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# SUPPORTED DECISION-MAKING IN THE UNITED STATES AND ABROAD

BY: EMILY A. LARGENT, JD, PHD, RN\* ANDREW PETERSON, PHD\*\*+

## I. INTRODUCTION

*Jane, a retired attorney, has been diagnosed with mild cognitive impairment caused by Alzheimer's disease. Jane's physicians warn that this is a likely precursor to dementia and expect Jane will reach a severe level of impairment, requiring constant supervision, in the next two to five years. At present, Jane has occasional difficulty understanding instructions and sometimes forgets appointments. She describes feeling increasingly overwhelmed by making decisions. Jane concedes that she needs help. Jane has expressed a desire to maintain her independence, while Jane's spouse wants to protect her in light of her obvious vulnerability. How should Jane and her spouse strike this balance? And, how might this balance evolve as Jane's cognitive and functional decline due to Alzheimer's disease progress?*

The principle of respect for persons requires giving weight to the choices of people with the capacity for self-determination; however, respect for persons also requires protecting the welfare of those with diminished capacity.<sup>1</sup> Balancing these two obligations is fundamentally an ethical challenge—but one for which Jane, her spouse, and others like them often seek a legal solution. The law has traditionally responded to cognitive disability and cognitive decline by authorizing surrogate decision-makers, legal proxies, or guardians to make

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1. Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 N. ENGL. J. OF MED., 1834, 1834 (2007); *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, ABA COMM. ON L. & AGING & AM. PSYCHOLOGICAL ASSN., 1, 3-5 (2005), <https://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>.

decisions on behalf of the impaired person.<sup>2</sup> Yet, the use of these surrogate decision-making regimes for persons with marginal capacity has increasingly been criticized for stripping people—in whole or in part—of their right to self-determination. Therefore, there have been calls domestically and internationally to supplant these regimes with alternative decision-making models that empower persons with disabilities.<sup>3</sup>

Supported decision making offers just such an alternative paradigm and is rapidly gaining favor.<sup>4</sup> Whereas surrogate decision-making regimes presume that decisions need to be made *for* persons with disabilities, supported decision-making regimes presume that decisions can be made *by* persons with disabilities if they are provided adequate assistance.<sup>5</sup> Open questions, remain, however, about how to understand the appropriate relationship between surrogate decision-making and supported decision-making. Are surrogate and supported decision-making regimes mutually exclusive, as some have suggested? Or is it possible to transition between the two decision-making models under appropriate circumstances? Here, we will argue that surrogate and supported decision-making regimes are best understood as serving different but complementary purposes. Parties should have access to both decision-making regimes and may permissibly switch between them based on the demands of the decision-making context.

Let's return to Jane. In the present, while she has mild cognitive impairment (MCI), supported decision-making seems ideal: it satisfies both Jane's desire to exercise her capacity for self-determination and her partner's (and the state's) desire to protect her welfare. However, as Jane's Alzheimer's disease progresses and her capacity for self-determination erodes, a surrogate decision-making regime, such as guardianship or conservatorship, will likely become essential. A similar transition (though in reverse) might occur for those recovering from neurological insult, such as a traumatic brain injury or stroke. Such individuals may require surrogate decision-making in the acute phase of injury. Yet, as they recover, surrogate decision-making might naturally give way to supported decision-making as cognitive function returns.

If we are correct that supported and surrogate decision-making are complementary regimes, then it is necessary to determine how best to chart the course between them. To date, much of the legal and ethical literature on supported decision-making has focused on its utility for individuals with "static

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2. Shana Wynn, *Decisions by Surrogates: An Overview of Surrogate Consent Laws in the United States*, 36 BIFOCAL 10, 10 (2014).

3. Nandini Devi et al., *Moving Towards Substituted or Supported Decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities*, 5 ALTER 249, 256 (2011).

4. Nina A. Kohn, et al., *Supported Decision-Making: A Viable Alternative to Guardianship*, 117 PENN ST. L. REV. 1111, 1111 (2012).

5. *Id.*

impairments”—in which cognitive and functional deficits do not change significantly over time—such as young adults with intellectual and developmental disabilities who are transitioning from being in the care of their families to independence.<sup>6</sup> As a result, the question of transitioning between decision-making models has been less urgent. But “[s]upported . . . decision-making arrangements become difficult where an adult’s decision-making ability . . . fluctuates.”<sup>7</sup> How might the transition from supported to surrogate decision-making (or vice versa) operate for individuals with “dynamic impairments”? Dynamic impairments are characterized by clinically and practically significant fluctuations in cognition and function, often due to progressive neurodegenerative diseases, such as Alzheimer’s disease or Parkinson’s disease, or recovery from neurological insult.<sup>8</sup> Millions of adults are affected by dynamic impairments in the United States and internationally.<sup>9</sup> Therefore, as supported decision-making draws growing political support across the United States, it is important and timely to consider how we might best facilitate the transition between surrogate and supported decision-making.

In this article, we examine the concept of supported decision-making in the United States and then look to the international context to better understand the interrelationship between surrogate and supported decision-making to improve U.S. laws. In Section II, we outline the general ethical framework of supported decision-making.<sup>10</sup> We argue that surrogate decision-making regimes should be a last resort for persons with marginal capacity; nevertheless, there remain cases in which surrogate decision-making is necessary due to the extent of a person’s cognitive and functional decline. Supported decision-making therefore cannot entirely supplant surrogate decision-making. In Section III, we review the relevant U.S. law, highlighting Texas’ supported decision-making law and *Olmstead v. L.C.*<sup>11</sup> Then, in Section IV, we turn to the international context.<sup>12</sup> First, we review the U.N. Convention on the Rights of Persons with Disabilities, which has been central to the international movement toward supported decision-

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6. See, e.g., Leslie P. Francis, *Understanding Autonomy in Light of Intellectual Disability in DISABILITY AND DISADVANTAGE*, 200-15, (Kimberley Brownlee and Adam Cureton eds., 2009) (explaining autonomy and diminished capacity in the context intellectual disabilities); see also Kristen Booth Glenn, *Supported Decision-making and the Human Right of Legal Capacity*, 3 *INCLUSION* 2, 2-16 (providing an account of supported decision-making as honoring the fundamental human right of legal capacity).

7. Shih-Ning Then, *Evolution and Innovation in Guardianship Laws: Assisted Decision Making*, 35 *SYDNEY L. REV.* 133, 161 (2013).

8. Hui-Ming Gao & Jau-Shyong Hong, *Why Neurodegenerative Diseases are Progressive: Inflammation Drives Disease Progression*, 29 *TRENDS IN IMMUNOLOGY* 357, 357 (2008).

9. Stephen W. Hawking, Foreword to *WORLD REPORT ON DISABILITY* at ix, (2011), [https://www.who.int/disabilities/world\\_report/2011/report.pdf](https://www.who.int/disabilities/world_report/2011/report.pdf).

10. See *infra* Section II.

11. See *infra* Section III; *Olmstead v. L.C.*, 527 U.S. 581 (1999).

12. See *infra* Section IV.

making regimes.<sup>13</sup> Second, we review the supported decision-making laws of three countries: Canada's British Columbia Representation Agreement Act, Ireland's Assisted Decision Making (Capacity) Act, and Australia's Victoria Medical Treatment Planning and Decisions Act 2016.<sup>14</sup> These countries have more experience with supported decision-making, and an analysis of international models provides useful guidance for the U.S. context. In Section V, we make recommendations for steps forward in the United States.<sup>15</sup> We conclude our thoughts in Section VI.<sup>16</sup>

## II. SUPPORTED DECISION-MAKING

Supported decision-making is a model of decision-making in which an adult with diminished capacity (the "beneficiary") enters freely into an agreement with a closely trusted person or persons (the "supporter(s)") who will assist the beneficiary in exercising self-determination.<sup>17</sup> While there is no single model of supported decision-making, implementation typically includes: (1) identifying the domains of life in which the beneficiary needs and desires help—for example, financial or medical decision-making—based on the nature and intensity of the beneficiary's impairments; (2) identifying the kinds of support that are needed and desired—for example, communication, interpretive, or representational support; and (3) establishing a formal supported decision-making agreement between the beneficiary and the supporter(s).<sup>18</sup> All supported decision-making models share a core feature: "the decision maker retains the right to make decisions and have them recognized by law."<sup>19</sup>

Justification for supported decision-making comes from the social model of disability, which holds that disability is not inherent to a person, but emerges from an interplay between a person's impairments and the environment.<sup>20</sup> Where a mismatch between a person's capabilities and the environment exists, accommodations can address socially constructed barriers, thus enabling people with disabilities to partake in the same rights and freedoms as their nondisabled peers. It is generally acknowledged that there are limits to the social model of disability and that even if all social barriers are removed, some impairments will

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13. See *infra* Section IV.A.

