of Trust: Stealing from Seniors*, ASBURY PARK PRESS (June 27, 2015), <http://www.app.com/story/news/investigations/watchdog/investigations/2015/06/27/guardianship-abuse-incapacity-trial/71006830/> [<https://perma.cc/H4XM-2ME2>]; Lucas Sullivan, Jill Riepenhoff, Mike Wagner & Josh Jarman, *Elderly, Mentally Ill & Children Trapped in Broken Court System*, COLUMBUS DISPATCH (May 18, 2014, 12:26 PM), <http://www.dispatch.com/content/stories/local/2014/05/18/elderly-mentally-ill-and-children-trapped-in-broken-court-system.html> [<https://perma.cc/7J7G-XQ5V>]; Lise Olsen, *Guardianship Putting Thousands of Elderly Texans at Risk*, HOUSTON CHRONICLE (Nov. 3, 2011, 11:01 PM), <http://www.chron.com/news/houston-texas/article/Guardians-for-the-elderly-and-disabled-paid-2251312.php> [<https://perma.cc/EZM4-CBNL>].

85. *See* Callahan & Romanick, *supra* note 44, at Slide 23 (noting that financial management was put in place in forty-three percent of case files reviewed and that services or care were arranged in forty-two percent of case files reviewed).

86. *See, e.g.*, NATIONAL GUARDIANSHIP NETWORK, WINGS TIPS: STATE REPLICATION GUIDE FOR WORKING INTERDISCIPLINARY NETWORKS OF GUARDIANSHIP STAKEHOLDERS 3–5 (2014), [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_wings\\_implementation\\_guide.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_wings_implementation_guide.authcheckdam.pdf) [<https://perma.cc/C54X-SS26>] (describing court-community partnerships promoted by the National Guardianship Network in a number of states to improve practices).

87. *See, e.g.*, *In re Gilvary*, 938 N.Y.S.2d 589 (N.Y. App. Div. 2012) (censuring guardian for writing checks out of the guardian account without authority to do so).

## II. DEVELOPMENT OF SUPPORTED DECISION-MAKING AND THE RIGHT TO “LEGAL CAPACITY”

A growing chorus of critics argues that even under the best guardianship, the mere fact that the guardianship has adjudged an individual as incapacitated or incompetent, and stripped her of the right to act on her own behalf, causes significant harm.<sup>88</sup> As Leslie Salzman argues, this deprivation of rights undermines an individual’s independence, diminishes her status in the eyes of others, stigmatizes her, and results in her constructive isolation from civil society.<sup>89</sup> The question is whether the law can offer an alternative mechanism in these situations, one that does not strip the individual of her legal rights and rather recognizes her as a legal actor who makes decisions. This is the goal of the movement for the right to legal capacity.

When states were reforming their guardianship laws, advocates for persons with intellectual disabilities were developing a wholly different model to address legal decision-making. Kristin Booth Glen traces this “paradigm shift,” which re-conceptualized the right to decision-making for persons with cognitive impairments, to three contemporaneous phenomena: the rise of the disability rights movement, the development of integration mandates for children and adults with intellectual disabilities, and the rise of human rights norms, both in general and as tools used by the disability rights movement.<sup>90</sup>

The concept of supported decision-making traces its roots to the early 1990s in Canada, where independent living advocates for persons with disabilities grappled with the obstacles that guardianship and other forms of surrogate decision-making imposed for persons seeking to live more autonomously.<sup>91</sup> Supported decision-making “was seen to be a way to remove legal barriers created by issues of competency, which prevented people with intellectual disabilities” from making decisions about finances.<sup>92</sup> Instead, advocates proposed

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88. See Salzman, *supra* note 10, at 168–69; see also Glen, *supra* note 25, at 119 (“[T]he person under guardianship is *not, or is no longer, a legal actor.*”) (alteration in original).

89. See Salzman, *supra* note 10, at 168–69.

90. Glen, *supra* note 25, at 123–38.

91. MICHAEL BACH & LANA KERZNER, LAW COMM’N OF ONTARIO, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY: ACHIEVING SUBSTANTIVE EQUALITY FOR PERSONS WITH DISABILITIES THROUGH LAW, POLICY AND PRACTICE 33–34 (2010), <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf> [<https://perma.cc/AA35-FPWU>].

92. Michelle Brownin et al., *Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice*, 1

a system of support that would assist persons with disabilities in making decisions even if the person would have been considered to lack sufficient cognitive ability to make such a decision under traditional doctrines of informed consent and capacity to contract.<sup>93</sup> Advocates also proposed providing legal recognition to relationships of trust in which supporters assist the person with a disability in making a decision through a number of means, such as explaining options in plain language, engaging in alternative forms of communication, and interpreting the individual's preferences.<sup>94</sup>

### A. The Development of a Right to Legal Capacity

The revolutionary approach of these proposals was to decouple the notion of “legal capacity”—the right “to make decisions and have those decisions respected”<sup>95</sup>—from cognitive decision-making ability, or what some have termed “mental capacity.”<sup>96</sup> Legal capacity is a human right, “a social and legal status accorded independent of a person's particular capabilities.”<sup>97</sup> Whether an individual has the cognitive ability to understand and appreciate consequences of her decisions—the traditional threshold of the common law—is simply not determinative of whether she has legal capacity. Even if she does not possess those decision-making abilities, she cannot be stripped of her legal capacity.<sup>98</sup>

Article 12 of the CRPD, adopted in 2006, embraced this approach and mandates, as a human rights matter, that states “may not strip individuals of their legal capacity based on disability.”<sup>99</sup> As a number of scholars have argued, Article 12 does not create any new rights to legal capacity, but merely restates the rights that already exist for all,

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RESEARCH AND PRACTICE IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 34, 35 (2014) (providing a useful and concise summary of the history of supported decision-making).

93. See BACH & KERZNER, *supra* note 91, at 72.

94. See Salzman, *supra* note 10, at 232–33.

95. BACH & KERZNER, *supra* note 91, at 18.

96. “Mental capacity” is the phrase used in the first General Comment to the CRPD. See CRPD General Comment, *supra* note 6, ¶ 13.

97. See BACH & KERZNER, *supra* note 91, at 18.

98. A number of human rights theorists further break down legal capacity into two parts: “legal status,” which is the ability to hold rights that the state must recognize, and “legal agency,” which is the ability to have one's decisions recognized by the law. Eilionóir Flynn & Anna Arstein-Kerslake, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, 10 INT'L J.L. IN CONTEXT 81, 83 (2014).

99. CRPD General Comment, *supra* note 6.

and applies them in the context of persons with disabilities.<sup>100</sup> Article 12 also imposes an obligation on states to provide support to individuals with disabilities so that they may exercise their legal capacity.<sup>101</sup> The individual, and not a surrogate, must hold the rights to make decisions.<sup>102</sup> All measures related to legal capacity must “respect the rights, will and preferences of the person.”<sup>103</sup>

When the CRPD was adopted, there was some debate about whether the convention permitted guardianship in certain circumstances with safeguards, or whether it barred guardianship completely.<sup>104</sup> The U.N. Committee on the Rights of Persons with Disabilities resolved this debate when it issued General Comment No. 1, which took the position that all forms of substitute decision-making are forbidden under Article 12.<sup>105</sup> “[S]ubstitute decision-making regimes such as guardianship, conservatorship and mental

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100. See Piers Gooding, *Navigating the ‘Flashing Amber Lights’ of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns*, 15 HUM. RTS. L. REV. 45, 46–47 (2015).

101. See CRPD General Comment, *supra* note 6, ¶ 3. Leslie Salzman argues that support is also required under domestic law, specifically the Americans with Disabilities Act. See Salzman, *supra* note 10, at 157 (arguing that guardianship violates the integration mandate of the Americans with Disabilities Act and that accommodations in the form of supported decision-making must be provided); see also Salzman, *supra* note 10, at 280.

102. See Leslie Salzman, *Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL’Y 279, 306 (2011) (individuals must hold the rights to make decisions in supported decision-making regimes as opposed to traditional guardianship models).

103. CRPD General Comment, *supra* note 6, ¶ 22.

104. Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?*, 34 SYRACUSE J. INT’L L. & COM. 429, 447–48, 455–56 (2007) (describing a variety of interpretations that nations ascribed to the text of Article 12).

