

# ARTICLE

## LEGISLATING SUPPORTED DECISION-MAKING

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### ABSTRACT

*Supported decision-making is a process by which individuals who might otherwise be unable to make their own decisions do so with help from others. It has the potential to transform the lives of individuals with cognitive and intellectual disabilities by enabling them to function as legal actors, and not merely legal subjects. Fueled by this promise, by mounting concerns about guardianship, and by rhetoric surrounding the Convention on the Rights of Persons with Disabilities, states are rapidly adopting statutes that purport to enable and promote supported decision-making and advance the rights of persons with disabilities. This Article shows how these statutes typically do neither. Rather, the statutes limit the rights of individuals with disabilities and place them at increased risk of exploitation. The Article further shows that the wide gap between the concept of supported decision-making and its actual implementation in state legislation is the result of a confluence of political agendas, but that an alternative, person-centered approach is essential if supported decision-making is actually to empower individuals with disabilities. Finally, it outlines five concrete legislative approaches states could adopt—separately or in combination—to encourage supported decision-making that will actually advance the rights of persons with disabilities and reduce restrictive guardianships.*

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## I. INTRODUCTION

An emerging concept—“supported decision-making”—is transforming how the law responds to cognitive and intellectual disability. Supported decision-making is a process by which an individual who might otherwise be unable to make his or her own decisions becomes empowered to do so through support from others.<sup>1</sup> By enabling individuals with disabilities to make personal and financial decisions for themselves, supported decision-making practices have the potential to transform individuals with disabilities from legal subjects into legal actors, and reduce the need for court-imposed guardianship and other restrictions on self-governance.

Although supported decision-making does not require legal authorization, statutes that purport to “allow” or “enable” such practices are rapidly proliferating in the United States and abroad.<sup>2</sup> Fueled by the adoption of the Convention on the Rights of Persons with Disabilities,<sup>3</sup> politics around the

<sup>1</sup> See *infra* Section II.A for further discussion of the scope of supported decision-making and competing definitions of the term.

<sup>2</sup> See, e.g., Oběanský zákoník [Civil Code], Zákon č. 89/2012 Sb. (Czech); Assisted Decision Making (Capacity) Act (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html> [<https://perma.cc/5NFX-HCEB>]; see also ISR. HUMAN RTS. CTR. FOR PEOPLE WITH DISABILITIES, SUPPORTED DECISION-MAKING SERVICE FOR PERSONS WITH DISABILITIES: SERVICE MODEL 58 (2016).

<sup>3</sup> The vast majority of United Nations member states have ratified the Convention; however, the United States has not done so. For a list of signatories and ratifying states, see *Convention on the Rights of Persons with Disabilities (CRPD)*, U.N. DEP'T OF ECON. AND SOC.

world are rewriting their laws to encourage practices termed “supported decision-making” and to curtail more restrictive interventions such as guardianship.

This Article shows how the statutory embrace of supported decision-making in the United States, to date, has been counterproductive and self-contradictory. Although new legislation is framed as advancing disability rights, this Article shows how it instead typically promotes a form of private family ordering that is antithetical to individual rights, consequently exposing individuals with disabilities to substantial risk of exploitation. It describes the dominance of this perverse approach as the product of the alignment of three interest groups: family members of individuals with disabilities, who benefit from the new powers this legislative approach gives them; disability rights advocates, for whom its rejection of professionalized care resonates; and fiscal and social conservatives, who find it attractive because it both reduces public expenditures and embraces a conservative vision of the family as a private, supportive unit that should be protected from government interference.

The Article then lays out an alternative, rights-oriented approach to supported decision-making that would more fully realize the potential of supported decision-making to empower individuals with intellectual and cognitive disabilities—and not merely their families and associates. This approach would reject the dominant approach of granting supporters legal status. Instead, it would facilitate supported decision-making by prohibiting courts from stripping individuals of the right to make decisions if they can make decisions with support, by expanding access to decision-making support, and by creating systems that make it easier for people to efficiently and effectively provide decision-making support to others.

The Article comes at a timely moment. Many states are considering supported decision-making legislation, but this is the first article to systematically review and critique the first wave of state statutes. As such, it is also the first to show how these statutes are fundamentally incompatible with the supported decision-making model’s key principles: protecting and expanding the rights of individuals with disabilities. Perhaps most importantly, it provides a much-needed alternative framework to guide legislation, and a set of legislative approaches that would fulfill the promise of the supported decision-making model to empower individuals with disabilities in practice, not just in name.

## II. OVERVIEW OF SUPPORTED DECISION-MAKING

Supported decision-making is rapidly emerging as a major topic of conversation in law reform circles and disability rights activism. Yet, as this

Section explains, it is often misunderstood. This Section therefore precisely describes supported decision-making, how it represents a profound paradigm shift in thinking about the state's *parens patriae* role, and how it compares to guardianship.

### A. *The Supported Decision-Making Model*

Supported decision-making is an umbrella term for processes by which an individual who might otherwise be unable to make his or her own decisions becomes able to do so through support from other people. This assistance may include help with obtaining information relevant to a decision, explaining issues, identifying and analyzing options, interpreting words or behavior to determine the individual's preferences, and communicating decisions once made.<sup>4</sup> Assistance can be with regard to any type of decision, personal or financial.<sup>5</sup>

Supported decision-making can thus allow individuals, who would otherwise need to rely on others to make decisions for them, to make their own decisions. Ideally, this results in decisions that are more consistent with the individuals' wishes and values. Even if it does not, it is likely to substantially increase the individuals' perceived sense of control, which has been found to result in improved mental and physical well-being.<sup>6</sup>

Supported decision-making can take a variety of forms. It can involve a single supporter or multiple supporters. Where multiple supporters are involved, they may work with the individual collaboratively as a group (sometimes referred to as a "circle of support").<sup>7</sup> Alternatively, they may support the individual independently by, for example, separately assisting the individual with separate types of decisions.<sup>8</sup>

<sup>4</sup> See UNIF. GUARDIANSHIP, CONSERVATORSHIP, & OTHER PROTECTIVE ARRANGEMENTS ACT § 102(31) (UNIF. L. COMM'N 2017) [hereinafter UGCOPAA] (defining supported decision-making as "assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions, which enables the individual to make the decisions, and in communicating a decision once made if consistent with the individual's wishes"); U.N. DEP'T OF ECON. & SOC. AFFS. ET AL., FROM EXCLUSION TO EQUALITY: REALIZING THE RIGHTS OF PERSONS WITH DISABILITIES 89–90 (2007) (using a longer, but parallel, definition that describes supported decision-making as a phenomenon in which "[t]he individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual"); MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 24 (2010).

<sup>5</sup> UGCOPAA, *supra* note 4, at § 102(31); U.N. DEP'T OF ECON. & SOC. AFFAIRS ET AL., *supra* note 4; BACH & KERZNER, *supra* note 4.

<sup>6</sup> See Nina A. Kohn, *Elder Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1 (2006) [hereinafter Kohn, *Elder Empowerment*] (discussing the literature on the positive impacts of perceived sense of control).

<sup>7</sup> See Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1123 (2013) (describing different forms of supported decision-making).

<sup>8</sup> Having multiple supporters also reduces risks of exploitation by decreasing the individual's social isolation. See *Supported Decision Making*, INCLUDENYC, <https://www.include>

Supported decision-making can be entirely informal. An individual may receive support in obtaining, analyzing, and communicating information without any explicit agreement with the person providing that support. Informal decision-making support can be a one-time occurrence or a long-standing phenomenon. For example, Professor Elyn Saks, describing how supported decision-making has empowered her as an individual with schizophrenia, noted:

I have never ‘officially’ had a Supported Decision-Making (SDM) plan. But I definitely make all major decisions with the support of family and friends. As an example, when my 15-day emergency commitment had run its course, I could either sign a ‘Voluntary’ and stay in the hospital, or be subjected to a civil commitment proceeding. I thought the answer was clear: I should contest the commitment. My dad, who is also a lawyer, urged me to sign in voluntarily. If I didn’t, I would likely have to report this on every bar application I made. He was exactly right.

Currently I make a lot of important decisions (e.g., I have had several serious physical illnesses requiring treatment) and I always consult my husband, Will, and my closest friends, like Steve and Esther.<sup>9</sup>

As Saks’s description suggests, the fact that a supported decision-making relationship is informal does not mean it is a casual one; informal supported decision-making arrangements are often long-term, stable, and structured relationships.

Supported decision-making can also be formalized by an explicit agreement between the individual and the supporter or supporters. Such agreements can create an opportunity for dialogue between the individual being supported and the supporter about the types of decisions with which support is sought, and what types of assistance and behaviors the individual being supported would find helpful.<sup>10</sup> Formalized agreements have also been promoted as a tool for helping third-parties to understand and respect the relationship between an individual and the individual’s supporter.<sup>11</sup> This, in turn,

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[nyc.org/images/uploads/content/Supported\\_Decision\\_Making\\_packet\\_%281%29.pdf](https://nyc.org/images/uploads/content/Supported_Decision_Making_packet_%281%29.pdf) [https://perma.cc/L6EY-7S3X] (“Being connected to supporters protects against the kind of exploitation or abuse that can occur when a person is isolated and powerless.”).

<sup>9</sup> Elyn R. Saks, *The Power of Making Decisions*, IMPACT, <https://publications.ici.umn.edu/impact/32-1/the-power-of-making-decisions> [https://perma.cc/R5W3-AAWG] (Saks also emphasizes the importance of evolving supporters: “Interestingly, I do not consult my parents, as I do not want to go back to being the kid in my family of origin. That said, I talk to them pretty much every day—just not about that.”).

<sup>10</sup> See Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, 39 CARDOZO L. REV. 495, 509 (2017) [hereinafter Glen, *Piloting Personhood*] (describing successful facilitation of supported decision-making agreements as involving discussion and negotiation between individuals and their supporters).

<sup>11</sup> For example, banks and other financial institutions may be concerned that the individual being supported is being unduly influenced or otherwise victimized by the supporter, and that

is promoted as an antidote to disability discrimination on the grounds that it will reduce the likelihood that a third party will refuse to recognize decisions made by a person with a disability.<sup>12</sup>

Within these general parameters there is some disagreement—although frequently not explicit—as to the proper definition of supported decision-making.<sup>13</sup> Some descriptions limit it to situations involving decision-makers with intellectual or cognitive disabilities.<sup>14</sup> Others suggest that all persons—regardless of whether they have a disability—can engage in supported decision-making.<sup>15</sup> Similarly, some descriptions of supported decision-making reserve the term for situations in which the individual being supported has voluntarily entered into a supported decision-making relationship, whereas others use the term to also describe situations in which support is provided to the individual without the individual opting into the relationship.<sup>16</sup> Another complicating factor is that supported decision-making is sometimes defined

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liability may result if they adhere to the supporter's articulation of decisions. Formalized agreements are seen as a tool to mitigate these concerns and the ensuing resistance to supporters. *See Supported Decision-Making: Frequently Asked Questions*, AM. CIV. LIBERTIES UNION, <https://www.aclu.org/other/faqs-about-supported-decision-making> [<https://perma.cc/9WZR-5Q5Z>] (noting a formalized agreement “would help doctors, bankers, lawyers, and other third parties to feel confident in accepting the decision of the person with a disability without fearing lawsuits or malpractice claims”); Zachary Allen & Dari Pogach, *More States Pass Supported Decision-Making Agreement Laws*, 41 *BIFOCAL* 159, 160 (2019) (“Among the advantages of having legally recognized supported decision-making agreements in your state: . . . They can indemnify third parties such as financial and healthcare institutions from liability for relying on a supported decision-making agreement and require them to honor supported decision-making agreements.”).

<sup>12</sup> *See* SUPPORTED DECISION-MAKING N.Y., PRINCIPLES FOR AN INITIAL SUPPORTED DECISION-MAKING AGREEMENT (SDMA) LAW 2 (2021) (describing supported decision-making legislation as anti-discrimination legislation).

<sup>13</sup> Given the plethora of ways the term “supported decision-making” is used and how it is portrayed in relation to other forms of decision-making, as discussed in Section II.B, *infra*, some scholars have understandably criticized the concept as poorly defined. *See* Terry Carney & Fleur Beaupert, *Public & Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making*, 36 *U. NEW S. WALES L.J.* 175, 178 (2013) (arguing that supported decision-making is a “conceptually ill-defined” model that “has been interpreted as spanning everything from targeted legal powers and authorities through to facilitation of the normal interactions of daily family or social intercourse”).

<sup>14</sup> *See, e.g.*, Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities*, 19 *HUM. RTS. BRIEF* 8, 10 (2012) (describing supported decision-making as “a series of relationships, practices, arrangements, and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life”).

<sup>15</sup> Indeed, Alaska takes the position that its supported decision-making agreements are for all people, not simply those with disabilities. *See Supported Decision-Making Agreement (SDMA)*, ALASKA DEP’T HEALTH & SOC. SERVS., <http://dhss.alaska.gov/gcdse/Pages/projects/SDMA/SDMA.aspx> [<https://perma.cc/ZXN2-Z33S>] (“Anyone who wants support one [sic] can have a written agreement . . . Supported Decision-Making Agreements are not only for people who experience disabilities or older Alaskans.”).