14. See *infra* Sections IV.B-IV.D.

15. See *infra* Section V.

16. See *infra* Section VI.

17. *Supported Decision Making and Health Care*, NATIONAL DISABILITY RIGHTS NETWORK (Apr. 25, 2019) <https://www.ndrn.org/resource/supported-decision-making-and-health-care/>.

18. *Id.*; see generally Kohn, *supra* note 4, at 1111-12, 1121.

19. Eliana J. Theodorou, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U.L. REV. 973, 975 (2018).

20. See Tom Shakespeare, *The Social Model of Disability*, IN THE DISABILITIES STUDIES READER 1, 195-97 (Lennard J. Davis 5th ed., 2017) (contrasting the social and the medical models of disability).

remain disadvantageous.<sup>21</sup> Nevertheless, the social model provides a framework for understanding social obligations to create inclusive environments for persons with disabilities.<sup>22</sup> For example, individuals with impaired mobility should not be excluded from public spaces; we should build ramps and install wheelchair lifts to make public spaces accessible.<sup>23</sup> The same reasoning leads to the conclusion that individuals with impaired cognition should not be unjustifiably excluded when decisions about their lives are being made.<sup>24</sup> Compared to surrogate decision-making regimes that bar the door to decision-making, supported decision-making is analogous to ramps or lifts—a cognitive prosthesis—for a person with marginal capacity.<sup>25</sup>

Yet, in thinking of the disability right’s movement credo “Nothing About Us Without Us,” it’s quickly apparent that supported decision-making cannot be imposed on people without consent.<sup>26</sup> Rather, a beneficiary must voluntarily agree to participate in a supported decision-making relationship. One puzzle raised by supported decision-making agreements is the assumption that the beneficiary is capable to enter into the agreement. Yet, the need for supported decision-making implies that the beneficiary’s capacity is—to some degree—diminished. Given this diminished capacity, why would the beneficiary be presumed to have capacity to enter into a supported decision-making agreement? Stated simply, the ethics and law of decision-making capacity emphasize the nature of the decision at hand when determining whether a person has or lacks the capacity to make that decision.<sup>27</sup> One implication of this assumption is that the type and level of ability needed to make one kind of decision—say, appointing a supporter or supporters—may be markedly different from the abilities needed to make more complicated and high-stakes decisions.<sup>28</sup>

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21. *Id.* at 201-02.

22. Andrew Peterson, Jason Karlawish, & Emily A. Largent, *Supported Decision Making for People at the Margins of Autonomy*, AM. J. OF BIOETHICS, (forthcoming).

23. *Id.*

24. *Id.*

25. See *The Right to Make Choices: International Laws and Decision-Making by People with Disabilities*, AUTISTIC SELF ADVOCACY NETWORK, 1, 9 <http://supporteddecisionmaking.org/sites/default/files/asan-toolkit-right-to-make-choices.pdf> (last visited Feb. 19, 2020) [hereinafter *The Right to Make Choices*] (stating “[I]magine that you want to find a place to live. . . . [i]f you are using supported decision-making instead of guardianship, you could simply call up your sister and have her help you through the process. If you have a guardian, you could not get an apartment without your guardian’s consent and assistance, even if you would rather have someone else help you instead of your guardian. Even if your guardian could only make decisions about how you send your money, you wouldn’t be able to pay the rent for your apartment without their help.”).

26. JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US DISABILITY OPPRESSION AND EMPOWERMENT*, 17 (1st ed. 2000).

27. Appelbaum, *supra* note 1, at 1834-840.

28. Scott Y. H. Kim & Paul S. Appelbaum, *The Capacity to Appoint a Proxy and the Possibility of Concurrent Proxy Directives*, 24 BEHAV. SCI. L. 469, 469-70 (2006).

A helpful analogy can be drawn between entering into a supported decision-making agreement and appointing a surrogate decision-maker at the end of life. In the end-of-life context, the law recognizes that someone incapable of giving consent to medical treatment may, nevertheless, retain the capacity sufficient to delegate decision-making authority to a surrogate.<sup>29</sup> It has, moreover, been argued that the threshold of capacity to appoint a surrogate should be low relative to the threshold for more complicated medical decisions.<sup>30</sup> This is consistent with an overall trend toward preserving autonomy even in persons with diminished capacity.<sup>31</sup> Further, appointing a surrogate is, fundamentally, about trusting someone to make care decisions on your behalf; for most of us, trust is a familiar concept, and assessing your degree of trust in a potential surrogate—typically a person with whom you are already in a close relationship—is an easier task than giving informed consent, which may require some mastery of medical or technical details.<sup>32</sup>

Surely, however, even if the threshold of capacity required to select a supporter and enter into a supported decision-making agreement is set quite low, there will be some people for whom the bar is nevertheless too high to surmount. Imagine Sam, a legal adult who suffers a catastrophic brain injury and is left in a vegetative state, a neurological condition characterized by wakefulness without awareness. Sam had the capacity to make decisions prior to injury, yet after his injury he is completely dependent on others to make decisions.<sup>33</sup> Supported decision-making simply would not work after his injury.

In other cases, supported decision-making may initially work but become untenable as a beneficiary's cognitive and functional status declines. Think back to Jane. Assume that Jane and her spouse entered into a supported decision-making agreement after Jane was diagnosed with MCI. Supported decision-making might work well for many years because Jane and her spouse continuously adjust the nature and intensity of support provided to compensate for Jane's progressive cognitive and functional decline. Yet, as Jane enters the late stage of dementia, she will no longer understand what is said to her and will have significant impairments in her ability to communicate. At this point in the trajectory of her illness, it would be implausible—even with fulsome support—that Jane would be capable of making her own decisions. As these examples suggest, surrogate decision-making regimes are still needed even if robust supported decision-making regimes are available.

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29. *Id.* at 469-71.

30. *Id.* at 473.

31. Theodorou, *supra* note 19, at 983-84.

32. Kim & Appelbaum, *supra* note 28, at 473-74.

33. We note that a host of options are available here. Sam might have anticipated loss of capacity and assigned a durable power of attorney to a trusted person in his life. Or, state law might have a hierarchy of health care agents. In some instances, however, Sam might need a guardian appointed.

The fact that that individuals like Sam and Jane (in the later stages of dementia) require a surrogate decision-making regime does not imply that it is no longer necessary to respect their autonomy.<sup>34</sup> A surrogate decision-maker might rely on *substituted judgement* to make decisions for Sam, Jane, and others like them. Substituted judgment is premised on the ideal that surrogates use evidence of incapacitated individuals' values, preferences, and interests to reach the decisions incapacitated individuals would have otherwise made for themselves had they retained capacity and been confronted with the same circumstances.<sup>35</sup> Although incapacitated persons cannot make decisions for themselves, others can respect their autonomy by approximating the decisions they would have made.<sup>36</sup> If the surrogate lacks sufficient information about the incapacitated individual's values, preferences, and interests to make substituted judgment practical, the surrogate may be guided by the *best interests* standard, or what would be good for the incapacitated individual. The underlying rationale for the best interests standard is beneficence, the moral obligation to act for the other's benefit by helping them further their interests or preventing harms.<sup>37</sup> Because, as we have explained, it is widely accepted that autonomy has primacy over beneficence, surrogates should employ substituted judgment whenever possible.<sup>38</sup>

Supported decision-making is preferable to surrogate decision-making in many—perhaps in most—circumstances because it allows the person with diminished capacity to exercise her autonomy.<sup>39</sup> But, supported decision-making is a complement, not a replacement, for surrogate decision-making regimes. Once we acknowledge that surrogate and supported decision-making regimes must co-exist to meet the full range of needs of persons with cognitive and functional disabilities, we must also determine how to transition between these regimes. Cognitive impairments place individuals on a spectrum of capacity: at one extreme, individuals have full capacity, while at the other, individuals are completely incapacitated.<sup>40</sup> Many individuals will have static cognitive impairments, meaning that decision-making can be consistently conducted within one decision-making regime, but other individuals will have dynamic impairments.<sup>41</sup> Persons with dynamic impairments fluctuate over time

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34. Thaddeus Mason Pope, *Legal Fundamentals of Surrogate Decision Making*, 141 CHEST 1074, 1075 (2012).