105. CRPD General Comment, *supra* note 6, ¶ 3 (“[T]he Committee observes that there is a general misunderstanding of the exact scope of the obligations of States parties under article 12 of the Convention. Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.”). In the human rights parlance of Article 12, “substitute decision-making” refers to regimes that “permit the removal of legal capacity from certain individuals and vest it in third parties, who generally base decisions on the perceived objective best interests of the person.” Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT’L L. 124, 125 (2014). In contrast, in the United States, “substituted judgment” has been used to refer to a particular type of decision-making that a surrogate engages in when she makes decisions based on what the person would have wanted. See Glen, *supra* note 25, at 116. Thus, in the human rights context of Article 12, “substitute decision-making” refers more broadly to all forms of surrogate decision-making not done at the person’s direction. *Id.*

health laws that permit forced treatment . . . must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others,” the committee opined.<sup>106</sup> Substitute decision-making is impermissible even with regard to a single decision, the General Comment states.<sup>107</sup>

In place of regimes such as guardianship, the General Comment called for states to instead provide support to assist persons with disabilities to exercise their legal capacity.<sup>108</sup> Support, the General Comment states, is “a broad term that encompasses both informal and formal support arrangements, of varying types and intensity.”<sup>109</sup> The General Comment further requires that when a person’s will and preferences cannot be ascertained, a decision must be made using the “best interpretation of will and preferences,” and not “best interests,” as many substitute decision-making regimes require.<sup>110</sup> What precise mechanism can be used to make this decision remains an open question.<sup>111</sup>

It is worth pausing here to consider why the U.S. legal community should care about the CRPD, or an interpretation of it, when the United States has not even ratified the treaty. Moreover, even if the treaty were ratified, its application to state guardianship laws would be somewhat attenuated. President Obama signed the treaty with the United States’ standard “federalism” reservation, which limits enforcement of the treaty to matters of federal law; state and local law—of which guardianship is a creature—could not be governed by the treaty unless those laws violated federal law or the Constitution.<sup>112</sup> Nonetheless, by signing the treaty, under established

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106. See CRPD General Comment, *supra* note 6, ¶ 7.

107. See *id.* ¶¶ 27, 28 (the CRPD requires the abolition of substitute decision-making regimes).

108. See *id.* ¶ 28.

109. See *id.* ¶ 17.

110. See *id.* ¶ 21 (stating that the “best interpretation of will and preferences” standard “respects the rights, will and preferences of the individual”).

111. Bach & Kerzner have called this state “facilitated decision-making” in which a facilitator might be appointed by an administrative tribunal (should there be no advance directives in place naming a chosen decision-maker) but have not spelled out in precise detail the mechanics for its implementation. See BACH & KERZNER, *supra* note 91, at 91.

112. See LUISA BLANCHFIELD & CYNTHIA BROWN, CONG. RESEARCH SERV., R42749, THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: ISSUES IN THE U.S. RATIFICATION DEBATE 10 (2015). Although guardianship is a creature of state law, the convention could nonetheless apply to it if guardianship were found to violate federal law. My colleague Leslie Salzman has argued compellingly that state guardianship laws do violate federal law by running

international law principles, the United States is bound not to defeat its object and purpose.<sup>113</sup>

Regardless of whether the treaty creates binding domestic legal obligations as a technical matter, it is having a significant impact on practice and on shaping the disability rights agenda. Internationally, the convention has prompted a number of nations to reexamine their guardianship laws.<sup>114</sup> In the United States, the convention has also been cited in several cases as persuasive authority on the rights of persons with disabilities to make their own decisions.<sup>115</sup> And perhaps most importantly, it serves as a guidepost for law reform advocates and others pursuing the development of alternatives to guardianship domestically.<sup>116</sup>

### B. Support in Practice

How do these concepts work in practice? There is no one model for supported decision-making, and the term is often used to connote a wide variety of arrangements that assist persons in making decisions and avoiding guardianship.<sup>117</sup> Some theorists distinguish between “support” and supported decision-making, with the former referring

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afoul of the integration mandate of the federal Americans with Disabilities Act. *See generally* Salzman, *supra* note 10, at 157.

113. HUMAN RIGHTS INST., COLUMBIA LAW SCH., BRINGING HUMAN RIGHTS HOME: HOW STATE AND LOCAL GOVERNMENTS CAN USE HUMAN RIGHTS TO ADVANCE LOCAL POLICY 3 & n.13 (2012), <https://web.law.columbia.edu/sites/default/files/microsites/human-rights-institute/files/Bringing%20Human%20Rights%20Home.pdf> [<https://perma.cc/2A7G-5BAB>].

114. For example, the Australian Law Reform Commission has issued a comprehensive report reviewing Australian laws for compliance with the right to legal capacity. *See generally* AUSTRALIAN LAW REFORM COMM’N, EQUALITY, CAPACITY & DISABILITY IN COMMONWEALTH LAWS (2014), [https://www.alrc.gov.au/sites/default/files/pdfs/publications/alrc\\_124\\_summary\\_report\\_whole\\_pfd.pdf](https://www.alrc.gov.au/sites/default/files/pdfs/publications/alrc_124_summary_report_whole_pfd.pdf) [<https://perma.cc/4H58-HPCW>]. For a compilation of the efforts that various countries have made to conform their laws to Article 12, see ARLENE S. KANTER, THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO HUMAN RIGHTS 269–77 (2015).

115. *See In re* Guardianship of Dameris L., 956 N.Y.S.2d 848, 855 (N.Y. Sur. Ct. 2012); *In re* Mark C.H., 28 Misc. 3d 766, 786 (N.Y. Sur. Ct. 2010).

116. *See generally* 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, 56–61 (2015).

117. Terry Carney and Fleur Beaupert have pointed out that supported decision-making is a somewhat ill-defined term that has come to refer to a variety of arrangements, some of which entail long-existing informal assistance with decision-making and some of which are done under the auspices of more recent legislation to create new types of legally recognized relationships. Terry Carney & Fleur Beaupert, *Public and Private Bricolage—Challenges Balancing Law, Services & Civil Society in Advancing CRPD Supported Decision Making*, 36 U. N.S.W. L.J. 175, 178 (2013).

to accommodations, such as accessible formats and technological assistance that enable an individual to process information and communicate a legally binding decision on her own. The latter, in contrast, entails arrangements in which a supporter whom the individual trusts interprets her will and preference and communicates that to third parties, who then legally recognize the decision as valid on behalf of the individual.<sup>118</sup>

As Jonathan Martinis and Peter Blanck point out, supported decision-making exists already in a multitude of forms; we all turn to supporters to assist us in making decisions—whether we ask advice, seek explanations, or designate someone to interface with an agency on our behalf.<sup>119</sup> Arlene Kanter also notes that individuals with intellectual disabilities have long turned to supportive arrangements with others—from informal programs such as “circles of support” (groups of volunteers convened to support an individual in realizing their goals) to more formal mechanisms such as joint accounts, powers of attorney and health care proxies—to avoid guardianship and its attendant finding of incapacity.<sup>120</sup>

Various legal regimes also have long acknowledged de facto supported decision-making, without naming it so. For example, the ABA Rules of Professional Conduct contemplate that a lawyer should maintain “as far as reasonably possible” a normal lawyer-client relationship with a person with diminished capacity and the comment suggests that the lawyer may have family members participate in the discussion in order to assist in the representation of the client.<sup>121</sup> Federal courts permit “incompetent” individuals to appear by a guardian ad litem or “next friend,” who may bring the

118. See Gooding, *supra* note 100, at 58–59 (describing distinctions drawn by Canadian Association of Community Living). Bach & Kerzner categorize three types of support:

- “Supports to assist in formulating one’s purposes, to explore the range of choices and to make a decision;
- Supports to engage in the decision-making process with other parties to make agreements that give effect to one’s decision, where one’s decisions requires this; and
- Supports to act on the decisions that one has made, and to meet one’s obligations under any agreements made for that purpose.”

BACH & KERZNER, *supra* note 91, at 73.

119. Peter Blanck & Jonathan G. Martinis, “*The Right to Make Choices*”: *The National Resource Center for Supported Decision-Making*, 3 INCLUSION 24, 26 (2015), [http://bbi.syr.edu/publications/2015/SDM\\_Overview.pdf](http://bbi.syr.edu/publications/2015/SDM_Overview.pdf) [<https://perma.cc/3B7K-THU3>].