<sup>16</sup> These later forms may then be called other terms, such as “co-decision-making” or “facilitated decision-making.” *See generally* LANA KERZNER, PAVING THE WAY TO FULL REALIZATION OF THE CRPD’S RIGHTS TO LEGAL CAPACITY AND SUPPORTED DECISION-MAKING: A CANADIAN PERSPECTIVE (2011) (discussing competing definitions); BACH & KERZNER, *supra* note 4 (same).

not merely as a process, but as a process that always reaches a successful outcome—at least from a procedural point of view. For example, a recent article stated that supported decision-making “is defined as a decision-making process in which individuals have control over the final decisions that pertain to their lives with the support and/or advice from their supporters who are personally appointed by the individual with a disability.”<sup>17</sup> This type of statement is emblematic of a common approach of describing supported decision-making as a process that necessarily results in individuals reaching their own decisions.

### B. Supported Decision-Making as Paradigm Shift

Supported decision-making is neither a complex nor novel concept. It is perhaps best described as a new way to label a nearly universal human experience: individuals looking to others for help when making decisions.<sup>18</sup> The notion that individuals may benefit from assistance when making decisions for themselves is indeed so universal that entire industries and professions have emerged to serve that need (e.g., investment advisors, career counselors, life coaches).<sup>19</sup> What is new is a growing recognition that individuals with intellectual and cognitive disabilities also benefit from that help—and that such help may make the difference in whether or not they are able make decisions for themselves.

Indeed, it is not an exaggeration to say that the emergence of supported decision-making as an approach to empowering individuals with substantial disabilities represents a paradigm shift.<sup>20</sup> It upends the conventional wisdom that individuals with cognitive challenges need to be “protected” from making poor decisions by having a surrogate decision-maker appointed to make decisions for them. It also shifts the narrative about decision-making involv-

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<sup>17</sup> Dalun Zhang et al., *A Call to Society for Supported Decision-Making: Theoretical and Legal Reasoning*, 28 J. CHILD & FAM. STUD. 1803, 1804 (2019); see also Dilip V. Jeste et al., *Supported Decision Making in Serious Mental Illness*, 81 PSYCHIATRY 28, 29 (2018) (“In [supported decision-making], typically individuals with cognitive disabilities receive assistance from family, friends, or other trusted persons to enhance their decision making capacity and skill so that they may retain autonomy during the decision making process.”).

<sup>18</sup> Nevertheless, perhaps reflecting an effort to build excitement about the potential for supported decision-making, the literature does include claims that supported decision-making is new. See, e.g., János Fiala-Butora & Michael Ashley Stein, *The Law as a Source of Stigma or Empowerment*, in INTELLECTUAL DISABILITY AND STIGMA: STEPPING OUT FROM THE MARGINS 195, 199 (Katrina Scior & Shirli Wener eds., 2016) (stating that “[f]or millennia, guardianship has been the only solution to help persons with decision-making difficulties” and, in so doing, disregarding common supportive practices as well legal instruments such as powers of attorney for healthcare and finances).

<sup>19</sup> See KARRIE A. SHOGREN ET AL., SUPPORTED DECISION-MAKING: THEORY, RESEARCH, AND PRACTICE TO ENHANCE SELF-DETERMINATION AND QUALITY OF LIFE 13 (2019) (commenting on how “[s]upported decision-making is consistent with the way most adults make their own decisions and order their lives”).

<sup>20</sup> See Dinerstein, *supra* note 14, at 8 (describing supported decision-making as a paradigm shift away from substituted decision-making).

ing individuals with intellectual and cognitive disabilities from an assumption that decisions will be made *for* such persons to an assumption that decisions will be made *by* them. Thus, it embraces individuals with disabilities as legal agents, not mere legal objects.

Supported decision-making also moves from a model of an autonomous actor whose needs and abilities can be considered in isolation from others to a model where the actor is embedded in a web of dependency and the actor's needs and abilities must be considered in a social context.<sup>21</sup> Traditionally, individuals were seen as capable of making decisions if they could independently make decisions without assistance from others. The capable decision-maker could consult others and consider knowledge obtained from others, but did not require another party to make a decision. In the supported decision-making model, the fact that the decision-maker requires the assistance of another party has no bearing on the validity of the decision.

Thus, the supported decision-making model can be seen as a natural extension of recent critiques of the law's prioritization of "autonomous" individuals<sup>22</sup> and of calls for the state to recognize the interdependency of actors.<sup>23</sup> Supported decision-making fully embraces the view that individuals are interdependent and that their individual capacities are shaped by relationships and networks. Thus, as further discussed in Section III.C.2, calls for state-recognized and state-facilitated supported decision-making are directly responsive to the progressive view that the state should support vulnerable people by supporting their family systems and networks.

The supported decision-making model is also consistent with modern theories of justice that call for equal rights and consideration to be given to human beings with cognitive and mental disabilities. For example, it is consistent with Martha Nussbaum's capabilities approach to social justice in that it treats individuals with cognitive disabilities as equal citizens and responds to their needs not simply by providing protection and care, but by actively facilitating individuals' abilities to make their own choices and make use of their own capabilities.<sup>24</sup> Notably, these modern theories find their embodi-

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<sup>21</sup> See generally EVA KITTAY, *LEARNING FROM MY DAUGHTER: THE VALUE AND CARE OF DISABLED MINDS* (2019) (promoting this viewpoint).

<sup>22</sup> See, e.g., MARTHA ALBERTSON FINEMAN, *THE AUTONOMY MYTH: A THEORY OF DEPENDENCY*, 20–30 (2004) (arguing that the value placed on autonomy in American society undermines substantive equality); MARY DONNELLY, *HEALTHCARE DECISION-MAKING AND THE LAW: AUTONOMY, CAPACITY AND THE LIMITS OF LIBERALISM* 10–48 (2010) (discussing the critiques of autonomy on the issue of agency and on the limited scope of a view of autonomy as non-interference); Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decisionmaking*, 79 MD. L. REV. 257 (2020) [hereinafter Wright, *Dementia*] (arguing that the traditional understanding of autonomy in health law is both inaccurate and incomplete when applied to persons with dementia, and that this recognition should lead to an embrace—and formalization—of supported decision-making).

<sup>23</sup> See FINEMAN, *supra* note 22, at 28–30.

<sup>24</sup> See MARTHA C. NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP* 195–99 (2006) (discussing the implications of the capabilities approach for guardianship and its alternatives).



ment in Article 12 of the Convention on the Rights of Persons with Disabilities, the adoption of which has fueled efforts to legislate around supported decision-making, as discussed later in this Article.<sup>25</sup>

### C. Comparison to Guardianship

Supported decision-making is commonly described as an alternative to surrogate decision-making and, in particular, to guardianship.<sup>26</sup> Guardianship is a process by which a court appoints a third party (called a “guardian” or “conservator”) to make decisions on behalf of an individual the court has found unable to make those decisions for him or herself.<sup>27</sup> At times, it is also presented as an alternative to all forms of surrogate decision-making, including opt-in instruments such as powers of attorney for healthcare or finances.<sup>28</sup>

Supported decision-making can be an appropriate alternative to surrogate decision-making for some individuals.<sup>29</sup> Individuals who would traditionally have been assumed to be unable to make decisions for themselves due to their disability in many cases will be able to make decisions for themselves if they have support in doing so.<sup>30</sup> Much as a person’s physical abili-

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<sup>25</sup> See *infra* notes 125–128 and accompanying text.

<sup>26</sup> See Jillian Craigie et al., *Legal Capacity, Mental Capacity and Supported Decision-Making: Report from a Panel Event*, 62 INT’L J.L. & PSYCHIATRY 160, 161 (2019).

<sup>27</sup> See Nina A. Kohn & Catheryn Koss, *Lawyers for Legal Ghosts: The Legality and Ethics of Representing Persons Subject to Guardianship*, 91 WASH. L. REV. 581, 587 (2016) (describing guardianship); Nina A. Kohn, *Fiduciary Principles in Surrogate Decision-Making*, in OXFORD HANDBOOK OF FIDUCIARY LAW 249 (Robert Sitkoff et al. eds., 2019) [hereinafter Kohn, *Fiduciary*] (discussing the use of the terms “guardian” and “conservator,” and explaining that some states use the term “guardian” to refer to a person appointed to make personal decisions and financial decisions, but many use “guardian” only to connote a person appointed to make personal decisions and “conservator” to connote a person appointed to make financial decisions).

<sup>28</sup> See, e.g., 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, 251 (2011) (describing supported decision-making as an alternative to all substitute decision-making approaches); David Godfrey, *Overview of Guardianship and Alternatives to Guardianship*, NAT’L CTR. ON L. & ELDER RTS. 1, 3–4 (July 2018), <https://ncler.acl.gov/Files/Overview-of-Guardianship-Alternatives-to-Guardians.aspx> [<https://perma.cc/MW37-X9ER>]. On the other hand, there are some articles that take the opposite approach, describing powers of attorney as a form of supported decision-making. See, e.g., Soumitra Pathare & Laura S. Shields, *Supported Decision-Making for Persons with Mental Illness: A Review*, 34 PUB. HEALTH REVS. 1, 4 (2012) (describing the use of these kinds of advance planning tools as a form of supported decision-making).

<sup>29</sup> The extent to which supported decision-making can obviate the need for surrogate decision-making remains unknown. Organizations working with individuals with intellectual disabilities have begun to build an evidence base showing that supported decision-making can empower individuals with intellectual disabilities to make decisions for themselves, but to date the evidence is limited to a handful of pilot studies.

<sup>30</sup> See Kohn et al., *supra* note 7, at 1127 (stating “[w]hile individuals with cognitive and intellectual disabilities tend to have preferences as to their daily living arrangements, they may need extensive support to understand the options they have relative to those preferences and to understand how to effectuate their wishes”).

ties are determined by the interaction between the individual's inherent abilities and the individual's environment,<sup>31</sup> so too are a person's decision-making abilities. For example, an individual may be able to assess options if another person helps them identify those options or helps them come up with a process for evaluating those options, but not be able do so without such assistance. For such individuals, the need for surrogate decision-making, including guardianship, can be avoided in whole or in part by the provision of support.

By reducing the need for guardianship, supported decision-making may improve the lives of individuals with disabilities. The ability to make decisions for oneself tends both to result in decisions that are more consistent with an individual's wishes and values and to increase an individual's perceived sense of control.<sup>32</sup> This sense of control, in turn, has been found to positively impact both physical and mental well-being.<sup>33</sup> The potential benefit of supported decision-making is likely to be especially pronounced for younger individuals with intellectual disabilities, as there has been a historical tendency of educators and attorneys to treat guardianship as a rite of passage for young adults with disabilities aging out of their minority status.<sup>34</sup> To the extent that supported decision-making processes also provide the opportunity for individuals to learn how to make their own decisions,<sup>35</sup> such processes may also enable younger adults to develop abilities they can use throughout their lives.

However, advocates for supported decision-making often describe it as not merely an alternative to guardianship, but as the antithesis of guardianship. One version of this description is to characterize guardianship as stripping individuals of all legal decision-making rights and supported decision-

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<sup>31</sup> For a discussion of disability as the interaction between the individual's abilities and their environment, see Carmelo Masala & Donatella Rita Petretto, *From Disablement to Enablement: Conceptual Models of Disability in the 20th Century*, 30 *DISABILITY & REHAB.* 1233, 1234 (2008). See also Saad Z. Nagi, *Disability Concepts Revisited: Implications for Prevention, in DISABILITY IN AMERICA: TOWARD A NATIONAL AGENDA FOR PREVENTION* 309, 325 (Andrew M. Pope & Alvin R. Tarlov eds., 1991).

<sup>32</sup> See Kohn, *Elder Empowerment*, *supra* note 6, at 27–29 (discussing the relationship between ability to make decisions—even inconsequential ones—and perceived sense of control).

<sup>33</sup> Social scientists have recognized the impact of perceived sense of control on well-being for generations. See *id.* at 3 (discussing this literature).

<sup>34</sup> Notably, this “tradition” has been facilitated in some states by specialized guardianship laws for individuals with intellectual or developmental disabilities that make it easier for guardianship to be granted over them relative to other individuals. See, e.g., ALA. CODE § 12-13-21 (2009); N.Y. SURR. CT. PROC. ACT § 1750 (2016); see also *In re Chaim A.K.*, 885 N.Y.S.2d 582, 585 (N.Y. Sur. Ct. 2009) (comparing Article 17-A guardianship and Article 81 guardianship in New York).

<sup>35</sup> Cf. Kristin Booth Glen, *Supported Decision-Making from Theory to Practice*, 13 *ALB. GOV'T L. REV.* 94, 120–23 (2020) [hereinafter Glen, *From Theory to Practice*] (describing the need for such education and how a pilot project helping individuals with disabilities enter into supported decision-making relationships is providing it).

making as allowing individuals to retain all legal decision-making rights.<sup>36</sup> This is inaccurate, at least in describing the U.S. guardianship system, because imposition of guardianship does not strip an individual of all legal decision-making rights. All U.S. states provide for limited guardianship, an arrangement in which the guardian is only given a subset of the powers available under state law.<sup>37</sup> In most, courts lack the authority to impose a full guardianship if a limited one is sufficient to meet an individual's identified needs.<sup>38</sup> In addition, all individuals subject to guardianship—even if the guardianship is plenary (or “full”)—retain certain legal rights, including the right to challenge the terms or conditions of the guardianship.<sup>39</sup> In some states, other rights—such as the right to vote,<sup>40</sup> marry,<sup>41</sup> or make a will<sup>42</sup>—are also retained even by persons subject to plenary guardianship.

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<sup>36</sup> See, e.g., Fiala-Butora & Stein, *supra* note 18, at 199–201 (acknowledging the existence of limited guardianship but nevertheless defining guardianship as if all guardianships are plenary).