35. Donna T. Chen et al., *Substituted Judgment*, 24 J. GEN. INTERNAL MED. 145, 145 (2009).

36. *Id.*

37. Agnieszka Jaworska, *Advance Directives and Substitute Decision-Making*, in *THE STANFORD ENCYCLOPEDIA OF PHILOSOPHY* (Edward N. Zalta, ed. Sum. 2007), <https://plato.stanford.edu/archives/sum2017/entries/advance-directives/>.

38. *Id.*

39. See Peterson, Karlawish, & Largent, *supra* note 22.

40. See Peterson, Karlawish, & Largent, *supra* note 22; see also Kohn, et al., *supra* note 4.

41. Peterson, Karlawish, & Largent, *supra* note 22; see also Kohn, et al., *supra* note 4.



between the two poles.<sup>42</sup> Thus, mechanisms for transitioning between supported and surrogate decision-making regimes are required to manage their decision-making needs.<sup>43</sup>

In what follows, we engage the question of transitioning between supported and surrogate decision-making for people with dynamic impairments. Supported decision-making is gaining traction across the United States, yet critical questions about how to bridge supported and surrogate decision-making are not adequately addressed in U.S. law. Under what conditions should this transition occur? Who decides when to execute this transition? And what legal mechanisms could facilitate this transition while also respecting autonomy and protecting welfare? In what follows, we first outline supported decision-making in the U.S. context. We then turn to supported decision-making laws in Canada, Ireland, and Australia for guidance.<sup>44</sup>

### III. SUPPORTED DECISION-MAKING IN U.S. LAW

All 50 states have laws about guardianship.<sup>45</sup> Over the last decade, however, supported decision-making as an alternative to guardianship for persons with cognitive and intellectual disabilities has gained traction in U.S. law.<sup>46</sup> Many disability rights and disability self-advocacy groups have argued that, whenever possible, supported decision-making should be pursued instead of guardianship.<sup>47</sup> This reflects a forceful disability rights movement. Disability advocacy led to—and gained significant momentum from—the ratification of the Americans with Disabilities Act (ADA), the 1990 civil rights law that prohibits discrimination against people with disabilities in public spaces.<sup>48</sup>

In 1999, the landmark case *Olmstead v. L.C.*<sup>49</sup> confronted the U.S. Supreme Court with “the question whether the [ADA] proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions.”<sup>50</sup> The Supreme Court answered with a “qualified yes,” holding that under the ADA, states are obliged to place institutionalized persons with disabilities in community-based programs, provided that the person with disabilities desires this, that the healthcare team deems this appropriate, and

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42. Peterson, Karlawish, & Largent, *supra* note 22; *see also* Kohn, et al., *supra* note 4.

43. Peterson, Karlawish, & Largent, *supra* note 22; *see also* Kohn, et al., *supra* note 4.

44. *See infra* Section IV.A-IV.C.

45. Morgan K. Whitlatch, *Guardianship Laws by State*, THE JENNY HATCH JUSTICE PROJECT, [http://jennyhatchjusticeproject.org/50\\_state\\_review](http://jennyhatchjusticeproject.org/50_state_review) (last visited Nov. 3, 2020).

46. *See* Kohn, et al., *supra* note 4.

47. *The Right to Make Choices*, *supra* note 25, at 17-18.

48. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified at 42 U.S.C. §§12101-12213).

49. 527 U.S. 581, 587 (1999).

50. *Id.* at 587.

that adequate resources are available.<sup>51</sup> Theorists, legal scholars, and disability rights advocates subsequently extended the conceptual foundations of *Olmstead*, arguing that the Court's holding implies a requirement to rectify unjust isolation and social exclusion in all forms.<sup>52</sup> This movement is sometimes referred to as "*Olmstead* Advocacy."<sup>53</sup>

One of the first cases to connect "*Olmstead* Advocacy" with supported decision-making involved a 29-year-old woman with Down Syndrome, Margaret "Jenny" Hatch, who lived independently in Hampton, Virginia until she was hit by a car while riding her bicycle.<sup>54</sup> Shortly thereafter, Jenny's estranged mother and step-father sought permanent, plenary guardianship over her, arguing that she had poor judgment about her own health, safety, and living arrangements.<sup>55</sup> The court adjudged Hatch incompetent and appointed a temporary, plenary organizational guardian.<sup>56</sup> The organizational guardian placed Hatch in a group home, limited her social contacts, and had her work in a supervised workplace for adults with disabilities.<sup>57</sup> Hatch challenged the necessity of having a legal guardian arguing that, although *Olmstead* addressed institutionalization, her loss of opportunity to live, work, and interact with others in the community should similarly be recognized as a violation of the ADA.<sup>58</sup>

In its ruling, the Circuit Court of Newport News asserted that it had duties to provide Hatch with a "voice and choice," to sufficiently explore alternatives to plenary guardianships, and to ensure that Hatch was considered an equal before the law.<sup>59</sup> It denied Hatch's mother and step-father's petition for permanent, plenary guardianship, and instead named two of Hatch's friends, Jim Talbert and Kelly Morris, temporary limited guardians for one year with the goal of transitioning to supported decision-making.<sup>60</sup> This 2013 decision marks one of the first instances that a U.S. court formally ordered supported decision-

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51. *Id.* at 597.

52. See generally Robert D. Dinerstein, *The Olmstead Imperative: The Right to Live in the Community and Beyond*, 4 INCLUSION 16 (2016).

53. *Self-Advocacy Materials*, OLMSTEADRIGHTS, [https://www.olmsteadrights.org/self-helptools/advocacy-materials/folder.520254-Main\\_Menu](https://www.olmsteadrights.org/self-helptools/advocacy-materials/folder.520254-Main_Menu) (last visited Feb. 19, 2020).

54. *Jenny Hatch*, THE JENNY HATCH JUSTICE PROJECT, <http://jennyhatchjusticeproject.org/jenny> (last visited Feb. 2, 2020).

55. Stephen A. Rosenbaum, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition Before the Law*, 39 J. LEGAL MED. 61, 71 (2019).

56. Sean Burke, *Person-Centered Guardianship: How the Rise of Support Decision-Making and Person-Centered Services Can Help Olmstead's Promise Get Here Faster*, 42 MITCHELL HAMLINE L. REV. 873, 875-876 (2016).

57. Margaret Jenny Hatch, Samantha Alexandra Crane, & Jonathan G. Martinis, *Unjustified Isolation is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship*, 3 INCLUSION 65, 65 et seq (2015).

58. *Id.*

59. *Ross v. Hatch*, No. CWF120000426P-03, 2013 Va. Cir. LEXIS 413, at 4 (Va. Cir. Ct. Aug. 2, 2013).

60. *Id.*

making as an alternative to guardianship,<sup>61</sup> and the decision acts as a template to advocate for subsequent cases.<sup>62</sup>

In 2015, Texas became the first state to statutorily recognize supported decision-making agreements as an alternative to guardianship for persons who need assistance but are not entirely incapacitated.<sup>63</sup> The law allows legal adults with cognitive or intellectual disabilities to enter into an agreement with a competent adult, according to which the individual with disabilities is enabled and supported to make decisions regarding living situations, medical care, and work.<sup>64</sup> This written plan can then be shared with others, such as doctors, who “shall rely” on it and shall not be held liable for actions taken in good faith.<sup>65</sup> In 2017, Texas expanded the law, engaging safeguards against abuse by the supporter.<sup>66</sup>

Texas’ supported decision-making law is generally intended to work in tandem with the state guardianship law to enhance opportunities for persons with disabilities and decrease the burden on the courts.<sup>67</sup> Indeed, according to the Texas state court system, “[t]he exploration of alternatives to guardianship has reduced the number of guardianship applications filed in Texas, a trend that was not occurring prior to the reforms.”<sup>68</sup>

While Texas was the vanguard, progress toward supported decision-making has been made across the United States. In 2016, Delaware became the second state to statutorily recognize supported decision-making agreements,<sup>69</sup> and several other states have followed suit or are currently considering similar legislation.<sup>70</sup> The Uniform Law Commission’s 2017 Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA) has also

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61. Jasmine E. Harris, *Processing Disability*, 64 AM. L. REV. 457, 512 (2015).

62. See Order *In re: Ryan Herbert King*, No. INT 249 (D.C. Super. Ct. Prob. Div. 2016).

63. S.B. 1881, 84th Leg., Sess. (Tex. 2015).

64. *Id.*

65. *Id.*

66. S.B. 39, 85th Leg., Sess. (Tex. 2017).

67. *Texas Guardianship Reform: Protecting the Elderly and Incapacitated*, THE ST. OF TEX. OFF. OF CT. ADMIN. 1, 3 (Jan. 2019), [https://www.txcourts.gov/media/1443314/texas-guardianship-reform\\_jan-2019.pdf](https://www.txcourts.gov/media/1443314/texas-guardianship-reform_jan-2019.pdf).