120. See Kanter, *supra* note 116, at 52–53, 60–61.

121. MODEL RULES OF PROF’L CONDUCT r. 1.14 & cmt. 3 (AM. BAR ASS’N 2016).

suit on the other's behalf without a formal proceeding or declaration of incompetency.<sup>122</sup> Social Security, Medicaid, and other government programs implicitly recognize that a recipient may need support from family members or others in accessing benefits.<sup>123</sup> For example, these programs have adopted mechanisms that permit assistance from others in the application and recertification processes.<sup>124</sup> Even the HIPAA medical privacy regulations—which are widely assumed to restrict the involvement of anyone other than a patient in her care—contemplate that there may be times in which a medical professional may need to communicate with a person involved in the patient's care in order to facilitate that care.<sup>125</sup>

The primary way in which supported decision-making has been implemented as a new formal concept has been through legislation recognizing supported decision-making agreements. These agreements permit a person to designate a supporter even if the person would be found to lack the requisite cognitive capacity to enter into other types of contracts or a power of attorney. The example often touted as a model internationally is the British Columbia Representation Agreement Act (BCRAA), enacted in 1996.<sup>126</sup> The Act permits an individual to enter an agreement to designate supporters (even if that individual lacks the mental capacity to contract) and requires third parties to recognize those agreements.<sup>127</sup> The BCRAA presumes that all adults are capable of entering such agreements.<sup>128</sup> However, the Act also contemplates that an adult may be deemed *incapable* of making an agreement based on several factors, including whether she is able to demonstrate

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122. FED. R. CIV. P. 17(c)(2).

123. For example, the Social Security Administration provides that a family member or other person responsible for the care of a claimant may sign an application for benefits and has long provided for the appointment of a representative payee when someone is unable to manage their benefits on their own. *See* Program Operations Manual System, Social Security Administration, POMS GN 00204.003(B)(1)(c), <https://secure.ssa.gov/poms.nsf/lnx/0200204003> [<https://perma.cc/AL6X-DKJZ>]; 20 C.F.R. § 416.601 (1995) (representative payee). The Medicaid program similarly permits recipients to designate authorized representatives to apply for benefits and otherwise interact with the agency on behalf of the individual. 42 C.F.R. § 435.923 (2013).

124. 42 C.F.R. § 435.923 (2013).

125. *See* 45 C.F.R. § 164.510(b)(3) (2013) (permitting limited disclosure of protected health information to third party involved in patient's care when patient is incapacitated or not present).

126. *See* Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.).

127. *Id.* § 8. For a concise description of the Act, *see* Glen, *supra* note 25, at 145-46.

128. *See* Glen, *supra* note 25, at 147.



choices and preferences and whether she has a relationship of trust with the supporter.<sup>129</sup> Thus, the model does not completely supplant the possible need to resort to guardianship for those unable to meet these thresholds. Additional legislative models that incorporate varying degrees of supported decision-making can also be found in several other Canadian provinces, as well as in Sweden and Germany.<sup>130</sup>

More recently, Texas became the first state in the United States to pass a supported decision-making statute. The Texas Supported Decision-Making Agreement Act's statutory purpose is to recognize "a less restrictive alternative to guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship" under the state's guardianship statute.<sup>131</sup> The new statute permits an adult with a disability to authorize a supporter who may assist the individual in making and communicating decisions, as well as in accessing information necessary for such decisions and providing assistance in understanding that information.<sup>132</sup> Notably, the Texas law does not contain an explicit cognitive threshold for entering into a supported decision-making agreement; instead, it merely requires that the individual act "voluntarily," in the absence of coercion or undue

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129. The Act states that adults can be deemed incapable of making a supported decision-making agreement by looking at these factors:

- Whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- Whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- Whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult; and
- Whether the adult has a relationship with the representative that is characterized by trust.

Representation Agreement Act, R.S.B.C. 1996, c. 405, § 2(8) (Can.); *see also* Glen, *supra* note 25, at 147. In this way, by retaining some level of functional analysis of decision-making ability, the Act does not go as far as the Article 12 General Comment, which calls for the abolition of all functional evaluations of decision-making on the grounds that they are "discriminatorily applied to people with disabilities" and used to deny basic human rights based on a presumption that they can "assess the inner workings of the human mind." *See* CRPD General Comment, *supra* note 6, ¶15.

130. *See* Salzman, *supra* note 10, at 235–37 (describing the Swedish model); Glen, *supra* note 25, at 140–53.

131. TEX. EST. CODE ANN. § 1357.003 (West 2015).

132. *Id.* § 1357.051.

influence.<sup>133</sup> The statute contemplates that a supporter would engage in:

[A] process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.<sup>134</sup>

The statutory form agreement permits an individual to authorize a supporter to assist with food, clothing, shelter, health, and finances and is clear that the supporter may not make decisions for the person.<sup>135</sup> Rather, the supporter is authorized to obtain information, help the person understand it, and help the person communicate her decision.<sup>136</sup> The statute also requires third parties who are presented a copy of the agreement to rely upon it and immunizes them from civil and criminal liability for acting in good faith in reliance on the agreement.<sup>137</sup>

Texas's law is new, having passed in 2015; the following year, Delaware also enacted a supported decision-making law.<sup>138</sup> The implementation of the laws in these two states will be closely followed and it is likely that additional laws and policies will formalize the practice of supported decision-making in the United States. In 2014, Virginia's legislature passed a resolution requiring the state Department of Health and Human Resources to complete a study on supported decision-making.<sup>139</sup> The federal Department of Health and Human Services has also endorsed the concept and funded the creation of a national resource center to train practitioners and research supported decision-making.<sup>140</sup>

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133. *See id.* The Texas Supported Decision Making Agreement Act does not define "voluntarily" other than to modify it by saying "without undue influence or coercion." *Id.*

134. *Id.* § 1357.002.

135. *Id.* § 1357.056.

136. *Id.*

137. *Id.* § 1357.101.

138. 2015 Tex. Sess. Law Serv. Ch. 214 (West); Del. Code Ann. Tit. 16, Chapter 94A (2016).

139. H.R.J. Res. 190 (Va. 2014) <https://lis.virginia.gov/cgi-bin/legp604.exe?141+ful+HJ190ER+pdf> [<https://perma.cc/DGB7-BCUF>].

140. *See* Bishop & Walker, *supra* note 12.

### III. SUPPORTED DECISION-MAKING AND THE RIGHT TO LEGAL CAPACITY FOR OLDER ADULTS

So far, supported decision-making has largely been talked about as an alternative to guardianship for persons with intellectual disabilities<sup>141</sup> and to a slightly lesser extent, persons with psychosocial disabilities.<sup>142</sup> Most of the supported decision-making pilot projects have identified persons with intellectual disabilities as their target groups.<sup>143</sup>

But, to date, supported decision-making has not taken hold to quite the same degree—in both the theoretical discussions and in practice—as an alternative for older adults who may be vulnerable to guardianship.<sup>144</sup> For example, while supported decision-making agreements have become popular within the intellectual disability community in Canada, they have not been embraced as readily by elder law practitioners or by the aging community.<sup>145</sup> This does not mean that older adults have not practiced supported decision-making informally, as many do turn to family and friends for support in critical decisions. But a recent report commissioned by the Ontario Law Commission on the experience of formal supported decision-making agreements in five provinces suggests that older adults do not

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141. See Dinerstein, *supra* note 36, at 3 (2012); Kohn et al, *supra* note 14, at 1133 (“supported decision-making is often seen as particularly likely to benefit those with ID”). But see TERRY CARNEY, GUARDIANSHIP, “SOCIAL” CITIZENSHIP AND THEORIZING SUBSTITUTE DECISION-MAKING LAW 1, 3, 22 (2012).

142. See generally Salzman, *supra* note 10.

143. See, e.g., *Pilot Project*, *supra* note 13; (describing pilot project for individuals with intellectual or developmental disabilities in Massachusetts); MARGARET WALLACE, OFFICE OF THE PUBLIC ADVOCATE, EVALUATION OF THE SUPPORTED DECISION MAKING PROJECT 15 (2012), [http://www.opa.sa.gov.au/files/batch1376447055\\_final\\_supported\\_decision\\_making\\_evaluation.pdf](http://www.opa.sa.gov.au/files/batch1376447055_final_supported_decision_making_evaluation.pdf) [<https://perma.cc/A6BU-T23P>] (describing pilot project for persons with disabilities).

144. But 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) (discussing the advances that Article 12 offers for older adults).