<sup>37</sup> Unfortunately, not only is limited guardianship not the norm in practice, but limited guardianship also may not be available to all individuals in a state. New York's special procedure for granting guardianships over individuals with intellectual and developmental disabilities only provides for plenary guardianship. See N.Y. Surr. Ct. Proc. Act § 1750 (2016). As discussed in this section subsequently, this reality helps explain the critique of guardianship law.

<sup>38</sup> See Kohn & Koss, *supra* note 27, at 606–08; see also, e.g., ALASKA STAT. ANN. § 13.26.266 (West 2020) (prohibiting a guardianship plan from being more restrictive than reasonably necessary and limiting the duties or powers assignable to a guardian to those proven necessary with no less restrictive alternative available); FLA. STAT. ANN. § 744.3215 (West 2020) (requiring a guardianship order to be the least restrictive alternative and reserving to individuals subject to guardianship the right to make decisions in all matters in which they have the ability to do so, to remain as independent as possible, to access the court, and to counsel, among others); IDAHO CODE ANN. § 15-5-303 (West 2020) (stating that minimizing interference with the legal capacity of individuals subject to guardianship to act in their own behalf best fulfills the objectives of guardianship). Notably, this is also the approach taken by the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act. See UGCOPAA, *supra* note 4, at §§ 301, 401.

<sup>39</sup> See Kohn & Koss, *supra* note 27 (exploring the contours of the right to challenge the terms and conditions of guardianship and to legal representation to do so).

<sup>40</sup> See Sally Balch Hurme & Paul S. Appelbaum, *Defining and Assessing Capacity to Vote: The Effect of Mental Impairment on the Rights of Voters*, 38 McGEORGE L. REV. 931, 950 (2007) (finding that nineteen states had “specific provisions that persons under full or limited guardianship retain all legal and civil rights not specifically taken away, which at least by implication would include the right to vote” and that a careful reading of state guardianship laws suggests that in thirty-two states individuals subject to guardianship may be eligible to vote under at least some circumstances) (emphasis added).

<sup>41</sup> See, e.g., CAL. PROB. CODE § 1900 (West 2020) (stating that an individual subject to conservatorship retains the right to marry); MINN. STAT. ANN. § 524.5-120 (West 2020) (stating that an individual subject to guardianship may vote or marry unless these rights are explicitly restricted by the court).

<sup>42</sup> See, e.g., GA. CODE ANN. § 29-4-20 (West 2020) (stating that appointment of a guardian is not a determination of the right to vote or testamentary capacity); N.Y. MENTAL HYG. LAW § 81.29(b) (McKinney 2020) (stating that appointment of a guardian is not conclusive evidence that an individual lacks the capacity to dispose of property by will); OKLA. STAT. ANN. tit. 84, § 41(B) (West 2020) (stating that an individual subject to guardianship may execute a will if it is signed and acknowledged in the presence of a judge).

A second way supported decision-making is described as the antithesis of guardianship is that the former is described as involving individuals in decisions whereas guardianship is described as excluding the individual.<sup>43</sup> A version of this argument is to present supported decision-making as reflecting the person's wishes and preferences, and guardianship as reflecting the guardian's preferences and judgments about what is in the individual's best interest.<sup>44</sup> However, this description draws a false comparison. It is true that state laws historically permitted guardians to make decisions without meaningful involvement by the individual.<sup>45</sup> But the modern approach is to require guardians to make the decision the adult would have made if able (taking into account the adult's own preferences, wishes, and directions)<sup>46</sup> and to only deviate from doing so under very limited circumstances (such as where the surrogate cannot reasonably ascertain the adult's preferences or where making the decision the adult would have made would cause harm).<sup>47</sup> This at least implicitly requires the surrogate<sup>48</sup> to consult the individual,<sup>49</sup> and some states make this explicit. For example, under the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act ("UGCOPAA")—which has been enacted into law by Washington state<sup>50</sup> and Maine<sup>51</sup>—guardians are required to take reasonable efforts to ascertain

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<sup>43</sup> See, e.g., SHOGREN ET AL., *supra* note 19, at 105 (describing guardianship as not recognizing the temporal quality of decision-making challenges or the need for individualized support to enhance the individual's agency).

<sup>44</sup> See Arlene S. Kanter & Yotam Tolub, *The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law for People with Disabilities in Israel and Beyond*, 39 CARDOZO L. REV. 557, 596 (2017) (stating that in comparison to guardianship, the supported decision-model "is based on the individual's wishes and preferences, rather than what someone else (i.e., the court or the guardian) decides or considers to be in the person's 'best interests'").

<sup>45</sup> Cf. Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491, 1494–96 (2012) (discussing decision-making standards to which states held guardians).

<sup>46</sup> See Kohn, *Fiduciary*, *supra* note 27, at 258. This approach is commonly referred to as "substitute judgment" or "substituted judgment," which can lead to confusion as it is often mistakenly assumed to refer to the surrogate substituting his or her judgment for that of the principal.

<sup>47</sup> This trend in the United States increasingly governs guardianship law and the law governing powers of attorney for health care and finances. Federal surrogate decision-making programs, such as the representative payee program and the Department of Veterans Affairs fiduciary program, continue to allow for a less progressive form of decision-making. See *id.*

<sup>48</sup> By comparison, even the modern approach does not require third parties to engage with the individual subject to guardianship. Indeed, part of the indignity of guardianship is that it can lead third parties to treat the individual as a non-person—and to deal exclusively with the guardian even in the individual's presence. Thus, even if the guardian does an excellent job consulting with the individual and making decisions consistent with the individual's preferences and values, the individual may experience profound exclusion from the decision-making process.

<sup>49</sup> Indeed, it will generally not be possible for the surrogate to comply with this standard without such consultation.

<sup>50</sup> See UGCOPAA, *supra* note 4; WASH. REV. CODE ANN. §§ 11.130.005–.915 (West 2020).

<sup>51</sup> See Maine Uniform Guardianship, Conservatorship and Protective Proceedings Act, ME. REV. STAT. ANN. tit. 18-C, §§ 5-101–963 (West 2019).

current directions, preferences, opinions, values, and actions of the individual and must generally make decisions consistent with their findings.<sup>52</sup>

There are several factors that may causally contribute to these false comparisons. One is a failure to recognize the diversity within guardianship law in different countries. The international interest in guardianship has unfortunately led to a great deal of advocacy-oriented writing that speaks of guardianship in general and does not distinguish jurisdictions that have reformed their guardianship systems to, for example, require the use of limited guardianships, require guardians to take individuals' preferences into account, or impose guardianship based solely on functional need and not disability status. Thus, guardianship law frequently is critiqued without a recognition of the modern law reform efforts.

Another factor may be the disconnect between guardianship law on the books and guardianship law in practice. For example, all indications<sup>53</sup> are that plenary guardianships are substantially more common than limited ones in the United States,<sup>54</sup> even though plenary guardianships are almost never legally appropriate in the United States.<sup>55</sup> Moreover, while little is known about how guardians actually make decisions on behalf of individuals subject to guardianship,<sup>56</sup> it is likely that many guardians do not in fact meaningfully involve individuals subject to guardianship in the decisions that involve them. Another factor may be that the lack of plentiful data has led

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<sup>52</sup> See UGCOPAA, *supra* note 4, at § 313(d) (“In making a decision for an adult subject to guardianship, the guardian shall make the decision the guardian reasonably believes the adult would make if the adult were able unless doing so would unreasonably harm or endanger the welfare or personal or financial interests of the adult. To determine the decision the adult subject to guardianship would make if able, the guardian shall consider the adult’s previous or current directions, preferences, opinions, values, and actions, to the extent actually known or reasonably ascertainable by the guardian.”).

<sup>53</sup> Unfortunately, data on guardianship is woefully inadequate. See S. SPECIAL COMM. ON AGING, 115TH CONG., ENSURING TRUST: STRENGTHENING STATE EFFORTS TO OVERHAUL THE GUARDIANSHIP PROCESS AND PROTECT OLDER AMERICANS 6 (Comm. Print 2018), (“Few states are able to report accurate or detailed guardianship data, and figures related to the number of individuals subject to guardianship are largely unavailable.”); PAMELA B. TEASTER ET AL., WARDS OF THE STATE: A NATIONAL STUDY OF PUBLIC GUARDIANSHIP 15–16 (2005) (discussing research on guardianship).

<sup>54</sup> See also Lawrence A. Frolik, *Guardianship Reform: When the Best is the Enemy of the Good*, 9 STAN. L. & POLY REV. 347, 354 (1998) (arguing that “as long as the law permits plenary guardianship, courts will prefer to use it”); Nina A. Kohn & David English, *Protective Orders and Limited Guardianship: Legal Tools for Sidelining Plenary Guardianship*, SYRACUSE U. L. REV. (forthcoming 2022) (reviewing the evidence of the relative rates of use of plenary and full guardianships).

<sup>55</sup> Even an individual with profound limitations typically has the ability to make certain decisions. For example, a person with a profound intellectual disability or severe dementia may be able to make non-harmful decisions for themselves about daily activities such as with whom to spend time, what to eat, what to wear, or on what to spend non-essential amounts of money (i.e., amounts of money that will not affect individuals’ ability to meet their needs). And, with support, these abilities may expand substantially.

<sup>56</sup> See generally Lawrence A. Frolik & Linda S. Whitton, *The UPC Substituted Judgment/Best Interest Standard for Guardian Decisions*, 45 U. MICH. J.L. REFORM 739 (2012) (discussing the lack of information about how guardians actually make decisions).

some researchers describing guardianship to rely on studies that are decades old and thus, by definition, not reflective of changes in practice.<sup>57</sup>

Perhaps most fundamentally, however, these false comparisons appear to stem from a tendency to compare a descriptive account of guardianship with an idealized, normative account of supported decision-making. Guardianship is commonly described in terms of how it is *actually practiced*, whereas supported decision-making is described in terms of how it *should be practiced*.<sup>58</sup> The result is that scholars and researchers are comparing a descriptive model to a normative model. This leads to a false comparison and a very rosy picture of supported decision-making relative to guardianship. Supported decision-making is considered in its ideal state, without any problems associated with implementation or how it plays out in practice. Guardianship by comparison is evaluated in light of such real-life problems—and often problems that guardianship reform efforts are already working to address.

In actuality, supported decision-making and guardianship are not antithetical but rather approaches that lie along of a continuum of decision-making approaches. At one end of the spectrum (the “independent” end), decisions are exclusively those of the subject of the decision, and are unconstrained by the values, beliefs, or preferences of others. At the other end of the spectrum (the “controlled” end), decisions are exclusively those of someone other than the subject, and are unconstrained by the subject’s own preferences, beliefs, and values.<sup>59</sup> Decision-making approaches can be charted along this theoretical continuum. Guardianship would typically lie far toward the “controlled end,” with plenary guardianship farther toward that end than limited guardianships. By contrast, successful supported decision-making would lie near the middle point as it is would be neither independent nor controlled.<sup>60</sup>

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<sup>57</sup> For example, to describe the process by which guardians currently are appointed for adolescents with intellectual or development disabilities, in their 2019 book on supported decision-making, Shogren et al. rely almost exclusively on a study of court files of individuals with development disabilities for whom a guardian was appointed in Michigan between 1994 and 1999. See SHOGREN ET AL., *supra* note 19, at 147–50 (analyzing Dorothy Squatrito Millar, *Age of Majority, Transfer of Rights and Guardianship*, 38 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 378 (2003)). Yet substantial changes have been made since 1999, not only in the guardianship law, but also in societal and judicial attitudes towards disability.

<sup>58</sup> See, e.g., SHOGREN ET AL., *supra* note 19, at 5–15 (in a chapter comparing supported decision-making to guardianship, describing guardianship in terms of its practice—and primarily its worst-case practices—and supported decision-making as it aims to practice—e.g., as necessarily increasing control over a person’s life and helping people avoid isolation).

<sup>59</sup> Supporters of collective decision-making might argue that this continuum mirrors a continuum of “good” decision-making (which considers multiple inputs and perspectives) at one end, and “poor” decision-making (which considers only one viewpoint) at the other.

<sup>60</sup> For an alternative mapping of different models, see John Brayley, Chief Psychiatrist, Office of the Chief Psychiatrist, Supported Decision-Making in Australia 6 (Dec. 14, 2009) (on file with author) (mapping approaches based on the degree of “Autonomy and Self-determination” on one axis and “Increasing intervention by the State” and “Increasing care and protection” on the other).

Along the spectrum, decision-making approaches can overlap to some degree. For example, while a guardian could theoretically make a decision for an individual without consideration of that individual's values and preferences, guardians can be expected to consider such factors.<sup>61</sup> Indeed, laws enabling surrogate decision-making typically require surrogates to consider the individual's preferences and values,<sup>62</sup> and increasingly also require the surrogate to consult with the individual to ascertain those preferences and values.<sup>63</sup> In addition, supporters' preferences, values, and judgments are likely to influence the decisions of individuals to whom they provide support. Even if a supporter has no intention to influence, such factors will affect what information the supporter deems relevant to the individual's decisions, what options the supporter sees as viable possibilities, how the supporter analyzes those options, and even how the supporter might communicate the individual's decision.

In short, the fact that supported decision-making can be a viable alternative to guardianship does not mean it is the antithesis of guardianship. Rather, supported decision-making techniques may overlap with decision-making processes used by guardians.

### III. SUPPORTED DECISION-MAKING LEGISLATION IN THE UNITED STATES

The past several years have seen successful lobbying by disability-focused advocacy groups<sup>64</sup> and families of individuals with disabilities for legislation that recognizes and encourages supported decision-making. This Section provides a descriptive account of the resulting legislation. It then shows how this legislation is ultimately inconsistent with the supported decision-making model and may undermine its stated goals of empowering individuals with disabilities.