68. *Id.*

69. DEL. CODE ANN. tit. 16, §§ 9401-02.

70. H.B. 21, 149th Gen. Assem., 1st Year (Del. 2017); see also B. 20-0723, 20th Council Period, Reg. Sess. (D.C. 2015), B. 22-154, 22nd Council Period, Reg. Sess. (D.C. 2017) (Prior Bill: 2015 Bill Text D.C. B. 385), H.B. 2343, 87th Leg., Reg. Sess. (Kan. 2018), H.R. 91, 128th Leg., 1st Reg. Sess. (Me. 2017), S. 792, 435th Gen. Assem., Reg. Sess. (Md. 2015), H.R. 4332, 189th Gen. Court, Reg. Sess. (Mass. 2016), S.B. 806, 99th Gen. Assem., 2nd Reg. Sess. (Mo. 2018), S.B. 264, 110th Gen. Assem., Reg. Sess. (Tenn. 2018), H.R.J. Res. 190, 2014 Leg., Reg. Sess. (Va. 2014), Assem. B. 655, 103rd Leg., Reg. Sess. (Wisc. 2017); see e.g., National Resource Center for Supported Decision Making, <http://supporteddecisionmaking.org/States> (last visited Feb. 2, 2020) (providing a continuously updated archive of U.S. supported decision-making).

sought to advance supported decision-making.<sup>71</sup> Notably, the UGCOPAA explicitly recognizes supported decision-making as a less restrictive alternative to surrogate decision-making regimes, such as guardianship.<sup>72</sup> It argues that a guardian should not be appointed unless there is a finding by clear and convincing evidence, that an individual “is unable to receive or evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making.”<sup>73</sup> At present, only Maine<sup>74</sup> and Washington<sup>75</sup> have adopted UGCOPAA,<sup>76</sup> while New Mexico<sup>77</sup> has adopted parts of it.<sup>78</sup> In 2018, Alaska,<sup>79</sup> the District of Columbia,<sup>80</sup> and Wisconsin<sup>81</sup> also formally recognized supported decision-making regimes. Indiana,<sup>82</sup> North Dakota,<sup>83</sup> Nevada,<sup>84</sup> and Rhode Island<sup>85</sup> passed supported decision-making agreement laws in 2019. These laws vary widely, including with respect to who may serve as a supporter (e.g., some states restrict who may serve as a supporter, while others do not) and the scope of decisions that may permissibly be enumerated in the agreement.<sup>86</sup> Numerous other states have made relevant changes to their guardianship laws without addressing supported decision-making agreements.<sup>87</sup> Collectively, these changes are viewed as “steps forward [...] in safeguarding rights, addressing abuse, and promoting less restrictive options.”<sup>88</sup>

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71. UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT (National Conference of Commissioners on Uniform State Laws, 2017).

72. *Id.* at § 102.

73. *Id.* at § 301.

74. ME. REV. STAT. ANN. tit. 18-C, §§ 5-101–5-817.

75. WASH. REV. CODE ANN. §§ 2.72.005-.050; WASH. REV. CODE ANN. §§ 11.88.005-11.92.190.

76. *Guardianship, Conservatorship, and Other Protected Arrangements Act*, UNIFORM L. COMMISSION (2017), <https://www.uniformlaws.org/committees/community-home?communitykey=2eba8654-8871-4905-ad38-aabb573911c&tab=groupdetails>.

77. N.M. STAT. ANN. §§ 45-5-301–45-5-315.

78. Commission on Law and Aging, *State Adult Guardianship Legislation Summary: Directions of Reform*, AMERICAN BAR ASSOCIATION 1 (2018) [hereinafter ABA], [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2018-adult-guardianship-legislative-summary.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-adult-guardianship-legislative-summary.pdf).

79. H.R. 336, 30th Leg., 2nd Sess. (Alaska 2018) (amending AK R. EVID. 420, prohibiting the execution of a supported decision-making agreement from being used as evidence of a principal’s incapacity).

80. D.C. Sess. L. 22-0154, 22nd Council Sess. (D.C. 2018).

81. Wis. Legis. Assemb. 655. Reg. Sess. 2017-2018 (Wis. 2017).

82. S IND. CODE §§29-3-14-1 – 29-3-14-13 (2019).

83. H.B. 1378, 66th Leg. Assemb. (N.D. 2019).

84. A.B. 480, 80th Legis. (Nev. 2019).

85. H.B. 5909, 2019 Reg. Sess. (R.I. 2019).

86. Zachary Allen and Dari Pogach, *More States Pass Supported Decision-Making Agreement Laws*, 41 J. OF THE AM. BAR ASSOC. COMM’N ON L. & AGING 1, 159-161 (2019).

87. ABA, *supra* note 78, at 1.

88. ABA, *supra* note 78, at 2.

Growing interest in and commitment to supported decision-making as an alternative to guardianship among U.S. courts, state legislatures, and legal practitioners suggests that “recent state laws are likely to serve as models for future legislation.”<sup>89</sup> Therefore, “it is important to evaluate whether these laws are effective in promoting supported decision-making – and supporting individuals with disabilities to make their own choices.”<sup>90</sup> We would suggest, however, that U.S. laws lag behind those of other countries, particularly in articulating the relationship between supported and surrogate decision-making regimes. We now turn to the international context to identify potential legal mechanisms that could rectify this gap. As we shall see, supported decision-making laws of other countries also raise critical questions about how to transition between supported and surrogate decision-making for people with marginal capacity.<sup>91</sup>

#### IV. SUPPORTED DECISION-MAKING IN THE INTERNATIONAL CONTEXT

How should supported decision-making laws balance respect for autonomy and protection of the vulnerable? How do we distinguish cases in which supported decision-making is preferable to surrogate decision-making and vice versa? How can we transition between supported and surrogate decision-making regimes for people with dynamic impairments? And what circumstances might precipitate a switch from one decision-making model to the other? In what follows, we address these questions through legal frameworks of other countries and international policy. We argue that the U.N. Convention on the Rights of Persons with Disabilities (CRPD), as interpreted by the U.N. Committee on the Rights of Persons with Disabilities, provides little guidance in answering these questions. By contrast, supported decision-making laws of other countries—Canada, Ireland, and Australia—provide preliminary answers, but there is no final resolution.<sup>92</sup>

##### *A. The U.N. Convention on the Rights of Persons with Disabilities*

The CRPD has been central to the international movement toward supported decision-making and other forms of disability advocacy.<sup>93</sup> The CRPD is designed “to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to

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89. Zachary Allen & Dari Pogach, *More States Pass Supported Decision-Making Agreement Laws*, 41 J. OF THE AM. BAR ASSOC. COMM’N ON L. & AGING 1, 161 (2019).

90. *Id.*

91. *See infra*. Sections IV.B-IV.D.

92. *Infra* Sections IV.B-IV.D.

93. *See generally* United Nations, *United Nations Convention on the Rights of Persons with Disabilities*, UNITED NATIONS: DEP’T OF ECON. & SOC. AFFAIRS, DISABILITY, [https://www.un.org/disabilities/documents/COP/cosp9\\_infographic.pdf](https://www.un.org/disabilities/documents/COP/cosp9_infographic.pdf) (Updated Oct. 10, 2016).

promote respect for their inherent dignity.”<sup>94</sup> It is unique in that it systematically recognizes rights drawn from the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social, and Cultural Rights (ICESCR) and establishes a conceptual link between the rights encapsulated by these foundational documents and their application in the context of disability.<sup>95</sup> The CRPD emphasizes the “importance for persons with disabilities of their individual autonomy, including the freedom to make their own choices.”<sup>96</sup>

Article 12 of the CRPD reaffirms the right of persons with disabilities to be recognized as equals before the law<sup>97</sup> and is broadly regarded as a cornerstone for supported decision-making.<sup>98</sup> Article 12(3), for example, specifically affirms that: “States Parties shall take appropriate measures to provide access by persons with disabilities to the *support* they may require in exercising their legal capacity.”<sup>99</sup> Article 12(4) clarifies the kind of support that might be required, as capacity-related measures, which must “respect the rights, will, and preferences of the person” and be “proportional and tailored to the person.”<sup>100</sup> This language implies that a range of support options will be required to accommodate diverse needs and preferences.<sup>101</sup> The emphasis on support, evident throughout the CRPD, is consistent with the social model of disability.<sup>102</sup>

The CRPD is regarded by some as an international mandate to adopt supported decision-making legislation for persons with cognitive or intellectual disabilities.<sup>103</sup> However, following its adoption, there have been open questions about the nature and scope of Article 12. A first concern is that, given the description of support structures within the Article, there is a need to ensure that the provision of supported decision-making offers genuine support rather than being surrogate decision-making in disguise.<sup>104</sup> Article 12(4) could plausibly justify the role that guardians, legal proxies, and surrogate decision-makers

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94. Convention on the Rts. of Persons with Disabilities (CRPD) Res. U.N. Doc. A/61/106, art. 1, (Dec. 13, 2006).