145. See generally KRISTA JAMES & LAURA WATTS, CANADIAN CTR. FOR ELDER LAW, UNDERSTANDING THE LIVED EXPERIENCES OF SUPPORTED DECISION-MAKING IN CANADA: A STUDY PAPER 18 (2014) (report commissioned by the Law Commission of Ontario assessing experiences with supported decision-making in five Canadian provinces). But see NIDUS PERSONAL PLANNING RESOURCE CTR. AND REGISTRY, A STUDY OF PERSONAL PLANNING IN BRITISH COLUMBIA: REPRESENTATION AGREEMENTS WITH STANDARD POWERS 2 (2010) [http://www.nidus.ca/PDFs/Nidus\\_Research\\_RA7\\_InAction.pdf](http://www.nidus.ca/PDFs/Nidus_Research_RA7_InAction.pdf) [<https://perma.cc/CW4A-GTDB>] [hereinafter Nidus] (finding that forty percent of representation agreements, which are a tool for supported decision making, entered into in a three and a half year period were by persons ages seventy to ninety-nine).

use them as frequently as might be expected.<sup>146</sup> Part III describes the differences in circumstances that give rise to guardianship for older adults with cognitive impairments versus younger persons with intellectual disabilities, and reviews possible explanations for different levels of engagement with supported decision-making.

There are several differences between the situations of older adults at risk of guardianship and younger adults with disabilities that may account for the different levels of interest in supported decision-making so far. Parents of persons with intellectual disabilities often commence guardianships over their young adult children because service providers suggest it as a routine step to take when the child turns eighteen.<sup>147</sup> Standard advice given to parents is that they need guardianships in order to continue being involved in assisting their child in obtaining benefits and services.<sup>148</sup> Thus, for young adults with intellectual disabilities and their families, supported decision-making can provide a welcome alternative that permits persons with disabilities to build skills that can promote independence while developing experience with making decisions that can facilitate independent living.<sup>149</sup>

For older adults, when guardianship is sought by a family member, it is often adult children who petition the court.<sup>150</sup> Often, some precipitating event prompts the guardianship, such as a legal transaction that needs to be accomplished which may involve assets that the person accumulated over the course of a lifetime, such as a house or retirement plan.<sup>151</sup> If the individual has executed advance directives such as a power of attorney for financial matters and health care proxy or medical power of attorney for health care decisions, guardianship will likely not be necessary, as third parties will recognize these instruments.<sup>152</sup> The family member seeking

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146. JAMES & WATTS, *supra* note 145, at 77–78.

147. *See, e.g.*, Kanter *supra* note 116, at 3, 15, 46.

148. *See, e.g.*, Kanter *supra* note 116, at 15.

149. *See, e.g.*, Kanter *supra* note 116, at 59–61.

150. JENUWINE, *supra* note 26, at 43 (“Among those cases in which the prospective guardian was an adult child of the proposed ward, the majority (66%) were cases where the ward was over the age of 75.”).

151. *See, e.g.*, *In re E.J.F.*, 983 N.Y.S.2d 202 (N.Y. Sup. Ct. 2013) (guardianship necessary, in part, because retirement plan refused to release benefits to individual due to his incapacity).

152. *See, e.g.*, *In re May Far C.*, 877 N.Y.S.2d 367 (N.Y. App. Div. 2009) (reversing appointment of guardian because allegedly incapacitated person had previously executed power of attorney which obviated the need for guardian). The standard advice given to someone with early dementia is to execute these documents. *See*

guardianship may be more concerned about expediency and ensuring that there is a legally recognized way to manage the person's affairs than with preserving or promoting decision-making.<sup>153</sup>

Persons without family support who are impaired may find themselves facing guardianship petitions after some sort of medical or financial crisis. Health care institutions seek guardianship to make health care decisions, effectuate discharge planning back to the community, transfer a person to a nursing home from a hospital, or to obtain payment.<sup>154</sup> State social services agencies also petition for guardianship over older adults, often in situations in which the individual is deemed to be at risk and has no one to assist them.<sup>155</sup>

This practice points to another difference between older adults and younger individuals who might enter a guardianship. Older adults tend to be more isolated and may lack other sources of family or community support. Michael Bach and Lana Kerzner, the architects of the British Columbia act and leading thinkers on supported decision-making, have attributed the lack of supported decision-making in the aging community to these factors, reasoning that because older people tend to be more isolated, they have fewer people in their lives who could play the role of supporters.<sup>156</sup>

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*Planning Ahead*, ALZHEIMER'S ASSOCIATION, <http://www.alz.org/care/alzheimers-dementia-planning-ahead.asp> [<https://perma.cc/2CNP>].

153. NIDUS, *supra* note 145, at 78 (noting that advance directives are viewed as more efficient than supported decision-making agreements).

154. *See* Callahan & Romanick, *supra* note 44, at Slide 13 (showing hospitals as petitioners in nine percent of cases and nursing homes as petitioners in fifteen percent). For an example of a guardianship petition in which a hospital sought to use the guardianship to transfer the person to a nursing home and to have the guardian make major medical decisions without the person's consent, see *In re St. Luke's Hospital Center*, 607 N.Y.S.2d 574 (N.Y. Sup. Ct 1993), *aff'd* 640 N.Y.S.2d 73 (N.Y. App. Div. 1996). For descriptions of nursing home petitions for guardianships in order to settle billing disputes, see Nina Bernstein, *To Collect Debts: Nursing Homes Are Seizing Control Over Patients*, N.Y. TIMES (Jan. 25, 2015), [http://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html?\\_r=0](http://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html?_r=0) [<https://perma.cc/8RFT-3WAV>]. For a description of nursing home guardianship practice in order to obtain Medicaid benefits for the resident, see Nancy Levitin, *Nursing Home Petitioners and Guardianship*, N.Y. ST. B. ASS'N J., Sept. 2015, at 54.

155. *See* N.Y. MENTAL HYG. LAW § 81.06(a)(6) (McKinney 2004) (providing that county department of social services may petition); Teaster et al., *supra* note 70, at 209 (noting that fifteen states permit public guardian programs to petition for guardianships); *see also In re Ardelia R.*, 812 N.Y.S.2d 140 (N.Y. App. Div. 2006) (example of an APS case in which older adult was found in her apartment without water, food, electricity or heat).

156. BACH & KERZNER, *supra* note 91, at 37 (report commissioned by the Law Commission of Ontario).

These explanations only go so far, however, in explaining the difference. There also has not been the same type of movement linking the right to legal capacity to a broader struggle for rights of self-determination and access to services and independent living for older adults with cognitive limitations. Organized groups concerned with progressive age-related cognitive decline, for example, are understandably focused on the urgent need for research and treatment resources, as well as the considerable demands of caregiving.<sup>157</sup> To the extent the aging community has focused on questions of legal decision-making, it has been much more in the area of state prevention of elder abuse.<sup>158</sup> In the words of the Canadian Centre for Elder Law, they “have not yet generally embraced supported decision-making as a formalistic concept of autonomy or personhood . . . .”<sup>159</sup>

The Canadian study also hypothesizes that older adults turn to advance directives such as powers of attorney because they are quicker and more efficient than supported decision-making agreements, which require work by the supporter to explain and assist in the decision-making process.<sup>160</sup> But supported decision-making will always require more work than substitute decision-making, whether the person being supported is a younger adult with intellectual disability or an older adult with dementia. The question is how much work and how many resources do supporters and society choose to put into the endeavor?

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157. See *Policy and Advocacy*, ALZHEIMER'S ASS'N, [http://www.alz.org/research/funding/alzheimers\\_policy\\_and\\_advocacy.asp#voicing](http://www.alz.org/research/funding/alzheimers_policy_and_advocacy.asp#voicing) [<https://perma.cc/D288-MKNG>].

158. See Benjamin Pomerance, *Finding the Middle Ground on a Slippery Slope: Balancing Autonomy and Protection in Mandatory Reporting of Elder Abuse*, 16 MARQ. BENEFITS & SOC. WELFARE L. REV. 439, 447–48 (2015) (describing debates over the development of mandatory elder abuse reporting laws).

159. NIDUS, *supra* note 145, at 77.

160. *Id.* at 52. Under a power of attorney, the principal empowers an agent to act on her behalf. The agent is supposed to follow the principal's instructions but if none exist the agent may act in the best interests of the principal. See, e.g., N.Y. GEN. OBLIG. LAW § 5-1505(2)(a)(1) (McKinney 2009). Thus, a power of attorney differs in certain critical ways from a supported decision-making agreement, under which the decision always remains in the hands of the individual and in which the will and preferences of the individual, and not her best interests, guide the decision-making. Like a supported decision-making agreement, a power of attorney can be revoked at any time by the principal and does not result in a loss of legal capacity.