#### A. Overview of Supported Decision-Making Statutes

In 2015, Texas became the first U.S. state to formally recognize supported decision-making agreements when it adopted the Texas Supported Decision-Making Act.<sup>65</sup> As of March 2021, ten states and the District of Columbia had enacted statutes giving formal legal recognition to state-sanctioned

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<sup>61</sup> Indeed, they may be required to do so. *See supra* notes 46–52 and accompanying text.

<sup>62</sup> Kohn, *Fiduciary*, *supra* note 27, at 258.

<sup>63</sup> *Id.*

<sup>64</sup> Key players include federally-funded protection and advocacy systems and state councils on developmental disabilities, groups that advocate around disability rights and provide advocacy-related services to individuals with disabilities and their families.

<sup>65</sup> *See* Supported Decision-Making Agreement Act, TEX. EST. CODE ANN. § 1357.001–.102 (West 2019).

tioned supported decision-making agreements,<sup>66</sup> and similar legislation was pending in other states.<sup>67</sup>

Although, as discussed at length in Section V, there are many ways that states could recognize or foster supported decision-making, all of the existing legislation takes a particular approach: providing formal, legal recognition and status to formalized supported decision-making agreements. That is, they state that individuals may enter into an agreement with one or more other individuals to provide support, and that the resulting agreement will create certain legal rights or duties. This includes legal status to those identified as “supporters” in these formal agreements.<sup>68</sup> They typically also include a form that individuals can use to create a supported decision-making agreement,<sup>69</sup> and some states limit recognition of supported decision-making agreements to those that substantially comply with this form.<sup>70</sup>

These statutes have four major features with significant implications for the supported decision-making model.

### 1. *No or Minimal Rights for Individuals with Disabilities*

Despite being promoted as advancing the rights of individuals with disabilities, the first wave of supported decision-making statutes typically provide no rights or only *de minimis* rights to individuals with disabilities. Even when they explicitly state that their purpose is to allow the use of supported decision-making,<sup>71</sup> the statutes do not provide individuals with a right to use supported decision-making. This right exists independently. Even without a statute, all people have the right to use support to make decisions. Indeed, any attempt by the state to deny that right would be con-

<sup>66</sup> See Supported Decision-Making Agreements Act, ALASKA STAT. ANN. § 13.56.010–.195 (West 2020); Supported Decision-Making Act, DEL. CODE ANN. tit. 16, §§ 9401a–9410a (West 2020); D.C. CODE ANN. § 7-2131–2134 (West, through Feb. 3, 2021); IND. CODE ANN. §§ 29-3-14-1–13 (West 2020); Supported Decision-Making Agreement Act, LA. ACT 258 (2020); Supported Decision-Making Act, NEV. REV. STAT. ANN. § 162c.010–.300 (West 2020); N.D. CENT. CODE ANN. § 30.1-36-01 to 30.1-36-08 (West 2019); Supported Decision-Making Act, 42 R.I. GEN. LAWS ANN. §§ 42-66.13-1–10 (West 2020); Supported Decision-Making Agreement Act, TEX. EST. CODE ANN. § 1357.001–.102 (West 2019); Uniform Guardianship, Conservatorship, and Other Protective Agreements Act, WASH. REV. CODE ANN. § 11.130.001–.915 (West 2021); WIS. STAT. ANN. § 52.01–.32 (West 2019).

<sup>67</sup> See, e.g., H.B. 192, 191st Gen. Ct. (Mass. 2019).

<sup>68</sup> See *infra* notes 91–95 and accompanying text.

<sup>69</sup> See ALASKA STAT. ANN. § 13.56.180 (West 2020); R.I. GEN. LAWS ANN. § 42-66.13-10 (West 2020); TEX. EST. CODE ANN. § 1357.056 (West 2020); WASH. REV. CODE ANN. § 11.130.745 (West 2020); WIS. STAT. ANN. § 52.20 (West 2020).

<sup>70</sup> See ALASKA STAT. ANN. § 13.56.180 (West 2020); R.I. GEN. LAWS ANN. § 42-66.13-10 (West 2020); TEX. EST. CODE ANN. § 1357.056 (West 2020); WASH. REV. CODE ANN. § 11.130.745 (West 2020); WIS. STAT. ANN. § 52.20 (West 2020).

<sup>71</sup> See DEL. CODE ANN. tit. 16, § 9402A(a)(3) (West 2020) (listing as a purpose: “Enable supporters to assist in making and communicating decisions for the adult . . . .”); NEV. REV. STAT. ANN. § 162C.100(1)(c) (West 2020) (listing as a purpose: “Enable supporters to assist in making and communicating decisions . . . .”).



stitutionally suspect in light of the First Amendment's protections for freedom of speech and freedom of association.

Nor do the statutes give individuals the right to require third parties to accept their decisions, although supported decision-making legislation is sometimes said to be rights-creating because, even if it does not provide a right to *use* support, it gives individuals the right to have decisions made using support *recognized* by third parties. Yet, as appealing as this description may be, the statutes to date do not actually provide such a right. Rather, they incentivize such recognition by offering third parties immunity from claims that the individual with a disability could assert as an incentive for acting on a decision actually or allegedly made in accordance with supported decision-making.<sup>72</sup> This type of immunity may have the impact of encouraging third parties to recognize the decisions of individuals with disabilities—but it is actually a removal of rights from such individuals, not a grant of new rights.

In most states, the only right that supported decision-making statutes actually affirmatively grant individuals being supported is the right to have their information kept confidential by supporters.<sup>73</sup> Under such circumstances, to describe the legislation as creating rights, as is commonly done,<sup>74</sup> is at best misleading.<sup>75</sup>

The most meaningful right granted to individuals with disabilities in one of these supported decision-making statutes is the right to a fiduciary level of care from the supporter.<sup>76</sup> Specifically, Texas grants an individual

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<sup>72</sup> See *infra* note 96 and accompanying text.

<sup>73</sup> See ALASKA STAT. ANN. § 13.56.120 (West 2020) (supporter required to keep information confidential and to protect it “from unauthorized use, access, or disclosure” and to “dispose of it properly when appropriate”); DEL. CODE ANN. tit. 16, § 9409A (West 2020) (supporter must keep information collected on behalf of an individual privileged and confidential and properly dispose of when appropriate); NEV. REV. STAT. ANN. § 162C.220 (West 2020) (supporter must keep information collected on behalf of an individual privileged and confidential, protect it against unauthorized access, use or disclosure, and properly dispose of it when appropriate); N.D. CENT. CODE ANN. § 30.1-36-06 (West 2019) (supporter may not allow unauthorized access, use or disclosure of confidential information unless the supported person directed otherwise); R.I. GEN. LAWS ANN. § 42-66.13-8(b) (West 2020) (supporter required to keep information obtained on behalf of the individual privileged and confidential); TEX. EST. CODE ANN. § 1357.054 (West 2019) (supporter shall insure personal information that the supporter helped obtain or access is kept privileged and confidential and not subject to unauthorized access, use, or disclosure).

<sup>74</sup> Sometimes these statutes are described as granting individuals with disabilities the “right” to choose to have their decisions communicated and accepted when mediated through a supporter. This may well be the intent of many of those advocating in favor of the statutes, but it is an inaccurate description because the person given a new legal entitlement is the supporter, not the individual with the disability. The individual with the disability is, at most, the beneficiary of the new right of the supporter.

<sup>75</sup> For a discussion of the dangers of enforced privacy of disability-related information, see generally Jasmine Harris, *Taking Disability Public*, 169 U. PA. L. REV. (forthcoming 2021).

<sup>76</sup> The failure of other states to classify the relationship as fiduciary should not be assumed to be an oversight. Rather, some advocates have explicitly opposed requiring a fiduciary level of care out of concern that it would deter individuals from serving as supporters, thus limiting the available pool of supporters.

who has entered into a formal supported decision-making agreement the right to a fiduciary level of care from supporters.<sup>77</sup> Thus, in Texas,<sup>78</sup> the supporter owes individual fiduciary duties as listed in the agreement (which include acting in good faith, with loyalty and without self-interest, and avoiding conflicts of interest).<sup>79</sup> This statutory language is rights-enhancing because without it, whether a fiduciary relationship existed would be an issue of fact and thus less certain.<sup>80</sup> Still, this right—albeit valuable—is hardly revolutionary or paradigm-shifting; after all, guardians have long been recognized to be fiduciaries.<sup>81</sup> It certainly falls well short of the type of robust rights suggested by the full-throated language of rights used to advance supported decision-making statutes.

## 2. *Limitations on the Rights of Individuals with Disabilities*

The first wave of supported decision-making statutes also tend to place significant limitations on the rights of individuals with disabilities. One common limitation is that states restrict the way in which the individual may revoke the agreement.<sup>82</sup> For example, Alaska requires the individual to terminate the agreement in the presence of two witnesses or have the termination notarized; in addition, the supporter must be notified in person, by certified mail, or by electronic means.<sup>83</sup> Similarly, Indiana, Rhode Island, and Louisiana require revocation to be in writing, and Indiana and Louisiana require that supporters be provided with a copy.<sup>84</sup> Other restrictions on revocation are less demanding, but still place limitations that would not otherwise exist absent the agreement.<sup>85</sup>

Many of the statutes also limit the privacy rights of the individuals with disabilities by requiring third parties to divulge otherwise confidential infor-

<sup>77</sup> TEX. EST. CODE ANN. § 1357.052(b) (West 2019).

<sup>78</sup> By contrast, Indiana's statute strongly implies that the supporter is a fiduciary as it deems the relationship to be one of "trust and confidence" and requires the supporter to "act honestly, diligently, and in good faith" and "avoid conflicts of interest." However, that statute effectively negates the duty by then making the supporter immune from liability if the supporter "perform[ed] supported decision making in good faith." Compare IND. CODE ANN. § 29-3-14-5 (West 2020), with IND. CODE ANN. § 29-3-14-11 (West 2020).

<sup>79</sup> TEX. EST. CODE ANN. §§ 1357.052(b); 1357.056 (West 2019). Texas further stipulates that supported decision-making creates a relationship that is one of "trust and confidence." *Id.* § 1357.052(c)(1).

<sup>80</sup> Cf. Daniel B. Kelly, *Fiduciary Principles in Fact-Based Fiduciary Relationships*, in OXFORD HANDBOOK OF FIDUCIARY LAW 9–11 (Robert Sitkoff et al. eds., 2019) (discussing fact-based fiduciary relationships).

<sup>81</sup> See Kohn, *Fiduciary*, *supra* note 27, at 250–51.

<sup>82</sup> Without such restrictions, individuals would be free to terminate the relationship in any manner of their choosing.

<sup>83</sup> ALASKA STAT. ANN. § 13.56.080 (West 2020).

<sup>84</sup> IND. CODE ANN. § 29-3-14-8 (West 2019); 42 R.I. GEN. LAWS ANN. § 42-66.13-5(g) (West 2019); 2020 La. Acts 258.

<sup>85</sup> NEV. REV. STAT. ANN. § 162C.200(3) (West 2021) (requiring notice, which can be oral, to supporters for revocation); N.D. CENT. CODE ANN. § 30.1-36-05(1) (2019) (requiring notice, which can be provided in various ways, to the supporter for revocation).

mation about the individuals. Specifically, several states subject those who enter into supported decision-making agreements to mandatory reporting for suspected abuse or exploitation.<sup>86</sup> This effectively limits the extent to which such individuals can engage in confidential relations with others (e.g., their doctor, lawyer, priest, etc.).<sup>87</sup>

Yet another limitation is more subtle: many of the statutes limit the degree of care the supporter is required to use<sup>88</sup>—thus preventing the individual from holding the supporter to a fiduciary level of care. Without this limitation, whether the supporter would have a fiduciary relationship with the principal would likely be a matter of fact—to be considered in light of the relationship.<sup>89</sup> North Dakota goes even further in limiting accountability, granting supporters immunity for negligence claims brought by the individual being supported.<sup>90</sup>

### 3. *Legal Rights for Supporters*

Although they create minimal or no rights for people being supported, the majority of state supported decision-making statutes do create new legal rights for *supporters*. This is deliberate, as indicated by several of these statutes including language stating that one of their purposes is to provide sup-

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<sup>86</sup> IND. CODE ANN. § 29-3-14-13 (West 2021) (stating that a person who knows of the agreement or receives a copy of it must report if the person reasonably believes that the individual is being abused, exploited, or neglected, even if the supporter is not the suspected perpetrator); R.I. GEN. LAWS ANN. § 42-66.13-9 (West 2020) (stating that any person who is aware of an agreement or receives a copy of it must report abuse, neglect, or exploitation); TEX. EST. CODE ANN. § 1357.102 (West 2019) (requiring a person who receives a copy of the agreement or is aware of its existence to report alleged abuse, neglect, or exploitation by the supporter).

<sup>87</sup> See generally Nina A. Kohn, *Outliving Civil Rights*, 86 WASH. U. L. REV. 1053 (2009) (discussing the practical and constitutional concerns associated with such mandatory reporting schemes).