95. Penny Weller, *Supported Decision-Making and the Achievement of Non-Discrimination: The Promise and Paradox of the Disabilities Convention*, 26 L. CONTEXT J. 85, 89 (2008).

96. Convention on the Rts. of Persons with Disabilities, *supra* note 94, at pmb1.

97. Convention on the Rts. of Persons with Disabilities, *supra* note 94, at art. 12.

98. Kohn et al., *supra* note 4, at 1113.

99. Convention on the Rts. of Persons with Disabilities, *supra* note 94, at art. 12.

100. Convention on the Rts. of Persons with Disabilities, *supra* note 94, at art. 12.

101. Fiona Morrissey, *The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law*, 19 EUR. J. OF HEALTH L. 423, 432 (2012).

102. 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).

103. *Id.*

104. See Anna Arstein-Kerslake et. al, *Future Directions in Supported Decision-Making*, 37 DISABILITY STUD. Q. (2017).

already play. But this may be antithetical to the original intent of the Article, namely, to enhance and guarantee the right of self-determination for persons with disabilities.<sup>105</sup>

A second, related concern is whether Article 12 instead *prohibits* these surrogate decision-making regimes. A conservative reading of Article 12 suggests that it does not, and some have argued that the Article even includes language that could plausibly justify surrogate decision-making under certain conditions.<sup>106</sup> However, in 2014, the U.N. Committee on the Rights of Persons with Disabilities published its first General Comment on Article 12, which takes a much more radical view.<sup>107</sup> According to the General Comment, “persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision making regimes such as guardianship [and] conservatorship,” and “these practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.”<sup>108</sup> The Comment goes on to state that States Parties have an obligation to *abolish* surrogate decision-making regimes and provide supported decision-making alternatives.<sup>109</sup> Maintaining both surrogate and supported decision-making regimes, the Comment states, “is not sufficient” to comply with Article 12.<sup>110</sup> We disagree with this radical reading of Article 12.

Significantly, the General Comment on Article 12 does not have binding force on nations that have adopted the CRPD.<sup>111</sup> There are several reasons why the General Comment should not guide supported decision-making legislation in the United States or abroad. First, the proposal to abolish surrogate decision-making regimes is infeasible. As we have argued above, even if supported decision-making is feasible and desirable in the majority of cases, not all persons with disabilities will be able to exercise their autonomy even with fulsome support.<sup>112</sup> The extent and nature of a person’s impairments, and the demands of some decision-making circumstances, will simply be too great for some individuals. Surrogate decision-making will be necessary in these cases.

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105. See Lucy Series & Anna Nilsson, *Article 12 CRPD: Equal Recognition Before the Law*, in THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: A COMMENTARY (I. Bantekas, M. Stein, & D. Anastasiou eds., 2018).

106. 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, 460-61 (2007).

107. See Committee on the Rts. of Persons with Disabilities, General Comment on Article 12: Equal Recognition Before the Law, U.N. Doc. GE. 13-49143/11 (2014).

108. *Id.* at 3.

109. *Id.*

110. *Id.* at 6.

111. Stig Langvad et al., *The Purpose and Use of UN Treaty Body General Comments*, THE EUROPEAN NETWORK ON INDEP.LIVING (2018), <https://enil.eu/news/the-purpose-and-use-of-un-treaty-body-general-comments/>.

112. Joseph Dute, *Should Substituted Decision-Making be Abolished?*, 22 EUR. J. OF HEALTH L. 315, 318 (2015).

Second, abolition of surrogate decision-making fails to strike any justifiable balance between the competing ethical duties of respect for autonomy and protection of the vulnerable.<sup>113</sup> Nations surely should endeavor to enhance the autonomy of persons with disabilities, but enhancing their autonomy should not come at the expense of safeguarding welfare. Enhancing autonomy at all costs could result in policies and practices that permit persons with diminished capacity to make decisions that could reasonably be expected to result in harm to them or others.<sup>114</sup> This is unacceptable.

Critical analysis of the scope and mandate of the CRPD points to, but does not resolve, the key tension at the heart of supported-decision making laws—how to balance respect for autonomy and protection of vulnerable individuals. Therefore, we must look elsewhere for guidance.

*B. Canada: The British Columbia Representation Agreement Act*

In the 1990s, Canadian disability advocacy groups conceived of supported decision-making as a means to facilitate the self-determination of people with intellectual disabilities in the receipt of provincial benefits and financial planning.<sup>115</sup> In 1992, the first framework for supported decision-making was outlined in the Canadian Association for Community Living Task Force report, *Alternatives to Guardianship*.<sup>116</sup> Among its enumerated principles, the report claimed that:

[A]ll adults have the right to self-determination with the support, affection, and assistance of family and friends of their choosing...; that the cornerstone of supported decision making is a trusting relationship between a person giving support and a person receiving support; and that the law must not discriminate on the basis of ... a person's capacity or competence.<sup>117</sup>

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113. *Id.*

114. See generally Alec Buchanan, *Mental Capacity, Legal Competence, and Consent to Treatment*, 97 J. ROYAL SOC'Y. OF MED. 415, 416-17 (2004).

115. See Michelle Browning, Christine Bigby, & Jacinta Douglas, *Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice*, 1 RES. & PRAC. INTELL. & DEV. DISABILITIES, 34, 35-36 (2014) (discussing the focus of Canadian reform efforts on eradicating barriers to self-determination and individualized funding); see also Robert M. Gordon, *The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making*, 23 INT'L J. L. & PSYCHIATRY, 61, 61-62 (2000) (discussing Canadian reforms in areas of adult guardianship and substitute decision-making).

116. Michelle Browning, Christine Bigby, & Jacinta Douglas, *Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice*, 1 RES. & PRAC. INTELL. & DEV. DISABILITIES, 34, 35 (2014).

117. *Id.*



These principles were subsequently adopted into Canadian provincial law in Manitoba, British Columbia, Saskatchewan, Yukon, and Alberta.<sup>118</sup>

British Columbia is recognized by the United Nations as “one of the leading jurisdictions in incorporating supported decision-making into law, policy and practice.”<sup>119</sup> The Representation Agreement Act of 1996 provides one model for balancing the competing goals of respect for autonomy and protection of the vulnerable.<sup>120</sup> It authorizes a person or persons to assist an adult (19 years of age or older) with decision-making or to act on the adult’s behalf.<sup>121</sup> A representation agreement is intended to serve as a legal alternative to guardianship but may also be an adjunct to it.<sup>122</sup> Here is an example from Nidus, a community-based resource center with expertise on representation agreements:

Cherry is a woman whose speech and memory has been affected by a brain injury. The Public Guardian and Trustee (PGT) is managing her financial and legal affairs . . . but nothing is in place for health and personal care. Cherry makes a [representation agreement] for health and personal care . . . and names her sister as her representative . . . to help her with her health and personal care decisions, such as decisions about rehabilitation and occupational therapy. Her representative will talk with the PGT for Cherry’s money to pay for treatments and equipment needed to improve quality of life.<sup>123</sup>

The Representation Agreement Act is also intended to accommodate conditions characterized by dynamic impairments, as illustrated by the case of Joyce, a woman diagnosed with Alzheimer’s disease:

[A]s Joyce’s dementia has progressed, she now needs help with her health and personal care decisions. It is more difficult for her to remember important details. Naming [her friend] Barb as her representative for health care and personal care matters . . . gave Joyce peace of mind. Barb can be present during medical appointments to help Joyce speak up for her wishes. Barb can help by picking up medications and the pharmacy and accessing information and communicating with health care providers on Joyce’s behalf.<sup>124</sup>

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118. The Vulnerable Persons Living with a Mental Disability Act, S.M. 1993, c.V90 (Can.); Representation Agreement Act, S.B.C. 1996 (Can.); Adult Guardianship and Co-Decision Making Act, R.S.S. 2000(Can.); Adult Guardianship and Trusteeship Act, S. A. 2008 (Can.).