#### IV. TOWARDS A NORMATIVE JUSTIFICATION OF SUPPORTED DECISION-MAKING FOR OLDER PERSONS

This is where the theoretical underpinnings of supported decision-making come into play. As articulated so far, they have been primarily aimed at the experiences of persons with intellectual disabilities and have not spoken in the same way to the situations encountered by older adults with cognitive impairments. The same principles, however, that animate the move away from guardianship have particular meaning for older adults, including those living with dementia. Part IV explores the chief arguments for the right to legal capacity—autonomy and personhood—and applies them to older adults.

Perhaps the most frequently invoked argument for a shift away from guardianship is the promotion of autonomy for persons with disabilities. Proponents have posited supported decision-making as a means of liberation for persons with disabilities who have heretofore been excluded from participating in the basic interactions that constitute participation in society.<sup>161</sup> Gerard Quinn, one of the foremost thinkers on legal capacity, has articulated the theoretical stakes as follows:

[Legal capacity] provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe – a web of mutual rights and obligations voluntarily entered into with others. So it allows for an expression of the will in the lifeworld. That is the primary positive role of legal capacity. Let me emphasise this. Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions. It does so primarily through contract law.<sup>162</sup>

Built into this concept of promoting autonomy is another, related idea—that one builds decision-making skills, and, with support, can move into a more independent state, in which less support may be necessary. For example, the CRPD General Comment states that governments “have an obligation to provide training for persons receiving support so that they can decide when less support is needed or when they no longer require support in the exercise of their legal capacity.”<sup>163</sup> Similarly, Bach and Kerzner talk about using facilitated decision-making—at least temporarily until the person has developed

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161. BACH & KERZNER, *supra* note 91, at 75.

162. GERARD QUINN, HARVARD LAW SCHOOL, PERSONHOOD & LEGAL CAPACITY PERSPECTIVES ON THE PARADIGM SHIFT OF ARTICLE 12 CRPD 10 (2010) (Concept Paper for the Harvard Law School Project on Disability Conference, Cambridge).

163. CRPD General Comment, *supra* note 6, ¶ 24.

relationships of trust so the supporter can interpret the individual's will and preferences.<sup>164</sup>

This notion of improving decision-making ability over time is designed to address the situation of persons with severe disabilities, who may have been isolated or institutionalized, and to guard against making assumptions about how much support an individual needs. However, it does not always resonate with the experience of many older persons, who have a lifetime of exercising legal capacity behind them and may need more support over time, not less. Among the very old, cognitive decline caused by Alzheimer's is, at the moment, progressive and irreversible. This is not to say that age-related conditions inevitably result in cognitive decline.<sup>165</sup> Other conditions, such as cognitive impairments caused by stroke, may be temporary and partially reversible.<sup>166</sup> Certain dementias may also be temporary or may progress quite slowly.<sup>167</sup> But older adults at risk of losing their capacity are generally in a different position than persons with intellectual disabilities. The former have had decades of exercising legal capacity and may require support for the first time to ensure that they can continue to do so. The latter have not yet exercised legal capacity and are developing the skills and experience that will facilitate their ability to do so.

Just as legal capacity can serve as a means of liberation for younger persons with disabilities, so too can it preserve the autonomy of older adults. Concerns for autonomy have long played a role in guardianship reform efforts, but efforts to increase the autonomy of persons under guardianship have simply not gotten very far in practice. Statutes and standards call for balanced approaches that limit the powers of guardians and respect the wishes of the person.<sup>168</sup> But the evidence shows that as long as guardianship is the default, the impetus will be to strip the individual of broad powers and accommodate the needs of third parties.<sup>169</sup> Thus, the default is one of paternalism and protection from oneself, not one of autonomy in which the individual is the legal actor.<sup>170</sup> A paradigm shift toward legal capacity as a right can take this thumb off the scale.

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164. BACH & KERZNER, *supra* note 91, at 24.

165. *See* Frolik, *supra* note 52, at 748.

166. *Id.*

167. *Id.*

168. *See, e.g.,* N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2016); NAT'L GUARDIANSHIP ASS'N, *supra* note 47, at 6.

169. *See* JAMES & WATTS, *supra* note 145, at 63 (addressing use of plenary guardianships).

170. *See generally* Glen, *supra* note 25, at 137 n.200.



By preserving autonomy and personhood for older persons, the right to legal capacity protects important interests in different ways than it does for younger persons. Bioethicist Bruce Jennings has offered a compelling critique of the underlying paternalism of the guardianship system as it applies to preventing risky behavior by persons with dementia.<sup>171</sup> He notes that the state finds its justification for curbing liberties in the promise that it is protecting an individual from harm so that she will be able to exercise more liberty later.<sup>172</sup> In the early dementia context, he argues, this justification does not really apply:

However worthwhile and valuable what comes in the future may be . . . it will not include greater freedom or autonomy. When freedom is curtailed in early dementia it is final chances that are being forgone, not first chances with plenty of second chances yet to come. These are the last times something will be attempted or done, and perhaps it is a recognition of this, however dimmed by disease, that makes the desire to do something so curiously linger, even intensify, after the physical or mental capacity to do it safely has begun to slip away.<sup>173</sup>

In contrast, Jennings and others talk about a different model for decision-making that is centered on the person as a subject, rather than an object to be protected or an entity that must be subdued for the convenience of third parties.<sup>174</sup> This approach finds its roots in the work of the late Tom Kitwood, a British Alzheimer's specialist who developed a theory of person-centered care for dementia.<sup>175</sup>

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171. Bruce Jennings, *Freedom Fading: On Dementia, Best Interests, and Public Safety*, 35 GA. L. REV. 593, 609 (2001).

172. *Id.* at 610.

173. *Id.*

174. *Id.* at 610–12, 610 n.27.

175. See generally TOM KITWOOD, DEMENTIA RECONSIDERED 8 (1997) [hereinafter DEMENTIA RECONSIDERED] (defining personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust”); Tom Kitwood, *Towards a Theory of Dementia Care: The Interpersonal Process*, 13 AGEING & SOC’Y 51 (1993) [hereinafter *The Interpersonal Process*]; Tom Kitwood & Kathleen Bredin, *Towards a Theory of Dementia Care: Personhood and Well-being*, 12 AGEING & SOC’Y 269 (1992) [hereinafter *Personhood and Well-being*]. The terms “person-centered,” “personhood,” and “patient-centered” are used interchangeably within the article, however they are synonymous. See INSTITUTE OF MEDICINE, CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY 3 (2001), <https://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf> [https://perma.cc/S5EV-RPKD] (defining “patient-centered” as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”); *Person Centered*

“Patient-centered” is a term used to signal a focus on the particular preferences, values, and wishes of an individual in health care; life planning for persons with disabilities; and other contexts.<sup>176</sup> The concept developed in the movement toward community integration for persons with disabilities and has come to connote a process in which an individual plans for her future by identifying goals and needed supports to reach those goals, with the assistance of others whom she chooses to involve.<sup>177</sup> In this way, person-centered planning laid some of the groundwork for supported decision-making.

In the Alzheimer’s context, person-centered care was a means of focusing on the persistence of the self even as the disease progresses<sup>178</sup> and society perceives a “loss of the self.”<sup>179</sup> Kitwood and others have urged against making assumptions that a diagnosis of dementia forecloses the ability to participate in person-centered care.<sup>180</sup> A small body of research from Kitwood and psychologists such as Steven Sabat has focused on the persistence of “self” in the face of Alzheimer’s disease and cautioned against taking cognitive loss, measured in standard assessments, as indicative of the loss of other aspects of the self that are socially constructed.<sup>181</sup>

The empirical literature on decision-making and independence for older adults also shows that retaining control over decisions of daily life is correlated with better physical and mental health outcomes.<sup>182</sup>

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*Planning*, NEW YORK STATE OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, [http://www.opwdd.ny.gov/opwdd\\_services\\_supports/person\\_centered\\_planning](http://www.opwdd.ny.gov/opwdd_services_supports/person_centered_planning) [<https://perma.cc/4BML-JNC4>] (describing person-centered planning as a “process directed by the person that helps us to learn how they want to live and describes what supports are needed to help them move toward a life they consider meaningful and productive”).