<sup>88</sup> ALASKA STAT. ANN. § 13.56.090 (West 2020) (adopting an ordinary care standard: “A supporter shall act with the care, competence, and diligence ordinarily exercised by individuals in similar circumstances.”); DEL. CODE ANN. tit. 16, § 9406A(d) (West 2021) (requiring supporters to use the “care, competence, and diligence ordinarily exercised by individuals in similar circumstances,” taking into account special skills or expertise); IND. CODE ANN. § 29-3-14-11 (West 2021) (stating that supporters are not liable if they “perform[ed] supported decision making in good faith”); R.I. GEN. LAWS ANN. § 42-66.13-6 (West 2019) (requiring the supporter to use “care, competence, and diligence ordinarily exercised by individuals in similar circumstances”); WIS. STAT. ANN. § 52.30(8) (West 2020) (“A supporter acting in the context of a valid supported decision-making agreement is immune from civil liability for his or her acts or omissions in performing duties as the supporter if he or she performs the duties in good faith, in conformance with the supported decision-making agreement or document of the adult with a functional impairment, and with the degree and prudence that an ordinarily prudent person exercises in his or her own affairs.”).

<sup>89</sup> See Kelly, *supra* note 80, at 9–11 (describing the various factors courts employ to assess whether a relationship of trust and confidence is a fact-based fiduciary relationship).

<sup>90</sup> N.D. CENT. CODE ANN. § 30.1-36-03 (West 2021) (“A supporter is not liable to the named individual and has not engaged in professional misconduct for acts performed as a supporter in good faith unless the supporter has been recklessly or grossly negligent or has intentionally committed misconduct.”).

porters “legal status.”<sup>91</sup> For example, three states give the supporter legal standing to enforce a decision made by the individual.<sup>92</sup> Neither the individual’s involvement or consent is needed to proceed with such enforcement.<sup>93</sup> Similarly, several states effectively allow the supporter to enforce decisions by preventing third parties from refusing to rely on the agreement<sup>94</sup> (e.g., by refusing to recognize a decision stated by the supporter as a decision by the principal), or by requiring such reliance except under limited circumstances.<sup>95</sup>

#### 4. *New Rights for Third Parties*

State supported decision-making statutes also typically create new rights for third parties interacting with people with disabilities. Specifically, the statutes commonly provide that those who rely on the agreement are immune from claims of civil or criminal liability or professional misconduct except under limited circumstances.<sup>96</sup> Historically,<sup>97</sup> such immunity was lim-

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<sup>91</sup> See DEL. CODE ANN. tit. 16, § 9402A (West 2021) (stating that a purpose is to “[g]ive supporters legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information”); NEV. REV. STAT. ANN. § 162C.100(1)(b) (West 2021) (stating that an enumerated purpose of the Act is to “[g]ive supporters legal status to be with [the] adult and participate in discussions with others when the adult is making decisions or attempting to obtain information”); R.I. GEN. LAWS ANN. § 42-66.13-2(a)(2) (West 2020) (stating that a purpose is to “[g]ive supporters legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information”).

<sup>92</sup> See ALASKA STAT. ANN. § 13.56.130 (West 2020) (providing for the supporter to independently enforce the principal’s decision); DEL. CODE ANN. Tit. 16, § 9407A (West 2021) (providing for the supporter to independently enforce the principal’s decision); NEV. REV. STAT. ANN. § 162C.310 (West 2021) (providing that the supporter may independently enforce a decision).

<sup>93</sup> See *id.*

<sup>94</sup> See TEX. EST. CODE ANN. § 1357.101(a) (West 2019) (requiring reliance on the agreement and not providing for exceptions).

<sup>95</sup> See N.D. CENT. CODE ANN. § 30.1-36-08 (West 2021) (requiring third parties to rely on the agreement unless there is cause to believe the supporter is abusing, neglecting or exploiting the individual, or has actual knowledge the agreement is invalid, or has actual knowledge or notice it is terminated); D.C. CODE ANN. § 7-2133(d) (West 2021) (requiring a third party who receives the agreement to rely on the agreement unless there is substantial cause to believe that the supported person is in need of protective services).

<sup>96</sup> ALASKA STAT. ANN. § 13.56.140 (West 2020) (stating that third parties are not civilly or criminally liable and have not engaged in professional misconduct for relying in good faith on an agreement assumed to be valid); D.C. CODE ANN. § 7-2133(e) (West 2021) (stating that third parties are not civilly or criminally liable and have not engaged in professional misconduct for acts done in good faith and in reasonable reliance on an agreement); IND. CODE ANN. §§ 29-3-14-10; 29-3-14-11 (West 2021) (stating that a third party may rely on an agreement unless the third party has actual knowledge that the agreement not valid, and is not criminally or civilly liable or subject to professional discipline for good faith reliance on or rejection of an agreement); NEV. REV. STAT. ANN. § 162C.320 (West 2021) (stating that persons who rely on an agreement in good faith, without actual knowledge that it is void, invalidated, or terminated, are protected from all liability and discipline for giving effect to the agreement or from “following the direction of a supporter named in the supported decision-making agreement”); N.D. CENT. CODE ANN. § 30.1-36-08 (West 2021) (making third parties immune from civil or criminal liability or professional misconduct for relying in good faith on a supported decision-

ited to those who act as “Good Samaritans” by engaging in well-meaning acts to help others that they have no duty to otherwise do. Here, the immunity can extend to those who have existing duties of care, and prevents them from being held accountable.<sup>98</sup>

In short, in the majority of states, supported decision-making statutes provide individuals with disabilities no substantial rights beyond those that they would have in the absence of such statutes, and remove certain rights (e.g., to revoke the agreement, to a fiduciary level of care, to privacy) that the individual might otherwise have. By contrast, the statutes provide supporters and third parties with new rights they would not otherwise possess. As discussed in the next subsection, these new rights for supporters and third parties have the effect of further limiting the rights of the individual being supported.

### B. *The Adverse Consequences of the Dominant Approach*

The previous subsection described supported decision-making legislation in the United States. This subsection now explains how that approach undermines the commonly stated goals of supported decision-making, and consequently disempowers individuals with disabilities and puts them at heightened risk. Specifically, it shows that by giving rights to supporters, protecting third parties who unreasonably rely on supporters’ statements, and otherwise limiting the rights of individuals with disabilities, the new wave of state supported decision-making statutes disempowers individuals with disabilities, increases the risk of exploitation, and compounds existing stereotypes.

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making agreement); TEX. EST. CODE ANN. § 1357.101(b) (West 2019) (making third parties immune from civil or criminal liability or professional misconduct for acts done in good faith and in reliance on a supported decision-making agreement); WIS. STAT. ANN. § 52.30 (West 2019) (making third parties who are not health care providers immune from criminal liability, civil liability, and professional discipline if they rely in good faith on a supported decision-making agreement).

<sup>97</sup> Notably, extensions of immunity to those not acting as Good Samaritans, but rather engaged in professional duties, have become a common policy response amid the COVID-19 pandemic, despite the objections of advocates for vulnerable populations. *See* Nina A. Kohn & Jessica Roberts, *Nursing Homes Need Increased Staffing, Not Legal Immunity*, HILL (May 23, 2020), <https://thehill.com/opinion/healthcare/499286-nursing-homes-need-increased-staffing-not-legal-immunity> [https://perma.cc/3SMB-MNMK].

<sup>98</sup> The immunity granted by the statutes adopted to date extends even beyond protecting third parties from claims that they should not have acted upon a decision made by the individual because the individual lacked capacity.

### 1. *Consequences for Individual Empowerment*

One of the primary—if not the primary—stated goals of supported decision-making is to empower individuals with disabilities.<sup>99</sup> Yet the statutes currently proliferating in the United States tend to do the opposite.

Perhaps the most disempowering provisions in the new wave of statutes are those that permit a person named as “supporter” to enforce a decision independently.<sup>100</sup> In other words, the individual being supported does not need to be involved in the enforcement of the decision. Consequently, these provisions may empower a supporter to require third parties to act on decisions with which the individual being supported may no longer agree. Because the individual’s involvement is not necessary for enforcement, the individual may have no awareness that the supporter is enforcing a decision the individual had made at one point in time and thus may be neither triggered to reconsider the decision nor have any reason to articulate a change to the supporter. Thus, individuals may effectively lose the ability to change their mind and have others act on the change of mind.<sup>101</sup>

Even in situations in which the individual makes decisions based on his own free will, the ability for the supporter to enforce the decision independently creates an opportunity for the supporter to exert significant control over the individual. Imagine, for example, that the supporter dislikes one of the individual’s best friends. The individual, perhaps after getting into a disagreement with the friend, tells the supporter he no longer wishes to see the friend. The supporter can then take action independently to prevent future visits, such as by blocking the friend’s phone number, unfriending the friend on social media, or informing the friend that visits with the individual are prohibited. Unless the individual affirmatively notifies the supporter that he has changed his mind, the supporter is free to continue to block access to the friend—preventing the individual from reconciling with the friend as one might otherwise naturally do.

Under these provisions, supporters are also effectively free to enforce decisions that the individual did not make independently, but rather as a

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<sup>99</sup> See, e.g., Dari Pogach, *COLA Explores Supported Decision-Making in 2019*, 41 BIFOCAL 181, 181 (2019) (“Supported decision-making empowers individuals who historically have been denied the right to make their own choices, including people with disabilities and older adults, to make decisions with the support of trusted individuals.”); Wright, *Dementia*, *supra* note 22, at 258–262 (describing supported decision-making as “an alternative decision-making model . . . which empowers persons with cognitive impairments to make their own decisions”).

<sup>100</sup> See *supra* notes 92–94 and accompanying text.

<sup>101</sup> In this regard, formalized supported decision-making agreements pose a similar risk to a durable power of attorney, a surrogate decision-making tool that has been so widely abused that it is often referred to as a “license to steal.” See generally Kohn, *Elder Empowerment*, *supra* note 6 (outlining the risks of abuse). Yet, unlike with a power of attorney, there is no capacity requirement to execute an agreement, and—in most states—no fiduciary duty. Thus, there is a similar risk with fewer protections to prevent that risk from materializing, and comparatively less legal recourse when it does.

result of the supporters' efforts to encourage a particular decision. Again, imagine a situation where the supporter believes that the individual should not associate with a particular friend. The individual disagrees. But the supporter keeps bringing up the issue until one day, perhaps again after a disagreement with the friend, the individual says he does not want to see the friend again. The supporter can now act to enforce that decision as in the previous example. In short, the supporter can continually prompt reconsideration of an issue and, once the individual comes to the decision the supporter wanted her to make, the supporter can drop the issue and ossify the decision going forward.

## 2. *Consequences for Abuse and Exploitation*

Another commonly stated goal of those advocating for supported decision-making statutes is to protect individuals with disabilities from abusive and exploitative guardianship. Yet, an analysis of the resulting statutes suggests they will actually place such individuals at increased risk of exploitation. This is because the statutes give supporters power, but do not provide any meaningful check on that power.

By giving legal status to supporters, statutes provide supporters with new tools that can be used to control and exploit individuals with disabilities. In many states, for example, a supporter who claims that an individual made a decision that was in fact not made, or which was the result of undue influence, can require third parties to adhere to that decision.<sup>102</sup> For example, a person named as a supporter could, acting in bad faith, insist that third parties act on "decisions" that benefit the supporter, financially or emotionally. Not only is there unlikely to be an opportunity to discover the misrepresentation, but third parties face potential liability for acting even on actual suspicion of misrepresentation.<sup>103</sup> Thus, third parties are incentivized not to question decisions articulated or enforced by the supporter, even when suspicious of their legitimacy.

Although individuals are legally free to end supported decision-making relationships, this "out" is unlikely to provide adequate protection for many. For example, a supporter acting in bad faith may continue to use a copy of the agreement after the supported decision-making relationship terminates to coerce third parties to listen to—and in many states to act based on—the supporter's claimed articulation of the individual's wishes.<sup>104</sup> Moreover, the

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<sup>102</sup> See *supra* notes 92–94 and accompanying text.

<sup>103</sup> This may be true even in situations where the third party has a duty to report that suspicion. For example, in Indiana, a third party is immune from civil liability, criminal liability, and professional discipline for good-faith reliance on an agreement. See IND. CODE ANN. § 29-3-14-11 (West 2021). This immunity applies even in situations where Indiana law might require reporting. See *id.* § 29-3-14-13.

<sup>104</sup> Indeed, it could continue long, long after the decision was made as supported decision-making agreements are in effect until revoked and do not automatically terminate. See *supra* notes 82–85 and accompanying text.

individual may be dependent on the support and thus not be in a position to terminate the agreement without significant repercussions. In addition, some states' revocation procedures may not be feasible for individuals with limited cognitive or physical abilities. For example, the individual may not be able to produce the type of writing required by statute, or to complete the steps necessary (e.g., proper notification or notarization) to make the revocation valid.

Similarly, the fact that abuse and exploitation is inconsistent with supporters' statutory or ethical obligations is unlikely to provide meaningful protection. Individuals who truly need decision-making support are likely not in a position to identify or report abusive behaviors.<sup>105</sup> Even when they are, there may not be a way to remedy the situation because many decisions are not reversible. For example, the supporter may have already spent the individual's money, caused an opportunity to be missed, or subjected the individual to a particular treatment. In addition, many of the statutes deny individuals with disabilities the ability to use the legal system to secure compensation for exploitation because they offer immunity to supporters and to third parties who rely on supporters' misrepresentations,<sup>106</sup> or limit the duty of care required.<sup>107</sup>

Indeed, the risks created by such statutes mirror the risks that guardianship reformers have worked for generations to minimize. Guardianship reform has focused on increasing accountability for guardians instead of simply "tak[ing] the words of guardians . . . without independent checking;" creating minimum standards for character and training of guardians; and creating processes that individuals subject to abusive guardianship can use to get help.<sup>108</sup>

Yet the current wave of supported decision-making statutes does not incorporate or build upon these important checks and safeguards that are now commonly built into guardianship laws. For instance, the supported decision-making statutes do not impose any meaningful limitations on the character of those who serve as supporters or mandate any minimum training requirements.<sup>109</sup> Nor do they provide clear avenues for individuals who have

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<sup>105</sup> Individuals with cognitive disabilities have been found to underreport abuse in other contexts, even if they have access to people to whom they could report. See generally M.D. Gil-Llario et al., *Prevalence and Sequelae of Self-Reported and Other-Reported Sexual Abuse in Adults with Intellectual Disability*, 63 J. INTELL. DISABILITY RSCH. 138 (2019).