119. U.N. DEP’T OF ECON. & SOC. AFFAIRS & OFF. OF THE U.N. HIGH COMM’N FOR HUM. RIGHTS & INTER-PARLIAMENTARY UNION., HANDBOOK FOR PARLIAMENTARIANS ON THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: FROM EXCLUSION TO EQUALITY REALIZING THE RIGHT OF PERSONS WITH DISABILITIES, at ch.6 U.N. Doc. HR/PUB/07/6, (2007).

120. See Representation Agreement Act, R.S.B.C.1996 (Can.).

121. *Id.*

122. *Id.*

123. *Representation Agreement: Section 7 Standard Powers*, NIDUS PERS. RESOURCE CTR. AND REGISTRY 1, 2 (2011) [hereinafter *Representation Agreement*], [http://www.nidus.ca/PDFs/Nidus\\_FactSheet\\_RA\\_Section7.pdf](http://www.nidus.ca/PDFs/Nidus_FactSheet_RA_Section7.pdf).

124. *Id.*

Thus, the Representation Agreement Act offers a useful way of thinking about the core issues under consideration in this article.

The beneficiary can give his representative(s)—comparable to supporters—authority to handle personal and health care matters, as well as legal and routine financial affairs.<sup>125</sup> The duties of the representative include “consult[ing], to the extent reasonable, with the adult to determine his or her current wishes and comply[ing] with those wishes when it is reasonable to do so.”<sup>126</sup> The depth and scope of the representative’s consultation with the beneficiary is not, however, well-defined.<sup>127</sup> This raises a potential concern that consultation may be only cursory, falling short of the meaningful exchange that is desired.<sup>128</sup> The Act qualifies the representative’s duties, stating that, if “the [vulnerable] adult’s current wishes cannot be determined or it is not reasonable to comply with them, the representative must comply with any instructions or wishes the adult expressed while capable.”<sup>129</sup> In these cases, the representative must apply a substituted-judgment or a best-interests standard, consistent with what is known about the beneficiary’s values.<sup>130</sup> Thus, the representation agreement anticipates and accommodates the need for transitioning between supported and surrogate decision-making regimes within a single document.

The key mechanism for transitioning between supported and surrogate decision-making is twofold.<sup>131</sup> First, the beneficiary’s wishes must themselves be reasonable.<sup>132</sup> Second, compliance with the beneficiary’s wishes must also be reasonable.<sup>133</sup> This distinction is important, as it suggests scenarios in which a beneficiary’s wishes are reasonable, but complying with those wishes is not.<sup>134</sup> A beneficiary might reasonably desire a certain living arrangement, yet

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125. See generally Representation Agreement Act, R.S.B.C. 1996, c 405 (Can.) (recognizing two types of agreements, one more expansive than the other); see *RA Overview Fact Sheet*, NIDUS PERS. RESOURCE CTR. & REGISTRY 2, <https://www.nidus.ca/representation-agreement/overview-fact-sheet/> (last visited Feb. 4, 2020) (describing a “Section 7 Agreement” which covers routine daily living requirements); see *Representation Agreement*, supra note 106 (describing a “Section 9 Agreement” which covers a broader swath of decisions); *Representation Agreement: Section 7 Standard Powers (RA7)*, NIDUS PERS. RESOURCE CTR. & REGISTRY, <https://www.nidus.ca/representation-agreement/ra-9-fact-sheet/> (last visited Feb. 4, 2020) (explaining the level of capacity required to make a Section 9 Agreement is higher than that required to make a Section 7 Agreement).

126. Representation Agreement Act, R.S.B.C. 1996, c 405, pt. 3, § 16.2(a)-(b) (Can.).

127. Sarah Burningham, *Developments in Canadian Adult Guardianship and Co-Decision-Making Law*, 18 DALHOUSIE J. LEGAL STUD. 119, 125 (2009).

128. *Id.*

129. Representation Agreement Act, R.S.B.C. 1996, pt 3, c 405, § 16 (3) (Can.).

130. *Id.* at § 16(4)(a)-(b).

131. See Shih-Ning Then, *The Evolution and Innovation in Guardianships Laws: Assisted Decision-Making*, 35 SYDNEY L. REV. 133, 155-57 (2013) (discussing similar conceptual issues).

132. *Id.*

133. *Id.*

134. *Id.*

compliance with this request might be infeasible, for example, due to cost.<sup>135</sup> A supporter would likely not be required to comply with this request.<sup>136</sup> The request's infeasibility makes compliance unreasonable, even though the request itself may be reasonable.<sup>137</sup>

Although this aspect of B.C. law provides helpful guidance for determining when, and under what circumstances, the transition between supported and surrogate decision-making is warranted, this approach may raise more questions than it resolves.<sup>138</sup> In particular, the meaning of 'reasonable' with respect to a beneficiary's request and the supporter's compliance with that request leaves considerable room for interpretation.<sup>139</sup> Although 'reasonability' is a familiar concept in the law, referring to *what would be appropriate in the circumstances*, this definition may be open to debate in practice.<sup>140</sup> For example, a request (e.g., to live alone or to obtain a driver's license) could be regarded as reasonable when made by one beneficiary, but deemed unreasonable if made by another beneficiary, or if made by the same beneficiary at a different time.<sup>141</sup> It is also unclear who should determine whether 'reasonableness' applies.<sup>142</sup> In practice, a supporter will often need to make these judgments in real time.<sup>143</sup> This could place supporters in a conflicted situation; they must commit to supporting the beneficiary while also faithfully determining whether it would be better to take on a surrogate decision-making role.<sup>144</sup> This raises the danger of slipping into *de facto* surrogate decision-making.<sup>145</sup>

### C. Ireland: *The Assisted Decision Making (Capacity) Act (2015)*

Ireland's Assisted Decision Making (Capacity) Act of 2015 offers another model for balancing respect for autonomy and protection of the vulnerable.<sup>146</sup> The Act, signed by Ireland's President in 2015, replaces the Ward of Courts system of the Lunacy Regulation Act of 1871.<sup>147</sup> Previous decision-making laws

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135. *Id.*

136. *Id.*

137. *Id.*

138. *Id.*

139. *Id.*

140. *Id.*

141. *Id.*

142. *Id.*

143. *Id.*

144. *Id.*

145. *See id.* at 164 (discussing the difficulty of determining helping a person who is capable of making decisions or assisting a person with a disability to make and communicate their decisions without influencing the final decision and becoming a *de facto* decisions maker).

146. *See generally* Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>.

147. Brendan Desmond Kelly, *The Assisted Decision-Making (Capacity) Act 2015: What It Is and Why It Matters*, IRISH J. OF MED. SCI. 351, 351 (2017).

in Ireland inadequately addressed the nuances of decision-making for people with marginal capacity.<sup>148</sup> Wardship courts were authorized to make all personal and financial decisions for incapacitated persons, and they lacked sufficient mechanisms to respond to changes in a person's capacity over time.<sup>149</sup> The Assisted Decision Making (Capacity) Act was designed to address these and other issues and is broadly regarded as "the most significant development in Irish capacity legislation in over a century."<sup>150</sup>

The Act builds upon complimentary policy regarding informal decision-making in clinical settings. Ireland's Health Service Executive National Consent Policy advises clinicians to support and encourage incapacitated patients to be involved in decisions, to identify incapacitated patient's previously expressed wishes, and to involve patient advocates in decision-making.<sup>151</sup> However, some legal scholars have noted that, in practice, these recommendations are not often adhered to and clinicians will usually seek consent from patients' next-of-kin.<sup>152</sup> The Assisted Decision Making (Capacity) Act thus fills a critical gap in Irish decision-making legislation for incapacitated persons.

The Act specifies two decision-making roles that might be relevant to U.S. supported decision-making legislation.<sup>153</sup> The first role is a "decision-making assistant" who is appointed by a beneficiary to *assist* in making decisions regarding welfare and property, as specified in a decision-making assistance agreement.<sup>154</sup> The assistant supports a beneficiary by obtaining and explaining information, determining the beneficiary's preferences, and assisting the beneficiary in expressing them.<sup>155</sup> The role of a decision-making assistant is thus consistent with that of a supporter in U.S. law.<sup>156</sup> A second role specified by the Act is a "co-decision maker."<sup>157</sup> Unlike a decision-making assistant, a co-decision maker is authorized to *jointly* make decisions with the beneficiary

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148. *Id.*

149. *Id.*

150. *Id.*

151. See generally *National Consent Policy – Quality Improvement Programmes*, NAT'L QUALITY IMPROVEMENT TEAM, <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy.html> (last visited Jan. 31, 2020).