176. See INSTITUTE OF MEDICINE, *supra* note 175, at 3; see also *Person Centered Planning*, *supra* note 175.

177. See Glen, *supra* note 25, at 130.

178. Ruth M. Tappan et al., *Persistence of Self in Advanced Alzheimer’s Disease*, 31 IMAGE J. NURSING SCH. 121 (1999) (describing research on subjective experience of persons).

179. See, e.g., David E. Guinn, *Mental Competence, Caregivers, and the Process of Consent: Research Involving Alzheimer’s Patients or Others with Decreasing Mental Capacity*, 11 CAMBRIDGE Q. OF HEALTHCARE ETHICS 230, 234 (2002).

180. See DEMENTIA RECONSIDERED, *supra* note 175, at 54–57; Katie Maslow, *Person-Centered Care for People with Dementia: Opportunities and Challenges*, AM. SOC’Y OF AGING (Nov. 2013), <http://www.asaging.org/blog/person-centered-care-people-dementia-opportunities-and-challenges> [<https://perma.cc/R8FX-XX2W>].

181. See generally Steve R. Sabat, *Surviving Manifestations of Selfhood in Alzheimer’s Disease*, 1 DEMENTIA 25 (2002).

182. See Melanie H. Mallery et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin’s work on Gerontological Theory, Policy, and Practice*, 54 GERONTOLOGIST 67, 67 (2014); see also Nina A. Kohn, *Elder*

These benefits accrue not just when older adults act completely independently, but also when they are given the opportunity to ask for assistance from others.<sup>183</sup> In that respect, the findings are consistent with the theory advanced by supported decision-making proponents that autonomy should be viewed not as wholly individual but rather that it is something exercised “relationally, interdependently, and intersubjectively with others.”<sup>184</sup>

In searching for ways to recognize the persistence of self, we can find a way to effectuate one of the most ambitious aspects of the legal capacity project: restoring and recognizing the humanity we all share, regardless of the degree of impairment. Recognizing personhood is, of course, central to the movement for legal capacity. Gerard Quinn has stated that “legal capacity is the tool for advancing personhood in the lifeworld—primarily by allowing us to construct our own legal universes and secondarily to fend off others who think they know better.”<sup>185</sup> By decoupling the ability to understand and appreciate from legal personhood, Quinn argues, we expand the notion of personhood to include those who have historically been excluded.<sup>186</sup> This is of no small value in the older adult context, as persons with Alzheimer’s and dementia are routinely dehumanized in institutional and other care settings through physical and chemical restraints and other, less severe, means.<sup>187</sup> In this way, supported decision-making in the older adult context can play a role in preserving the individual’s personhood and assisting them in what Bruce Jennings has called “find[ing] new and different ways of being a self” for as long as it is possible.<sup>188</sup>

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*Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1, 27-29 (2006) (summarizing psychological literature on benefits of decision-making for seniors).

183. MALLERS et al., *supra* note 182, at 69.

184. BACH & KERZNER, *supra* note 91, at 40 (internal quotations omitted).

185. See QUINN, *supra* note 162, at 12.

186. See *id.* at 5-6.

187. See generally Julie A. Braun & Lawrence A. Frolik, *Legal Aspects of Chemical Restraint Use in Nursing Homes*, 2 MARQ. ELDER’S ADVISOR 21 (2000); Marshall B. Kapp, *Physical Restraint Use in Acute Care Hospitals: Legal Liability Issues*, 1 MARQ. ELDER’S ADVISOR 1 (1999).

188. See Jennings, *supra* note 171, at 617-18.

## V. BUT CAN IT WORK? TESTING THE THEORETICAL AGAINST PRACTICE

No one assumes that the shift away from guardianship will happen overnight.<sup>189</sup> Advocates anticipate a lengthy process during which supported decision-making alternatives and infrastructure develop while governments begin to review guardianship and other laws to progressively implement reforms that respect the right to legal capacity.<sup>190</sup> The main arguments against supported decision-making are not that it lacks normative justification, but rather that it is untested and likely cannot work in all situations, that it requires enormous resources, and/or that it will permit persons to make bad choices or to be taken advantage of.<sup>191</sup> It is hard to know how and if supported decision-making could work in every case, which is why many have called for pilot projects and assessments.<sup>192</sup> But granting that there are tremendous unknowns remaining, Part V sketches out a number of ways in which the availability of supported decision-making statutes and services for older persons could lead to reductions in the use of guardianship and provide other benefits. It then outlines two areas in which thinking needs to develop further.

### A. Tangible Benefits of the Right to Legal Capacity for Older Adults

In this Section, I sketch three ways in which more widespread availability of support and supported decision-making can offer immediate benefits that enhance autonomy for older adults and reduce the use of guardianship. First, the availability of supported decision-making alternatives and services has the potential to limit the already rickety enterprise of assessing mental capacity to restrict a person's legal right to make decisions. Assessments of capacity are fraught with subjectivity and there appears to be no clear, consistent way to measure mental capacity. In a fascinating summary of the research on assessments of older adults' capacity to consent to health care, Jennifer Moye and Daniel C. Marson find wild variations in the assessment of capacity.<sup>193</sup> For example, when physicians conduct

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189. See Glen, *supra* note 25, at 163-64 (describing the "incremental process" proposed by the disability rights group Inclusion Europe).

190. See *id.* (describing the implementation of the plan as "gradual").

191. See Gooding, *supra* note 100.

192. See Salzman, *supra* note 10, at 303-05.

193. See Jennifer Moye & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62 J. OF GERONTOLOGY 3 (2007).

assessments of capacity based on their perceptions of different patient cognitive skills, “agreement between physicians is near chance.”<sup>194</sup> When using established instruments for measuring capacity, agreement between physicians ranged from poor to good.<sup>195</sup> They conclude that “[c]linical judgments of capacity can often be inaccurate, unreliable, and even invalid.”<sup>196</sup> Thus, it seems as though the entire enterprise of assessing mental capacity, from which so many other legal consequences flow, is deeply flawed.

Nonetheless, these assessments are not likely to disappear anytime soon. But, by incorporating principles of support into at least the legal definitions of incapacity, it may be possible to reduce the frequency of incapacity findings. So far, advocates have had greatest success with presenting supported decision-making as an alternative that can justify the termination of a guardianship. One of the best-known examples is the case of Jenny Hatch, a young adult with an intellectual disability who contested her parents’ petition for guardianship and her placement in a group home, where she was cut off from her friends and life in the community. The judge granted the guardianship petition but appointed her friends as guardians instead of her parents and instructed the guardians to prepare for a transition to supported decision-making after a year.<sup>197</sup> Such precedent—along with several other recent cases<sup>198</sup>—holds promise for older adults who may wish to get out from under guardianship, a notoriously difficult process.<sup>199</sup> The same principles of looking to whether a person can make decisions with support should apply to deciding guardianship applications at the outset. For most vulnerable older adults, the initial petition for guardianship is the important moment at which the availability of supported decision-making could prevent a declaration of incapacity.

Second, to the extent that many older adults are pushed into guardianship due to various third parties or “gatekeepers” rejecting

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194. *Id.* at 6.

195. *Id.*

196. *Id.* at 9.

197. *See* Ross v. Hatch, No. CWF120000426P-03, Slip Op. at \*7 (Va. Cir. Ct. 2013), [http://jennyhatchjusticeproject.org/docs/justice\\_for\\_jenny\\_trial/jhjp\\_trial\\_final\\_order.pdf](http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf) [<https://perma.cc/XH78-RWBZ>].

198. *See, e.g., In re* Guardianship of Dameris L., 38 Misc. 3d 570, 579-80 (N.Y. Sur. Ct. 2012); *In re* Mark C.H., 906 N.Y.S.2d 419 (N.Y. Sur. Ct. 2010); *see also* Cassidy, *supra* note 78, at 85-86.