<sup>106</sup> See *supra* notes 72–78 and accompanying text.

<sup>107</sup> See *supra* notes 88–90 and accompanying text (discussing how some statutes specifically preclude holding supporters to a fiduciary standard of care).

<sup>108</sup> Sally Balch Hurme & Erica Wood, *Guardianship Accountability Then and Now: Tracing Tenets for an Active Court Role*, 31 STETSON L. REV. 867, 868–69 (2002) (discussing historical trends in guardianship reform, including accountability mechanisms and training for guardians). See also STAFF OF H. COMM. ON AGING, 100TH CONG., REP. ON ABUSES IN GUARDIANSHIP OF THE ELDERLY AND INFIRM: A NATIONAL DISGRACE 7 (Comm. Print 1987) (identifying key guardianship reform objectives).

<sup>109</sup> By contrast, proposed legislation in New York State would like legal recognition of supported decision-making relationships to training for those who enter into them.



supporters to seek relief from abuse; instead, many create barriers to revoking supported decision-making agreements.<sup>110</sup> In addition, they typically require third parties to take the word of “supporters” without any opportunity for independent fact checking.<sup>111</sup> Thus, while supported decision-making statutes are touted as rights-enhancing and empowering for individuals with disabilities, they may, as a practical matter, not represent a novel approach to decision-making but rather a return to the practices that have been long rejected in the guardianship context as unduly risky.<sup>112</sup>

### 3. *Expressive Consequences*

One commonly cited benefit of formalized supported decision-making laws is that they “normalize” the idea that decisions made with support are valid decisions.<sup>113</sup> In reality, however, the current wave of legislation sends the opposite signal. It suggests that certain individuals are not capable of making decisions without a structured system of support and, more perniciously, are unable to make a decision without a formal supported decision-making agreement in place. Indeed, perhaps the most powerful critique the author has heard of supported decision-making was expressed by an individual with an intellectual disability who was very concerned that if her state adopted a proposed supported decision-making statute, those she interacted with (including doctors) would be less willing to listen to her voice and would expect her to have a supporter with her when making decisions.

Of course, one could argue that these laws advance supported decision-making by expressing support for it. A law can have expressive value even if it does not achieve its ends.<sup>114</sup> For example, as Cass Sunstein noted, “a society might, for example, insist on an antidiscrimination law for expressive reasons even if it does not know whether the law actually helps members of minority groups.”<sup>115</sup> However, a law cannot necessarily be justified on expressive grounds if it also functions to undermine its purported ends. Even those who see a very large role for the expressive function of the law do not take it so far as to conclude that legislation has expressive value when in practice it undermines the values it claims to support. For example, Sun-

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<sup>110</sup> See *supra* notes 82–84 and accompanying text.

<sup>111</sup> See *supra* notes 92–93 and accompanying text.

<sup>112</sup> These provisions are often promoted as a way to ensure that decisions can be communicated effectively even though the individual may use non-traditional means of communication or cannot easily be understood by third parties. However, the provisions are not limited to this situation.

<sup>113</sup> See, e.g., Wright, *Dementia*, *supra* note 22, at 306 (arguing that formalization is “necessary” and suggesting that one reason for this necessity is that formalization will encourage “routine practice of supported decisionmaking,” even for persons without cognitive impairments).

<sup>114</sup> See Cass R. Sunstein, *On the Expressive Function of Law*, 144 U. PA. L. REV. 2022, 2027–28 (1996).

<sup>115</sup> *Id.*

stein's writing does not contemplate expressive value for law that would harm minority groups.

### C. *Factors Shaping the Legislative Response*

As the prior subsections show, U.S. supported decision-making statutes, albeit to varying degrees, have created systems that are antithetical to both the rights of persons with disabilities and the conceptual basis of supported decision-making. This Section shows how the underlying ideology and the political environment that has shaped the legislative response has led to this perverse result.

#### 1. *Mounting Criticism of Guardianship*

The rapid proliferation of supported decision-making language is fueled by growing criticism of the guardianship system and its implications for the rights of persons with disabilities. Critics correctly point out that guardianships are imposed where not necessary, and thus unjustifiably deny individuals of their fundamental rights and liberties;<sup>116</sup> that plenary guardianships are granted when limited ones would be sufficient to meet an individual's needs;<sup>117</sup> and that guardians may abuse their authority, not only through outright exploitation and abuse, but also by making decisions that are inconsistent with the individual's values and reasonable preferences.<sup>118</sup> In addition, guardianship is criticized as anti-therapeutic,<sup>119</sup> and as stifling the development of an individual's capabilities, sense of self, and underlying physical and psychological well-being by reducing their sense of control over their own lives.<sup>120</sup> There is even a growing moral critique of guardianship as a violation of fundamental human rights.<sup>121</sup>

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<sup>116</sup> Indeed, the author has made this point in her own work. See, e.g., Kohn & English, *supra* note 54 (discussing the problem with unnecessary and overbroad guardianships and proposing reforms to curtail their use).

<sup>117</sup> See Frolik, *supra* note 54, at 354 (discussing the fact that plenary guardianship is commonly ordered even when limited guardianship would be appropriate); Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 233 (2007) (finding as part of a national study that "[c]ourts rarely appoint the public guardian as a limited guardian").

<sup>118</sup> See UGCOPAA, *supra* note 4, at § 313 (requiring guardians to consider the individual's values and preferences).

<sup>119</sup> See generally Jennifer Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J.L. & PSYCHIATRY 350 (2010) (discussing ways in which guardianship may be anti-therapeutic) [hereinafter Wright, *Guardianship for Your Own Good*].

<sup>120</sup> See *id.* at 355–56 (critiquing guardianship as harming individuals subject to guardianship by reducing their sense of control).

<sup>121</sup> Michael Bach, Canadian Ass'n for Cmty. Living, Presentation at Seventh Session of the United Nations Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities (Jan. 2006), <http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii3.ppt> [https://

Supported decision-making legislation is touted as a solution to the “problem” of guardianship. An excerpt from a “Fact Sheet” on pending legislation to recognize supported decision-making agreements in Massachusetts is representative of the rhetoric employed:

**THE NEED:** Too many people are unnecessarily placed under restrictive guardianships when they would be able to make their own decisions if they received individualized assistance from people they trust, allowing them to retain their legal rights and dignity.

**THE SOLUTION:** Supported decision-making.<sup>122</sup>

Beyond legitimate critiques of guardianship, supported decision-making legislation is also buoyed by a variety of inaccurate descriptions of guardianship. In addition to those discussed in Section II.C, some critiques incorrectly suggest that guardianship can be imposed on an individual “simply because of a disability” and thus that guardianship fails to recognize the more modern understanding that individuals’ abilities depend on the interaction between them and their environment.<sup>123</sup> Yet, as noted previously, modern guardianship laws generally require courts to assess individuals’ functional abilities and not to impose a guardian based on the status of being disabled.<sup>124</sup>

Notably, the argument that supported decision-making should replace guardianship is fueled in part by the United Nations’ adoption of the Convention on the Rights of Persons with Disabilities (“CRPD”).<sup>125</sup> The CRPD, adopted in 2006, embraces the use of supported decision-making; it states that “persons with disabilities enjoy legal capacity on an equal basis with others” and requires signatories to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”<sup>126</sup> Many within the disability rights community (especially outside the United States)—as well as the United Nations’ Com-

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perma.cc/SD8G-BFKU] (categorizing guardianship as “[s]tate-sanctioned removal of personhood”).

<sup>122</sup> MASS. ADVOCS. FOR SUPPORTED DECISION-MAKING, AN ACT RELATIVE TO SUPPORTED DECISION-MAKING AGREEMENTS FOR CERTAIN ADULTS WITH DISABILITIES (2020), <https://supporteddecisions.org/resources/fact-sheet-on-mass-sdm-bill-s-64-h-172/sdm-bill-fact-sheet-h43-49-s-2490-3-11-2020/> [<https://perma.cc/7BWZ-FLDQ>] [hereinafter Massachusetts SDM Fact Sheet].

<sup>123</sup> See, e.g., SHOGREN ET AL., *supra* note 19, at 107 (“One fundamental and flawed assumption of guardianship models is that decision-making skills are static and that taking away a person’s right to engage in legal and fiduciary principles is appropriate simply because of the presence of a disability. This approach does not consider a socio-ecological perspective.”).

<sup>124</sup> AM. BAR ASS’N COMM’N ON L. & AGING, CAPACITY DEFINITION & INITIATION OF GUARDIANSHIP PROCEEDINGS (2020), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/chartcapacityandinitiation.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/chartcapacityandinitiation.pdf) [<https://perma.cc/RMJ8-V45F>] (indicating what must be shown in each state in order to impose a guardianship, current as of August 2020).

<sup>125</sup> See *id.* (“The rise in knowledge and use of supported decision-making may be traced, in large part, to the [CRPD]”).

<sup>126</sup> G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, at 9 (Jan. 24, 2007) [hereinafter CRPD].

mittee on the Rights of Persons with Disabilities<sup>127</sup>—interpret Article 12 as demanding the embrace of supported decision-making and precluding the use of guardianship or at least plenary forms of guardianship.<sup>128</sup>

Finally, the popularity of the legislation that grants formal legal status to supported decision-making agreements and appointed supporters appears to reflect confusion as to the scope of individuals' existing rights. Formalization is often presented as necessary to enable individuals with disabilities to use supported decision-making.<sup>129</sup> For example, a fact sheet describing pending formalization legislation in Massachusetts states that the bill would “allow people with disabilities and elders to enter into an SDM agreement with people they trust.”<sup>130</sup> Likewise, several states' statutes state that their purpose is to allow the use of supported decision-making.<sup>131</sup> Of course, this is not necessary. Each of us—whether we have a disability or do not—has a right to ask others for help in making decisions and a right to use that help. No statute is needed to create such a right. Indeed, as previously noted, any attempt by the state to deny that right would be constitutionally suspect in

<sup>127</sup> In 2014, the Committee adopted a General Comment on Article 12 that declared that states had misunderstood Article 12, reflecting “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.” See Comm. on the Rights of Persons with Disabilities, General Comment No. 1: Article 12: Equal Recognition Before the Law, ¶3, U.N. Doc. CRPD/C/GC/1 (May 19, 2014). This “interpretation” is not defensible; however, a discussion of the proper interpretation is outside the scope of this article and the fact that it is not defensible does not necessarily blunt its rhetorical force.

<sup>128</sup> See ARLENE S. KANTER, *THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO HUMAN RIGHTS* 235–78 (2014) (taking the view that Article 12 requires “the end of guardianship laws, as we know them”); Barbara Carter, *Adult Guardianship: Human Rights or Social Justice?*, 18 J.L. & MED. 143, 143–55 (2010) (describing the debate over whether guardianship is permitted under Article 12); 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, 460–62 (2007) (interpreting Article 12 as precluding guardianship although acknowledging that the text does not do so); Michael L. Perlin, ‘*Striking for the Guardians and Protectors of the Mind*’: *The Convention on the Rights of Persons With Mental Disabilities and the Future of Guardianship Law*, 117 PENN ST. L. REV. 1159, 1176–77 (2013) (“The Convention forces us to abandon substituted decisionmaking paradigms and to replace them with supported decisionmaking ones.”); TINA MINKOWITZ, SUBMISSION TO THE COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES, DAY OF GENERAL DISCUSSION ON CRPD ARTICLE 12 (2010) (declaring guardianship to be contrary to the CRPD); cf. Dinerstein, *supra* note 14 (discussing different countries' responses to Article 12 in relation to guardianship).

<sup>129</sup> See, e.g., Rebekah Diller, *Legal Capacity for All: Including Older People in the Shift From Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L.J. 495, 518 (2016) (describing Texas's then-newly adopted Supported Decision-Making Act, stating “[t]he 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>130</sup> Massachusetts SDM Fact Sheet, *supra* note 122.

<sup>131</sup> See DEL. CODE ANN. tit. 16, § 9402A(a)(3) (West 2021) (listing as a purpose: “Enable supporters to assist in making and communicating decisions for the adult”); NEV. REV. STAT. ANN. § 162C.100(1)(c) (West 2021) (listing as a purpose: “Enable supporters to assist in making and communicating decisions”).

light of the First Amendment's protections for freedom of speech and freedom of association.<sup>132</sup>

## 2. *Alignment of Political Interests*

There are many different ways that legislative bodies could embrace and promote supported decision-making as an alternative or complement to guardianship. Yet all supported-decision-making-focused statutes passed to date opt for a single primary approach: granting legal status to formal supported decision-making agreements and corresponding legal status to persons identified as "supporters" in such agreements.<sup>133</sup>

To understand the current legislative approach, therefore, one must understand not only why supported decision-making is of interest, but also what accounts for this particular approach.