152. See Mary Donnelly, *Deciding in Dementia: The Possibilities and Limits of Supported Decision-Making*, 66 INT'L J. L. & PSYCHIATRY 1, 6 (2019) (explaining that CDM Agreements will be overlooked in favor of the more commonly known instrument, Power of Attorney, due the complexity and novelty of co-decision-making).

153. See generally Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>; see also *supra* Section III.

154. Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html> (defining decision-making assistant in pt. 3 § 9).

155. Donnelly, *supra* note 152.

156. See *supra* note 63 and accompanying text.

157. Donnelly, *supra* note 152.

regarding welfare and property, as specified in a co-decision-making agreement.<sup>158</sup> This role provides the supporter greater authority in the decision-making process. The general purpose of the co-decision-making role is to aid the beneficiary in relevant decisions, but a co-decision maker may also block the beneficiary from making decisions in particular circumstances.<sup>159</sup>

The Act states that, “a co-decision-maker shall acquiesce with the wishes of the appointer in respect of the relevant decision, unless it is reasonably foreseeable that such acquiescence [...] will result in serious harm to the appointer or to another person.”<sup>160</sup> This co-decision-making mechanism is interesting for two reasons. First, it defaults to supported decision-making by requiring that the co-decision-maker “acquiesce” with the wishes of the beneficiary.<sup>161</sup> This is similar to the role of a decision-making assistant, who is required to support a beneficiary’s legal capacity and not make decisions for her.<sup>162</sup> Yet, a co-decision-maker is also provided limited ‘veto power’ over the beneficiary’s decisions.<sup>163</sup> This oversight mechanism prevents the co-decision-maker from actively making decisions for the beneficiary, yet allows her to temper decisions that are not agreeable. This suggests a surrogate decision-maker may still be needed.

This decision-making mechanism is also interesting because it specifies the conditions under which a ‘veto’ is authorized.<sup>164</sup> The co-decision-maker is only permitted to block a beneficiary’s decision if that decision will likely result in serious harm.<sup>165</sup> This feature of Irish law might provide greater specificity for the conditions sufficient to refuse a beneficiary’s wishes, as compared to the B.C. Representation Agreement Act.<sup>166</sup> As described above, B.C. law hinges on a legal standard of reasonableness for compliance with a beneficiary’s wishes, but Irish law defers to probability of serious harm to the beneficiary or others.<sup>167</sup> If a dispute arises between a supporter and beneficiary, the probability of serious

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158. *Id.*; see also Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html> (referring to pt. 4, § 19).

159. Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html> (referring to pt. 4, § 19).

160. *Id.*

161. *Id.*

162. See Donnelly, *supra* note 152.

163. See Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html> (referring to pt 4, § 19(5)(a)-(b) which allows co-decision makers to refuse to sign a document if he or she finds that signing the documents would result in serious harm to the appointer or to another person).

164. *Id.*

165. *Id.*

166. See *supra* Section IV.B.

167. Representation Agreement Act, R.S.B.C. 1996, c 405, § 16 (Can.); Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html> (referring to pt 4, § 19 of the Act).

harm standard may be easier to apply in practice than the reasonableness standard. We hypothesize that it might also allow the beneficiary greater latitude to exercise her autonomy, as it will often be a higher bar to surmount. All decisions that result in serious harm will likely be unreasonable, but not all unreasonable decisions will result in serious harm.

Although the Assisted Decision Making (Capacity) Act constitutes a considerable advancement in Irish decision-making law, and may provide guidance for U.S. legislation, several critical questions have been raised about its features. Some theorists have questioned the distinction between a decision-making assistant and a co-decision maker.<sup>168</sup> The Assisted Decision Making (Capacity) Act implies that co-decision-makers are more involved in the decision-making process than decision-making assistants, yet, according to critics, this is not clearly stated in the legislation.<sup>169</sup>

One way to respond to this concern, as we have highlighted above, is to note a co-decision-maker's 'veto power' over a beneficiary's decision, which is not held by decision-making assistants.<sup>170</sup> This 'veto power' is perhaps akin to the decision-making relationship between a parent and a teenager, in which the parent supports the teenager's nascent autonomy. A teenager is not yet of legal majority, and thus is not authorized to provide consent; however, a caring parent can support the teenager in decision-making by acquiescing to her requests unless a veto is warranted. In our reading of the legislation, a decision-making assistant would not play this decision-making role, but a co-decision maker would.

A second question concerns the Act's relation to Article 12 of the CRPD.<sup>171</sup> The Assisted Decision Making (Capacity) Act is broadly regarded as Ireland's commitment to the CRPD.<sup>172</sup> However, contrary to the above-outlined General Comment on Article 12, the legislation does not eliminate surrogate decision-making regimes.<sup>173</sup> Rather, Ireland's Department of Justice and Equality has indicated that, "on ratification, Ireland will issue a declaration, along similar lines to the declarations issued by Australia, Canada and Norway that it is the State's understanding that the CRPD allows for substitute decision-making where such arrangements are necessary as a last resort and subject to safeguards."<sup>174</sup> We

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168. Kelly, *supra* note 147, at 355.

169. Donnelly, *supra* note 152, at 6.

170. *See supra* notes 163-65 and accompanying text.

171. Donnelly, *supra* note 152, at 5.

172. Donnelly, *supra* note 152, at 5.

173. Compare *supra* Section IV.A., with Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>.

174. *See Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)*, DEP'T OF JUST. & EQUALITY 4-5, <http://www.justice.ie/en/JELR/Roadmap%20to%20Ratification%20of%20CRPD.pdf/Files/Roadmap%20to%20Ratification%20of%20CRPD.pdf> (last visited Feb. 16, 2020) (indicating that the enactment of

agree with this approach, as it is consistent with our view that supported and surrogate decision-making regimes are complementary. Yet, in a notable oversight, the Act does not provide for the transition between supported and surrogate decision-making.

*D. Australia: The Victoria Medical Treatment Planning and Decisions Act 2016*

Australia has also taken steps to integrate supported decision-making into state law. In 2014, the Australian Law Reform Commission released a report, *Equality, Capacity and Disability in Commonwealth Laws*.<sup>175</sup> The report echoed much of the language of Article 12 in the CRPD.<sup>176</sup> Yet, despite advocating for a supported decision-making regime, the report noted that “*some* system of appointment of others is a necessary human rights backstop.”<sup>177</sup> The report observed that the Offices of the Public Advocate (South Australia and Victoria) “identified the danger that an ‘overemphasis’ on a person’s autonomy may be ‘to the detriment of protection for people who need guardianship *as a rights enhancing mechanism.*”<sup>178</sup> The report identified many of the challenges that animate our work here, namely, when is it appropriate to appoint someone to act on behalf of another, and what test should be used to determine when this should happen?<sup>179</sup>

Presently, Victoria is among the Australian states boasting the most well-developed legislation, with four laws that include provisions for supported decision-making: National Disability Insurance Scheme Act 2013; Powers of Attorney Act 2014; Mental Health Act 2014; and Medical Treatment Planning and Decisions Act 2016.<sup>180</sup> Each law recognizes a distinct legal role for supporters.<sup>181</sup> For example, the Powers of Attorney Act recognizes a ‘supportive attorney’ who has power to access or provide information about the beneficiary to organizations (e.g., banks or hospitals); to communicate with organizations; to communicate their decisions; and to give effect to their decisions.<sup>182</sup> By

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the Assisted Decision-Making (Capacity) Bill 2013 was an effort to comply with certain provisions of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities).

175. See generally AUSTRALIAN LAW REFORM COMM’N, *EQUALITY, CAPACITY AND DISABILITY IN COMMONWEALTH LAWS* (Aug. 29, 2014).

176. See 2515 U.N.T.S. 44910.

177. AUSTRALIAN LAW REFORM COMM’N, *EQUALITY, CAPACITY AND DISABILITY IN COMMONWEALTH LAWS* 1, 60 (Aug. 29, 2014).

178. *Id.*

179. *Id.* at 61.

180. OFFICE OF THE PUBLIC ADVOCATE, *SUPPORTED DECISION-MAKING IN VICTORIA: A GUIDE FOR FAMILIES AND CARERS* 6-7 (Nov. 2017), <https://www.publicadvocate.vic.gov.au/resources/booklets/advance-planning-booklets/447-guide-to-supported-decision-making/file>.