199. *See* Cassidy, *supra* note 78, at 119-20 (describing several recent successful restoration cases in which persons under guardianship had developed supports as alternatives).

their capacity to understand and appreciate financial and medical decisions, the broader availability of support and supported decision-making can reduce this practice.<sup>200</sup> Typically, a person must understand the relevant information, appreciate the consequences of a decision and be able to communicate that decision voluntarily in order for it to be legally binding.<sup>201</sup> These elements underlie both the doctrine of informed consent<sup>202</sup> and capacity to contract.<sup>203</sup>

Frequently, family members of older adults turn to guardianship because someone at a benefit program, a health care provider, or a financial institution has decided that the older adult cannot understand and appreciate a decision or because the older adult has an impairment that prevents her from being able to obtain information and communicate consent directly.<sup>204</sup> Thus, the concept of “capacity” becomes a barrier toward accessing needed benefits and services. At this point, often the only recourse for a family member trying to support the person in obtaining benefits or accessing services or funds is to seek guardianship.<sup>205</sup>

But legal recognition for the role of a supporter who can assist the older adult in obtaining information and making a decision could enable the person to make legally binding decisions, and thus obviate the need to resort to guardianship just to access services, benefits, or funds. In addition, more explicit mandates for support would enable the person to make the decision directly, without another acting as her supporter. Forms of support might include plain language explanations, accessible formats, and the like, as well as more extensive use of some of the basic techniques for enhancing a person’s

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200. See Soumitra Pathare & Laura S. Shields, *Supported Decision-Making for Persons with Mental Illness: A Review*, 34 PUB. HEALTH REVS. 1, 2-4 (2012); see also TOLUB, *supra* note 41, at 14.

201. See BACH & KERZNER, *supra* note 91, at 83.

202. See, e.g., *In re Conroy*, 486 A.2d 1209, 1222 (N.J. 1985) (finding that the patient must be able to understand information conveyed, evaluate options, and communicate a decision).

203. On capacity to contract, see RESTATEMENT (SECOND) OF CONTRACTS § 15(1) (AM. LAW INST. 1981) (providing that contract is voidable “if by reason of mental illness or defect . . . he is unable to understand in a reasonable manner the nature and consequences of the transaction” or “he is unable to act in a reasonable manner . . . and the other party has reason to know of his condition” ); see also *Ortelere v. Teacher’s Retirement Bd.*, 250 N.E.2d 460, 464 (1969) (providing that the traditional test for contractual mental capacity requires that the party is able to make a rational judgment about the transaction). It is also black-letter law that each party to a contract manifest her assent. RESTATEMENT (SECOND) OF CONTRACTS § 17 (AM. LAW INST. 1981).

204. See TOLUB, *supra* note 41, at 14.

205. See *id.*

decision-making capabilities: taking extra time; engaging in multiple visits, especially during the morning if that is when the person is most alert; discussing one discrete issue at a time; repeating information, and providing cues that enhance recall.<sup>206</sup> Research on the ability to provide informed consent confirms that such types of techniques, and particularly those that minimize memory demands and verbal retrieval—can support some individuals with dementia to the point they can provide informed consent when they would otherwise be deemed unable under standard screening instruments.<sup>207</sup> These techniques are feasible and should be already required by anti-discrimination laws, though application of those laws for these particular accommodations has been underdeveloped to date.<sup>208</sup>

Third, on a practical level, the wider availability of supported decision-making could force the legal, health care, and social services systems to confront underlying failures without depriving persons of their decision-making rights. As the expression goes, to a hammer, everything looks like a nail. Guardianship is currently used as a means of fixing many problems, only some of which have to do with impairments in decision-making.<sup>209</sup> For example, in New York City, where I practice, it is common for the social services agency to file for guardianship when a senior is on the verge of eviction.<sup>210</sup> It is also used by hospitals when patients disagree with a discharge plan, particularly when the hospital wishes to discharge an individual to a

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206. See BACH & KERZNER, *supra* note 91, at 72–80 (describing decision-making supports); A.B.A. COMM’N. ON L. & AGING, ASSESSMENT OF OLDER ADULTS WITH DIMINISHED CAPACITY: A HANDBOOK FOR LAWYERS 29 (2005).

207. See Julia Haberstroh et al., *Can the Mini-Mental State Examination Predict Capacity to Consent to Treatment?*, 27 J. OF GERONTOLOGY & GERIATRIC PSYCHIATRY 151, 156 (2014).

208. When an entity blocks an individual from accessing benefits or services that she is otherwise entitled to on the grounds that she lacks cognitive capacity, such a refusal should be deemed disability-based discrimination under the Americans with Disabilities Act, which prohibits a public agency or public accommodation from denying benefits or services on the grounds of disability. See 42 U.S.C. §§ 12132, 12182(a) (2015).

209. The need for guardianship is often justified by the need for services or assistance, which might alternatively have been provided through other means. See, e.g., *In re of Ella C.*, No. 100016/11, 2011 WL 6757850 (N.Y. Sur. Ct. 2011) (holding that a guardian was necessary in part because of individual’s complicated real estate holdings and finances).

210. See Shlomo S. Hagler, *Innovative Part Integrates Guardianship and Housing Matters; Outside Counsel*, N.Y.L.J., June 22, 2011, at 4, 9 (describing special court part that combines housing and guardianship matters).

nursing home and the person wants to go home,<sup>211</sup> or when other discharge planning obstacles arise.<sup>212</sup> Guardianship is also used by nursing homes when no one is available to manage the person's funds so that she can become Medicaid eligible or to settle payment disputes with relatives.<sup>213</sup> To be sure, all of these situations present significant problems and challenges; however, there is no reason that these thorny problems should necessarily be resolved by stripping individuals of their legal capacity. More rigorous protection of the right to legal capacity would ensure that guardianship is not resorted to as readily when problems concerning older adults arise.

### B. Outstanding Questions

Many challenges lie ahead for advocates seeking to promote the right to legal capacity. It is beyond the scope of this Article to respond to every objection or obstacle to supported decision-making.<sup>214</sup> However, this section will focus on two key questions that have particular significance for older adults and propose an agenda for further thinking on those points.

First, how might the right to legal capacity apply in the really hard cases of advanced Alzheimer's when there are no advance directives in place? According to the General Comment to Article 12, any form of substitute decision-making, such as a guardianship—even imposed for one transaction—would violate the individual's right to legal capacity.<sup>215</sup> Instead, the General Comment proposes that “[w]here, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the ‘best interpretation of will and preferences’ must replace the ‘best interests’ determinations.”<sup>216</sup>

What mechanism should be used to discern a person's will and preferences if that person cannot use a supported decision-making agreement? The General Comment does not answer this question.

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211. See *In re Bricker*, 702 N.Y.S.2d 535 (N.Y. Sur. Ct. 1999) (discussing apportionment of costs when hospitals bring guardianships because patient disagrees with a discharge plan).

212. See Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in A Snapshot of Adult Guardianship Cases in New York City*, 16 GEO. J. ON POVERTY L. & POL'Y 315, 342 (2009) (discussing use of guardianship to facilitate discharge planning by hospitals).

213. See Bernstein, *supra* note 154.

214. Piers Gooding has provided a useful list of common objections to Article 12 and responses. See Gooding, *supra* note 100, at 52–60.

215. See CRPD General Comment, *supra* note 6, ¶¶ 27, 28.

216. See *id.* ¶ 21.



In Texas and British Columbia, guardianship is the only option for these individuals.<sup>217</sup> However, Article 12 says guardianships are never allowed.<sup>218</sup> Thus, Article 12 seems to rely on a legal fiction that persons will remain the legal actors making their own decisions under circumstances where it may not be possible to discern their will and preferences. The fiction serves a purpose in that it ensures that those with the most severe impairments remain persons under the law. But the contradiction and the mechanics of following Article 12's requirements need further elaboration in the literature, as the pragmatic problems are so substantial that they risk undermining the rest of the project.<sup>219</sup>

A tribunal or facilitator attempting to interpret the will and preferences of an older person suffering from progressive cognitive decline at least has the benefit of a lifetime of decisions and wishes to examine – something that may not be the case when discerning the will and preferences of younger persons with disabilities who have not been afforded many decision-making opportunities. Nonetheless, the record does not answer all the questions and there has been a debate over how much prior wishes should matter as compared with wishes expressed after the onset of Alzheimer's disease.<sup>220</sup> Ronald Dworkin advocated for respecting the person's earlier wishes, which he views as reflecting her values and judgments built over a lifetime.<sup>221</sup> Rebecca Dresser, in contrast, has emphasized adherence to the person's current wishes because the person may not be who she used to be.<sup>222</sup> Agnieszka Jaworska contrasts the two notions of autonomy at play in Dworkin's and Dresser's work and stakes out a third position that constructs autonomy as connected to values and convictions, which she contends do not require someone to necessarily recall their whole life story.<sup>223</sup> For Jaworska, the capacity to value requires that “the person thinks she is correct in wanting

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217. Under many existing substitute judgment regimes, courts hold that decisions should be made for a person based on her wishes, if known, and if not known based on her best interests. *See, e.g., In re M.R.*, 638 A.2d 1274, 1280 (N.J. 1994) (discussing substituted judgment test as discerning “what choice the patient would have made if able to choose”).