One reason for this particular approach is that British Columbia's much-touted Representation Agreement Act provided a ready model for states.<sup>134</sup> The Act, adopted in 1996, granted formal recognition to "Representation Agreements," documents an individual with a disability can use to authorize a third party to help the individual make decisions.<sup>135</sup> The Representation Agreement approach was groundbreaking in that it gave formal legal recognition to documents executed by persons who in all other regards would be deemed incapable of executing a contract or managing their affairs.<sup>136</sup> Notably, however, it also allowed individuals to appoint another person to make a broad swath of decisions on their behalf;<sup>137</sup> thus, while the approach is often described as paradigmatic of supported decision-making legislation, it also facilitated surrogate decision-making.

However, even at the time Texas adopted its Supported Decision-Making Act, the British Columbia approach was one of a series of potential models that U.S. states could have adapted. Indeed, other Canadian provinces embraced supported decision-making in very different ways that were also well documented. For example, Manitoba took the approach of requiring the state to provide for support to assist individuals with disabilities in making decisions.<sup>138</sup>

Bringing the British Columbia approach to the United States was attractive not only because it was a ready model, but because the approach aligned with the interests of three (sometimes overlapping) constituencies: (1) family members outraged by abuses in the guardianship system, often especially by

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<sup>132</sup> See *supra* Section III.A.1 and accompanying text.

<sup>133</sup> See *infra* Section III.B.

<sup>134</sup> See Representation Agreement Act, R.S.B.C. 1996, c 405 (Can.).

<sup>135</sup> *Id.*

<sup>136</sup> *Id.* § 3.

<sup>137</sup> *Id.*

<sup>138</sup> See BACH & KERZNER, *supra* note 4, at 31 (outlining Canadian provinces' competing approaches to promoting supported decision-making prior to the adoption of the Texas Supported Decision-Making Act).

professional guardians; (2) disability rights advocates energized by the CRPD; and (3) fiscal and social conservatives interested in reducing government expenditures and intervention into family life.

For family members upset by the guardianship system, the approach was not only a way to undermine and avoid that system, but also a move that would empower families to support individuals with intellectual and cognitive disabilities—and guard against—others who might question that support.<sup>139</sup> For those concerned primarily about undermining guardianship, whether the legislation actually enabled individuals to make their own decisions was not necessarily a priority.<sup>140</sup>

For disability rights advocates, the approach not only used the language of the CRPD but also adopted an anti-professional approach that has long resonated in the disability rights movement.<sup>141</sup>

A key subset of these advocates—family members of individuals with intellectual and development disabilities—also stand to directly benefit from the legislation. The formalization approach (unlike alternative approaches) creates new legal status and power for this constituency. As discussed in Section III.C.2, the laws typically create a way for them to enforce decisions made by the individual and to demand that others recognize decisions they articulate on behalf of their family member with a disability.<sup>142</sup> Such formal standing was particularly empowering for those supporting individuals with more than a mild cognitive impairment.<sup>143</sup>

The dominant approach also represents a potential cost savings for this group of advocates. To the extent that supported decision-making agreements obviate the need for guardianship, the approach reduces the need to spend time and other resources on petitioning for guardianship or complying with monitoring required by a court. Thus, for example, The Arc of California, which advocates for persons with intellectual and developmental disa-

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<sup>139</sup> Cf. Glen, *Piloting Personhood*, *supra* note 10, at 518 (arguing that “[g]etting third parties like healthcare providers, financial institutions, etc. to accept SDMAs requires legislation”).

<sup>140</sup> See Eliana J. Theodorou, Note, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973, 989–94 (2018) (describing how the Texas Supported Decision-Making Act adoption was facilitated by a legislature “already primed to address guardianship”); Kristin Booth Glen, *What Judges Need to Know About Supported Decision-Making, and Why*, 58 JUDGES’ J. 26, 28–30 (2019) (describing how the Texas Supported Decision-Making Act came about as a result of an effort to address problems of abusive guardianship practices, and that Nevada’s supported decision-making legislation also arose from a process designed to address concerns about guardianship).

<sup>141</sup> See Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 75–77 (2004) (describing the disability rights movement’s embrace of “consumer control” and critique of professionals’ paternalism).

<sup>142</sup> See *supra* Section III.C.2.

<sup>143</sup> But Bigby and colleagues suggest that such individuals cannot necessarily make decisions even with support, and thus the supporter needs some degree of authority—not to do the person’s bidding but to act on the person’s behalf. Christine Bigby et al., *Delivering Decision Making Support to People with Cognitive Disability*, 52 AUSTRALIAN J. SOC. ISSUES 222, 235 (2017).

bilities, urges parents of such persons to “try” supported decision-making<sup>144</sup> as a way to promote the independence of their children and to save (by avoiding conservatorship) “thousands of dollars on attorneys and court costs, experts, and evaluations.”<sup>145</sup> Likewise, provisions that allow supporters to enforce decisions independently reduce the costs associated with such enforcement.

Finally, the approach furthers two key conservative agendas. First, for fiscal conservatives, it is consistent with reducing public expenditures. By keeping individuals out of the court system, public costs (including those associated with monitoring guardianships) are reduced.<sup>146</sup> By contrast, taking the Manitoba approach of requiring the state to provide decision-making support comes with a fiscal cost.

Second, for social conservatives, having families care for their own without government involvement aligns with a traditional vision of the family as a private, supportive sphere that should be free from government interference.<sup>147</sup> Thus, the British Columbia model—which encourages private ordering that is largely beyond the reach of government oversight—is appealing both because it embraces the view of family as a place of safety and refuge and because it insulates the family from governmental oversight (in part by minimizing the need for guardianship, which involves court oversight).<sup>148</sup>

The power of this alignment is evidenced by how it has supported past waves of “disability rights” legislation. For example, as Carlos Ball has explained, the Americans with Disabilities Act—the nation’s most far-reaching “disability rights” legislation—was possible because of its

appeal to political sensitivities of both liberals and conservatives; the former approve because there is a role for government to help a group that has traditionally been marginalized, both politically and economically; the latter approve because the legislative mea-

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<sup>144</sup> *Supported Decision-Making (SDM) Bootcamp: Training Videos and Materials*, ARC CAL., <https://thearca.org/info-resources/supported-decision-making/> [https://perma.cc/Y6DK-AEW5] (“So, if your child has disabilities, you don’t HAVE to get conservatorship. Supported Decision-Making is an option, if your child is able to use it. And, in most cases, you can’t know if your child can use it unless you try.”).

<sup>145</sup> *Id.*

<sup>146</sup> *Accord* Theodorou, *supra* note 140, at 979–80 (discussing how the Texas Supported Decision-Making Act can appeal to a conservative agenda by reducing the costs associated with monitoring guardianships).

<sup>147</sup> See generally Martha A. Fineman, *What Place for Family Privacy*, 67 GEO. WASH. L. REV. 1207 (1999) (describing and critiquing the traditional separate spheres view and urging an approach that will “reconcile both concerns and balance family privacy with protection for family members”).

<sup>148</sup> Moreover, the model is not threatening to social conservatives because, as one commentator noted, supported decision-making “imitates familiar support systems that already exist in modern societies.” See Gabrielle Davis-Jones, *Probate Law—A New Guardian Angel: A Proposed Change to Arkansas’s Public Policy on Guardianship for Individuals with Intellectual Disabilities*, 42 ARK. L. REV. 279, 293 (2020).

tures are viewed as promoting self-reliance and responsibility with the ultimate goal of reducing the dependence of individuals on government.<sup>149</sup>

Similarly, the success of the independent living movement, and its push for deinstitutionalization of persons with disabilities, has been attributed in part to its appeal to conservative values of small government and locating power with individuals and families in lieu of government.<sup>150</sup>

Notably, this embrace of family-centered decision-making has been challenged by feminist legal scholars who have, in other contexts, persuasively challenged the notion that family should be assumed to be a safe space for vulnerable individuals.<sup>151</sup> However, the power of this critique has had virtually no impact on supported decision-making legislation, perhaps because it has been blunted by the progressive critique of autonomy, which has also risen to prominence in feminist legal theory circles. That critique argues for recognition that individuals' capacities are shaped by their relationships and networks, and that individuals are members of a larger, connected network.<sup>152</sup> The current wave of supported decision-making statutes can be seen as responsive to the recommendations of those who argue that the state should support vulnerable people by supporting these networks. After all, the statutes strengthen the power of the network to enforce its wishes, and to prevent government intrusion into the life of any member of that network.

Thus, the current approach to supported decision-making legislation can be explained as the result of aligning the interests of key constituencies within the disability rights movement with conservative ideology about the role of the government and with progressives' calls for the government to recognize the importance of family care and to support families.

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<sup>149</sup> Carlos A. Ball, *Autonomy, Justice, & Disability*, 47 UCLA L. REV. 599, 601 (2010); accord KATHARINA HEYER, RIGHTS ENABLED: THE DISABILITY REVOLUTION FROM THE US, TO GERMANY AND JAPAN, TO THE UNITED NATIONS 33–34 (2015); Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 926–27 (2003) (describing how the ADA's enactment was supported by arguments that it would reduce the societal cost of dependency); SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 29 (2009) (discussing the political context surrounding the enactment of the ADA).

<sup>150</sup> See generally Andrew Batavia, *Ideology and Independent Living: Will Conservatism Harm People with Disabilities?*, 549 ANNALS AM. ACAD. POL. & SOC. SCI. 10 (1997) (discussing the role of conservatism in furthering the independent living movement).

<sup>151</sup> See Suzanne A. Kim, *Reconstructing Family Privacy*, 57 HASTINGS L.J. 557, 568–77 (2005) (providing an overview of the critique).

<sup>152</sup> See MARTHA NUSSBAUM, FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP (2007) (on capabilities and disabilities).



#### IV. AN ALTERNATIVE, PERSON-CENTERED APPROACH TO SUPPORTED DECISION-MAKING

Despite their disempowering impacts and incompatibility with the core tenets of supported decision-making, current supported decision-making statutes in the United States have been met with nearly uniform support, both in the public arena and in the (limited) scholarship to date.<sup>153</sup> With disability advocates and families clamoring for recognition of supported decision-making, and ever-growing concerns about guardianship, more legislation on supported decision-making is virtually inevitable. After all, legislation is how politicians speak to the electorate and signal their attention to interest groups.<sup>154</sup>

Merely critiquing existing approaches is therefore unlikely to hinder further proliferation of the existing approach. It is therefore critical to suggest alternative legislation that could satisfy the interests of key constituencies and politicians' need to signal support of their agendas. Accordingly, this Section outlines five concrete legislative approaches states could take—either separately or in combination—to legislatively recognize and facilitate supported decision-making, and to increase the likelihood that it can and will be a viable alternative to guardianship for a broad swath of the population for which guardianship would otherwise be considered.

All five approaches focus on supporting individuals with disabilities and creating structures that can expand their capacities. Thus, they might be termed “person-centered approaches” because they focus on the wishes and interests of the individual being supported, and on empowering that individual (as opposed to focusing on and empowering those providing support).<sup>155</sup> These person-centered approaches are consistent with a disability rights perspective because they treat the individual about whom decisions are to be

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<sup>153</sup> See, e.g., Wright, *Dementia*, *supra* note 22, at 290–91. See generally SHOGREN ET AL., *supra* note 19 (arguing for expansive use of supported decision-making across contexts).

<sup>154</sup> Avlana Eisenberg, *Expressive Enforcement*, 61 UCLA L. REV. 858, 868–69 (2016) (describing the expressive function of the enactment of hate crime legislation and highlighting elected officials' acknowledgement of this role as reflected in the stated desire to “send a message”).

<sup>155</sup> This use of the term “person-centered” parallels how the term is increasingly used in a social services context. In this context, “person-centered planning” for individuals with disabilities is typically described as a process in which the individual's wishes, values, and personhood determine plans. This stands in contrast to “less enlightened” approaches, in which the person's disability or a third-party assessment of needs drives the process. See *Person Centered Planning*, ADMIN. FOR CMTY. LIVING, <https://acl.gov/programs/consumer-control/person-centered-planning> [<https://perma.cc/NJQ7-MKFV>] (defining “person-centered planning”); cf. Lynn K. Jones, *Person-Centered Thinking in Developmental Disabilities*, SOC. WORK TODAY, [https://www.socialworktoday.com/archive/exc\\_011909.shtml](https://www.socialworktoday.com/archive/exc_011909.shtml) [<https://perma.cc/TXZ3-GSSY>] (contrasting person-centered planning to a “systems-centered approach”: “In a system-centered approach you see someone as a client and focus on their deficits and their needs, which lead you to certain conclusions as to what kind of treatment the client needs or what kind of support the client needs. In a person-centered approach, we see someone as a person first, not someone who is defined by their disability.”).

made as the principal decision-maker and look to the individual's wishes (and not merely objective interests) to guide decision-making. At the same time, however, they are also consistent with the growing "disability-justice" perspective, which has pushed back against an individualist approach to disability rights on the grounds that a recognition and appreciation of interdependence is critical to the "liberation" of individuals with disabilities.<sup>156</sup> Consistent with a disability-justice approach, these person-centered approaches recognize that empowering the person who is at the center of a decision requires strengthening and expanding the supports available to that person.

A. *Promote and Facilitate Agreements that Lack Independent Legal Status*

As discussed at length in Section III, granting formal legal status to supported decision-making agreements and to supporters undermines the rights of people with disabilities and exposes them to heightened risk of exploitation and coercion. In addition, it sends a counterproductive message about the rights of individuals with cognitive and intellectual abilities by signaling that they cannot make decisions without a formal supported decision-making agreement in place.

However, states should consider encouraging the use of supported decision-making agreements that do not have independent legal status.<sup>157</sup> This approach would recognize the significant value that supported decision-making agreements can have even without formal legal status. It would thus allow states to capture the primary benefits of supported decision-making without the costs (discussed in Section III) associated with giving status to supporters or protecting third parties who negligently harm people with disabilities.