181. *Id.*

182. *Id.* at 7.

contrast, the Mental Health Act recognizes a ‘nominated person’ who represents a mental health consumer’s interests and serves as a support in the event they become a patient under the Mental Health Act.<sup>183</sup> A practical challenge for supporters, beneficiaries, and those who work with them is to understand and determine how best to navigate this multiplicity of laws.

Here, we will focus on one of these laws, the Medical Treatment Planning and Decisions Act 2016.<sup>184</sup> Given that existing laws were fragmented and leading to confusion in practice, the Act created clear obligations for clinicians caring for people who lack decision-making capacity.<sup>185</sup> Under the Act, Victorians are able to appoint a “medical treatment decisionmaker.”<sup>186</sup> A medical treatment decision-maker is responsible for making medical decisions *for* an incapacitated individual. The Act also introduced the process for formally appointing a “support person.”<sup>187</sup> A support person is responsible for representing the interests of the beneficiary in making, communicating, and effectuating treatment decisions.<sup>188</sup> Once appointed, a support person has automatic access to medical information, allowing her to compile or to help interpret information.<sup>189</sup> A support person’s potential role does not necessarily end when the beneficiary is determined to lack decision-making capacity, however. The support person may, for instance, explain previous treatment preferences to the medical staff.<sup>190</sup> The distinction between medical treatment decision-makers and support persons is similar to the difference in roles we have identified between surrogate decision-makers and supporters.<sup>191</sup> Whereas surrogates make decisions *for* the beneficiary, supporters assist beneficiaries in making *their own* decisions.<sup>192</sup>

The Act specifies that “being a support person does not preclude a person from also being a medical treatment decision maker.”<sup>193</sup> Both roles are governed by distinct agreements, which must be authorized by the beneficiary, provided that she has the capacity to do so.<sup>194</sup> When the same person occupies both roles, this may facilitate the transition between supported and surrogate decision-making. Here is an illustrative vignette from the Office of the Public Advocate:

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183. *Id.*

184. *See generally* *Medical Treatment Planning and Decisions Act 2016* (Austl.).

185. *Id.*

186. *Id.* at pt 1 s 1.

187. *Id.* at pt 3 div 3 s 31.

188. *Id.* at pt 3 div 3 s 32.

189. *Id.* at pt 7 s 94.

190. OFFICE OF THE PUBLIC ADVOCATE, *supra* note 180, at 7.

191. *See supra* Section II.

192. *Id.*

193. *Medical Treatment Planning and Decisions Act 2016* pt 3 div 3 s 32 (Austl.).

194. *Id.* at pt 3 div 2 s.



Elizabeth, 79, is a widow with dementia. She has a fall at home . . . and is taken to hospital with a broken hip. Elizabeth[’s daughter], Catherine . . . receives a call from the hospital telling her Elizabeth needs surgery. The doctor seeks consent from Catherine to operate because Elizabeth cannot provide it herself. Catherine tells the doctor Elizabeth has appointed her as Medical Treatment Decision Maker and Support Person. Catherine provides verbal consent for the surgery . . . and catches the first available flight to be with Elizabeth.<sup>195</sup> \_

The vignette goes on to describe how, after surgery, Catherine transitions back to the role of support person, and assists Elizabeth in deciding to go to rehabilitation by taking notes, asking questions, and drawing on her knowledge of her mother’s priorities.<sup>196</sup>

Supported and surrogate decision-making regimes are thus recognized as complementary in Australian law, but a beneficiary’s autonomy is best respected by creating a bulwark against allowing supported decision-making to slide into surrogate decision-making. Unlike Canadian and Irish law, Victoria’s Medical Treatment Planning and Decisions Act does not provide clear guidance in cases of conflict between the support person and the beneficiary, nor does it clearly specify when a support person is authorized to transition into a treatment decision maker role, other than specifying that the beneficiary lacks decision-making capacity. A document for clinicians published by the Victoria State Government states that “[a] support person may help to ensure that the person is able to make their own decisions for longer,”<sup>197</sup> but it is unclear about how the line between capacity with support and lack of capacity with support is to be assessed in practice. This places Australian law in a similar predicament as U.S. legislation: the roles of guardians and supporters are clear when a beneficiary’s cognitive and functional impairments are relatively stable, but they are unclear when the beneficiary’s impairments change dynamically.

## V. LESSONS FOR THE UNITED STATES

Supported decision-making continues to be a work in progress—at home and abroad. An examination of legislation in other countries highlights potential strategies for furthering the project of supported decision-making in the United States. Here, we draw several lessons.

As a first step, consistent with the laws of some other countries, supported decision-making agreements should be formally recognized across the United States because they are less restrictive alternatives to guardianship and promote

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195. OFFICE OF THE PUBLIC ADVOCATE, *supra* note 180, at 10.

196. OFFICE OF THE PUBLIC ADVOCATE, *supra* note 180, at 10-11.

197. VICTORIA STATE GOV’T HEALTH AND HUMAN SERV., A GUIDE TO THE MEDICAL TREATMENT PLANNING AND DECISIONS ACT 2016: FOR HEALTH PRACTITIONERS 11 (Victorian Government, 2d ed. 2017).

the rights of persons with disabilities. While there has been significant progress in this direction, more work is needed to ensure that supported decision-making is available to all Americans who might benefit from it.

Second, it is important to recognize that a beneficiary may desire support across many decision-making domains, such as medical, legal, financial, or others. It is desirable to limit the work that beneficiaries must do to formally access support for the breadth of their decision-making needs. In this respect, the B.C. Representation Agreement Act, which allows for one agreement to govern a range of decisions, is clearly preferable to the legal framework in Victoria, where different kinds of decisions are governed by distinct agreements.<sup>198</sup>

Third, as the vignettes throughout this article illustrate, individuals with dynamic impairments may need to transition between supported and surrogate decision-making.<sup>199</sup> Because capacity is decision- and context-specific, the two modes of decision-making need to be available simultaneously. Therefore, it is necessary to consider how supported and surrogate decision-making regimes can complement each other in practice. In this respect, B.C. has again struck an appealing compromise by permitting one agreement to anticipate both kinds of decision-making.<sup>200</sup>

Fourth, U.S. lawmakers will need to provide greater specificity regarding the conditions under which respect for autonomy is outweighed by a duty to protect the vulnerable, thereby triggering a switch from supported to surrogate decision-making. As we observed, B.C. law invokes a reasonableness standard for compliance with a beneficiary's wishes, while Irish law permits a supporter to refuse to comply if the beneficiary's wishes will likely result in harm.<sup>201</sup> These are helpful starting points for optimizing U.S. supported decision-making laws. We've suggested that the reasonableness standard may be more difficult to apply in practice and may permit greater restrictions on a beneficiary's decision-making. Similar mechanisms will also be needed to specify when surrogate decision-making can transition to supported decision-making, for instance, during recovery from neurological insult.

Existing laws leave room for interpretation and refinement. We expect that this will be an important area of future research for disability law scholars and bioethicists as supported decision-making continues to spread across the United States.

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198. Representation Agreement Act, R.S.B.C. 1996, c 405, pt 2, § 7 (Can.); OFFICE OF THE PUBLIC ADVOCATE, *supra* note 180 and accompanying text.

199. *Supra* Section II.

200. *Supra* Section IV.B.

201. Representation Agreement Act, R.S.B.C. 1996, c 405, pt 3, § 16.2(a)-(b) (Can.); Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), pt 4, § 19, <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>; *supra* Section II.

## VI. CONCLUSION

We have argued here that supported and surrogate decision-making regimes are both complementary and necessary for people at the margins of autonomy, and particularly for those individuals with dynamic impairments. Our view sits in contrast to a radical reading of the CRPD, which suggests that surrogate decision-making regimes should be abolished.<sup>202</sup> We further argued that recognition of both supported and surrogate decision-making regimes requires legal mechanisms to transition between them, either in cases in which a person needs greater protections as cognitive and functional impairments worsen, or in which a person should be given greater autonomy as they recover from neurological injury. We briefly reviewed aspects of three international supported decision-making laws to determine how other countries have addressed this issue. Further analysis of the laws of other countries will prove fruitful as supported decision-making gains momentum in the United States.

The formal project of supported decision-making is still relatively new in the United States, though supported decision-making as a general practice is not. Supportive relationships for people with cognitive impairments have long emerged organically from family ties and friendships. The formal project of supported decision-making merely seeks to build upon these tried-and-tested methods. The task at hand for legal scholars and lawmakers is to systematize these relationships so they can be incorporated in U.S. law and utilized by a broad population of stakeholders.

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202. *See supra* notes 107-110 and accompanying text.