218. *See* CRPD General Comment, *supra* note 6, ¶ 4.

219. *See* Gooding, *supra* note 100, at 52.

220. *See* Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value*, 28 PHIL. & PUB. AFF. 105 (1999).

221. *See* RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 218-41 (1993).

222. Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 373-405 (1986).

223. *See* Jaworska, *supra* note 220, at 116, 109.

what she wants; achieving what she wants is tied up with her sense of self-worth; and the importance of achieving what she wants is, for her, independent of her own experience.”<sup>224</sup> The neurological evidence, she contends, shows that this capacity to value usually remains in the brain long after the ability to remember and to reason may have been damaged by Alzheimer’s.<sup>225</sup>

This recognition of values is a different formulation from the “will and preferences” that Article 12 seeks to protect but, ultimately, is not inconsistent with that idea and may have more resonance for older persons with serious cognitive impairment. Jaworska roots autonomy “in the ability to lay down the principles that will govern one’s actions,” as opposed to the notion of will and preferences.<sup>226</sup> Still, there is a kinship between the two concepts in that personhood does not derive from the ability to effectuate either will and preferences or values. As Jaworska notes, “means-ends reasoning and planning are mere tools for implementing the principles” that a person may have laid down for running their life.<sup>227</sup> This formulation of autonomy provides an underlying principle that may be useful in guiding the development of mechanisms for determining will and preferences to effectuate the right to legal capacity.

The second, and most significant challenge to supported decision-making, is to ensure that it will not make older adults more vulnerable to abuse.<sup>228</sup> Older adults, especially those with cognitive impairments are at significant risk of being abused, especially financially. Studies show that “between 3% and 5% of the older adult population has experienced financial exploitation by a family member in the past year.”<sup>229</sup> A person’s declining cognitive function, even among those who do not have dementia, appears to play a role in their susceptibility to scams.<sup>230</sup>

The question is not whether there is elder abuse, as there is, or whether older adults suffering from cognitive impairments are more likely to be the targets of such abuse, as they are. The question is whether a shift from a guardianship to supported decision-making

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224. *See id.* at 116, 109.

225. *See id.* at 130.

226. *See id.* at 128-29 (noting that autonomy does not consist in the ability to “devise and carry out the means and plans . . .”).

227. *See id.*

228. *See* BACH AND KERZNER, *supra* note 91, at 37.

229. *Prevalence and Diversity*, DEP’T OF JUSTICE, <http://www.justice.gov/elderjustice/research/prevalence-and-diversity.html> [<https://perma.cc/WZ8C-8N3H>].

230. Bryan D. James et al., *Correlates of Susceptibility to Scams in Older Adults Without Dementia*, 26 J. ELDER ABUSE & NEGL. 107, 109 (2014).

system would make individuals more vulnerable to abuse and limit the ways in which they can seek redress for their harms. In thinking about what the paradigm shift may bring, it is important to recognize that guardianship itself can be the vehicle for elder abuse,<sup>231</sup> as can powers of attorney.<sup>232</sup> It is impossible to say that supported decision-making will not be a vehicle, too.

The specific concerns about abuse and undue influence are as follows. First, how can older adults with cognitive impairments be protected from abuse and undue influence from those whom they have appointed as supporters?<sup>233</sup> The Texas statute builds in protections by placing language on the supported decision-making agreement form that requires persons who see it, and believe that the individual is being abused, to report it to a state abuse hotline.<sup>234</sup> The British Columbia statute requires the appointment of a monitor, with certain exceptions, in agreements authorizing the involvement of a supporter in financial decisions; the monitor can request accounts and other records and investigate whether the representative is complying with the individual's wishes.<sup>235</sup> In addition, the statute explicitly imposes some fiduciary duties on the supporter.<sup>236</sup> More empirical work remains to be done on how effective these mechanisms are.

In addition, if we move away from a guardianship system, are there other mechanisms that can substitute for the remedies by which a guardian can assist a cognitively impaired individual in un-doing abusive transactions? How can we overcome the challenges to implementing them? It is worth noting that elder abuse advocates have raised questions about the limits of guardianship as a tool to address elder abuse. In a piece describing typical cases at an elder abuse shelter in the Bronx, New York, advocates note that abuse may produce cognitive and emotional decline, and result in “anguish, guilt, and shame—feelings that may present as a lack of decision-making ability. These factors make it even more likely that, for victims of elder abuse, guardianship petitions may be filed inappropriately.”<sup>237</sup>

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231. See GAO-10-1046, *supra* note 79 at 6-7.

232. See Kohn, *supra* note 182, at 3.

233. In the review of experience with supported decision-making in five provinces, the Canadian Centre for Elder Law found that concern about abuse was a significant barrier for older adults with dementia. See JAMES & WATTS, *supra* note 145, at 52.

234. See TEX. EST. CODE ANN. § 1357.056(a) (West 2015).

235. See Representation Agreement Act, R.S.B.C. 1996, c. 405 §§ 12, 20 (Can.).

236. See *id.* § 16.

237. Joy Solomon et al., *Changing of the Guardians: A Criticism and Analysis of the New York Guardianship Statute's Impact on Elder Abuse Victims*, 10 NAT'L ACAD. ELDER L. ATT'Y J. 149, 162 (2014).

But it is undeniable that guardianship can be a useful tool for stopping abuse and voiding one-sided transactions, entered into directly by the person or by an agent abusing a power of attorney.<sup>238</sup> However, it is likely that guardianship has been used as a tool to do the work that other doctrines designed to protect persons from exploitation could do, but without depriving the victims of their right to legal capacity. More thinking and empirical work needs to be done to identify the particular ways in which common law doctrines of undue influence, fraud, unconscionability, unjust enrichment, and the like, along with consumer protection statutes, can be utilized in situations in which guardianships currently provide a ready and expedient remedy.<sup>239</sup>

### CONCLUSION

The growing call for a shift from guardianship to supported decision-making reflects the convergence of two different reform efforts: one historically devoted to improving the process of guardianship and another emerging out of the disability rights and independent living movements. Despite the historical disconnect between these groups, they are increasingly converging, and those concerned with the guardianship process have begun to embrace supported decision-making as a viable and worthwhile alternative.<sup>240</sup> Supported decision-making and the right to legal capacity have become topics at conferences on guardianships and aging, and have been endorsed by a range of entities concerned with the legal rights of older adults.<sup>241</sup> Supported decision-making has significant promise as a legal arrangement and practice that can preserve and enhance the autonomy of older adults who would otherwise be at risk of

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238. See, e.g., N.Y. MENTAL HYG. LAW § 81.23(b) (McKinney 2004) (authorizing guardianship court to craft broad injunctive relief to prevent harm to incapacitated person); N.Y. MENTAL HYG. LAW § 81.43 (McKinney 2004) (creating clawback procedure by which guardian can get back property taken from incapacitated persons).

239. See Carney & Beaupert, *supra* note 117, at 197 (noting that “these remedies are ill-suited in practice to the needs of ordinary people lacking the financial and other resources to successfully correct financial abuse or mismanagement”).

240. See Glen, *supra* note 25, at 138–39 (describing embrace of supported decision-making concepts at the 2011 National Guardianship Summit).

241. See *id.*; see also A.B.A. COMM’N ON L. & AGING, *Supported Decision-making Encouraged at National Aging and Law Conference*, [http://www.americanbar.org/news/abanews/aba-news-archives/2015/11/supported\\_decision-m.html](http://www.americanbar.org/news/abanews/aba-news-archives/2015/11/supported_decision-m.html) [<https://perma.cc/P6AM-53CM>] (describing session encouraging supported decision making at National Aging and the Law Conference). The author was a participant in this session.

guardianship while preserving their personhood in the eyes of the law. In order to realize these significant benefits, more work remains to be done to articulate a model that rings true for the situation of older adults and addresses their particular pragmatic concerns.<sup>242</sup>

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242. *See generally* Kohn et al., *supra* note 14 (arguing that little was known about how supported decision-making works in practice and proposing an empirical research agenda).