Even when no rights are created by their execution, supported decision-making agreements can help individuals with disabilities make their own decisions and have those decisions recognized by others. The process of creating a supported decision-making agreement creates an opportunity for dialogue between individuals and their supporters, including dialogue about the types of decisions for which support will be sought, and about what types of assistance and behaviors the individual being supported would find helpful.<sup>158</sup> By catalyzing a discussion about what any given supporter will do in

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<sup>156</sup> See Patricia Berne et al., *Ten Principles of Disability Justice*, 46 *WOMEN'S STUD. Q.* 227, 227–29 (2018) (describing the disability justice perspective's guiding principles).

<sup>157</sup> To the extent that states continue to insist on instilling such agreements with legal status, they should consider how they then can minimize the risks of that status. For example, they might not allow supporters to enforce decisions made by individuals being supported, or might not allow that outside of the presence of, or without the explicit consent of, the individual.

<sup>158</sup> See Glen, *From Theory to Practice*, *supra* note 35, at 112–13 (describing how a pilot project has facilitated substantial dialogue and cross-learning between individuals and would-

that role, agreements may also create an opportunity to coordinate among a circle of supporters, and create a plan for enlarging the individual's social and decision-making support. Thus, individuals and supporters can use agreements as a way of discussing needs and establishing expectations without supporters being granted legal status.

Once executed, such agreements continue to have value. In addition to guiding the relationship between individuals and supporters, agreements can help others understand and respect those relationships. Regardless of whether an agreement grants the supporter legal rights, the agreement can be shared with third parties to help them understand the supporter's role and the legitimacy of the support provided.<sup>159</sup> As one user of supported decision-making explained, his supported decision-making agreement—even though it does not have legal effect in his state—“gives me and my family a paper to show other people that I can make my own decisions and that people shouldn't decide things for me but help me decide for myself.”<sup>160</sup>

Perhaps most importantly, supported decision-making agreements do not need legal status in order for supported decision-making to obviate the need for guardianship. When an individual is able to make decisions for him- or herself with help, courts have found guardianship improper even in the absence of any legislation on the subject of supported decision-making.<sup>161</sup>

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be supporters as part of the process of helping such individuals execute supported decision-making agreements).

<sup>159</sup> Even the most ardent advocates for legislation acknowledge that the agreements can be used to communicate the relationship absent legislation. *See, e.g.*, Kristin Booth Glen, *Introducing a “New” Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 21 n.87 (2018) (recognizing that third parties may choose to recognize agreements even without accompanying legislation).

<sup>160</sup> *See* Letter from Craig Kinney to Sen. Sonia Chang-Diaz and Rep. Kay Khan, Chairpersons, Joint Comm. on Child., Fams. & Persons with Disabilities (undated), <https://supporteddecisions.org/wp-content/uploads/2019/06/Craig-Kinney-SDM-written-testimony.pdf> [<https://perma.cc/5PY3-F3QS>] (notably, however, the letter advocated for granting legal status to such agreements).

<sup>161</sup> *See, e.g.*, *In re Chenel D.*, 2019 NYLJ LEXIS 125, at \*18–19 (N.Y. Sur. Ct. 2019) (finding that guardianship was not in order where the respondent “clearly has a supportive decision making network that can help guide her through the important decisions affecting her life”); *In re Estate of Caitlin*, 2017 NYLJ LEXIS 714, at \*18 (N.Y. Sur. Ct. 2017) (dismissing a petition for guardianship based on a finding that it was in the respondent's best interest to “maintain [her] legal right to make personal decisions about her own affairs, while providing her with the necessary assistance to make those decisions in a supported decision making framework”); *Guardianship of Sean O.*, 2016 NYLJ LEXIS 3455, at \*10 (N.Y. Sur. Ct. 2016) (finding that guardianship was not in order because the respondent, a young man with an intellectual disability, was “functioning on his own in society as a capable adult who engages in supportive decision making with his family and support professionals[,] . . . is aware of his limitations[,]” and “recognizes his need to turn to others for guidance on certain matters”); *In re Hytham M.G.*, 41 N.Y.S.3d 719 (N.Y. Sur. Ct. 2016) (finding that guardianship was not proper where the respondent was supported in making decisions by his family); *In re Michelle M.*, 41 N.Y.S.3d 719 (N.Y. Sur. Ct. 2016) (finding that guardianship was not in order because the respondent's best interest would be served by allowing her to continue to make decisions “in a supported decision-making framework [that] she already has in place”); *In re D.D.*, 50 Misc.3d 666, 677 (N.Y. Sur. Ct. 2015) (finding that the grounds for guardianship had not been

States could encourage the use of supported decision-making agreements that do not have legal status by mandating that an appropriate state agency develop and disseminate model agreements for use by citizens of the state. Model agreements could help reduce the time and smooth the learning curve associated with executing a supported decision-making agreement. Model forms could help individuals readily delineate the parameters of their chosen supportive relationships, and thus provide clarity for the benefit of persons being supported, supporters, and third parties who might benefit from such explication. Consistent with best practices identified by Supported Decision-Making New York, the forms should provide opportunity to (1) identify the supporter and person being supported, (2) identify types of decisions with which the supporter will assist, (3) identify types of assistance the individual would find most helpful, and (4) clarify roles of multiple supporters.<sup>162</sup>

States could also promote the use of supported decision-making by requiring an appropriate state agency to provide training for those who are interested in entering into supported decision-making agreements, or by appropriating funds to support non-governmental organizations who would provide that training. Supporters would benefit from training on techniques that they can use to help individuals process and analyze options. Supporters would also benefit from training to identify techniques that may be counter-productive or (perhaps unintentionally) coercive. Indeed, even the most ardent advocates of supported decision-making have expressed concern that supporters may have limited experience with techniques that can be used to help persons with disabilities make decisions, and have suggested that supporters' attitudes about the decision-making abilities of individuals may pose a barrier to providing effective support.<sup>163</sup>

Individuals being supported can benefit from training, especially if they have limited experience in making decisions.<sup>164</sup> The less experience such individuals have, and the less engaged they are with their community, the

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satisfied because “[t]he network of supported decision-making provided [to the respondent for] . . . the past 11 years of his adulthood has yielded a safe and productive life where he has thrived and remained free from the need to wholly supplant the legal right to make his own decisions”); *Ross v. Hatch*, 2013 Va. Cir. LEXIS 413, at \*7 (Va. Cir. Ct. 2013) (ordering that the guardianship for Margaret “Jenny” Hatch terminate after a year on the basis that after that point Hatch would instead be assisted through supported decision-making); *In re Demaris L.*, 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2013) (finding that guardianship was unnecessary because the individual could “make and act on her own decisions” with assistance from an existing support network).

<sup>162</sup> See Glen, *From Theory to Practice*, *supra* note 35, at 111–12.

<sup>163</sup> SHOGREN ET. AL., *supra* note 19, at 154 (expressing concern that supporters may take a “deficit-based” view of individuals’ decision-making capacities).

<sup>164</sup> See Glen, *Piloting Personhood*, *supra* note 10, at 518 (observing that decision-making “is a skill that must be explicitly and systematically taught to those with intellectual and developmental disabilities”).

more intensive this training may need to be to enable them to make effective use of support.<sup>165</sup>

In order to provide effective training, states will need to seek out best evidence about the techniques that are most effective in helping individuals with disabilities. There is a small but emerging body of literature considering what type of training is most effective for decision-making supporters, and this has begun to be used to develop training for supporters.<sup>166</sup> Nevertheless, given that the literature base is highly limited,<sup>167</sup> those creating evidence-based training should also—at least in the immediate future—look at the broader literature on decision-making by persons with cognitive challenges and on tools and techniques that can help minimize the cognitive load associated with decision-making. For example, as Shogren and colleagues suggest, this literature might support training supporters on how to help individuals use decision-making aids, or how to present information in formats that are more cognitively accessible.<sup>168</sup> Training might also help supporters to identify resources that they can use to provide support or which they could share with the person being supported.<sup>169</sup>

### B. Amend State Guardianship Statutes

As outlined above, a key goal of advocates of supported decision-making is to avoid the imposition of guardianship. If an individual's needs can be met through supports, there is no need to strip the individual of his or her

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<sup>165</sup> Cf. *id.* at 506 n.61 (noting the lengthier training required for individuals with intellectual and developmental disabilities who participated in a supported decision-making project in Bulgaria because many “had recently been returned to the community from special institutions in which they had no social contacts and no opportunity to make even the simplest decisions”).

<sup>166</sup> See, e.g., *The La Trobe Support for Decision-Making Practice Framework Learning Resource*, LA TROBE UNIV., <http://www.supportforddecisionmakingresource.com.au/> [<https://perma.cc/A96W-6L7J>] (building on a series of small, empirical studies by researchers in Australia).

<sup>167</sup> Indeed, an observation the author and her colleagues made in a 2013 article outlining a research agenda on supported decision-making remains disturbingly current. It noted:

Perhaps surprisingly for a model in its second decade of development, there is little empirical evidence directly evaluating supported decision-making. Indeed, a number of recent discussions of supported decision-making note the lack of, and need for, empirical evidence that evaluates the different models of supported decision-making. Even articles that provide extensive discussions of the benefits and potential drawbacks of supported or co-decision-making provide little or no empirical support for their claims.

Kohn et al., *supra* note 7, at 1128–29 (footnote omitted); see also SHOGREN ET AL., *supra* note 19, at 183–99 (in a book chapter on research about supported decision-making, providing no meaningful empirical evidence that supported decision-making achieves its goals, describing the research that is happening by reference to a series of small pilot projects, and noting that “we are not aware presently of published studies of the type called for by Kohn, Blumenthal, and Campbell (2013)”).

<sup>168</sup> SHOGREN ET AL., *supra* note 19, at 216–17.

<sup>169</sup> For example, the La Trobe model, *supra* note 166, provides such resources for supporters.

rights by imposing a third party upon them. Indeed, even in jurisdictions that do not explicitly state that the grounds for guardianship are not satisfied if an individual can make decisions with support, guardianship-enabling legislation could be read to reach that result.<sup>170</sup>

Guardianship statutes should be amended to explicitly prohibit the use of guardianship where supported decision-making would meet the individual's needs.<sup>171</sup> Doing so would make it clear that the use of support is not an indication of a need for guardianship,<sup>172</sup> but rather that support can obviate the need for guardianship.

This is the approach promoted by the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (“UGCOPAA”), based in part on recommendations of the Third National Guardianship Summit.<sup>173</sup> Under the UGCOPAA, a court may only appoint a guardian for an adult if the court finds by clear and convincing evidence that “the respondent lacks the ability to meet essential requirements for physical health, safety, or self-care because the respondent is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or *supported decision making*.”<sup>174</sup> Thus, under the UGCOPAA, a court may not impose a guardianship where supported decision-making would meet what the court has determined to be the individual's needs. In this way, the UGCOPAA explicitly recognizes that a person's abilities and needs can vary based on whether or not they have support and, consistent with the text of the CRPD, does not treat decision-making accomplished with support differently from that accomplished without support. As I have noted elsewhere, this is “the equivalent of the state allowing an individual to wear glasses (i.e., the support used to see) when taking a vision test to get a driver's license, and not testing vision without such support (which would not give an accurate read of the individual's functional abilities).”<sup>175</sup>

Texas has taken a similar (although less explicit) approach by prohibiting imposition of guardianship unless

alternatives to guardianship that would avoid the need for the appointment of a guardian have been considered and determined not

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<sup>170</sup> See *supra* note 161.

<sup>171</sup> For an example of the type of guardianship statute language that should be amended consistent with this approach, see Vermont's statute: VT. STAT. ANN. tit. 18 § 9304 (West 2021) (stating that “[g]uardianship may be provided to any person with developmental disabilities who: (1) is at least 18 years of age; and (2) is in need of supervision and protection for the person's own welfare or the public welfare”).

<sup>172</sup> Some have suggested that the opposite is currently the default. See Fiala-Butora & Stein, *supra* note 18, at 200 (stating that “[g]uardianship law . . . label[s] the use of support by persons with disabilities as a proof of incapacitation”). However, it is unclear what the basis of this contention is. Nevertheless, amending the law in the way recommended in this Section would set a clear default to the contrary.

<sup>173</sup> See generally UGCOPAA, *supra* note 4, at prefatory note.

<sup>174</sup> *Id.* § 301(a)(1)(A) (emphasis added).

<sup>175</sup> See NINA A. KOHN, ELDER LAW: PRACTICE, POLICY, AND PROBLEMS 109 (2020).

to be feasible; and supports and services available to the proposed ward that would avoid the need for the appointment of a guardian have been considered and determined not to be feasible.<sup>176</sup>

Thus, in Texas, just like under the UGCOPAA, a guardian may not be appointed if supported decision-making would address an individual's identified needs. Notably, even Texas does not require a supported decision-making agreement to be in place for a court to find guardianship improper based on the availability of decision-making support. The court is simply tasked with assessing whether the person's needs could be met through support, not the validity or existence of an agreement.

Given the current unsettled state of the research as to the extent to which supported decision-making can empower individuals with disabilities to make their own decisions (e.g., to what extent it is a viable approach for those with progressively deteriorating abilities, severe dementia, or profound intellectual disabilities),<sup>177</sup> this approach has a certain elegance to it. If supported decision-making is in fact meeting an individual's needs—or can in fact meet them—then no guardianship may be imposed. If not, it may be. Thus, the focus is on the individual in his or her particular context. And such individualized determinations do not wager an individual's life or welfare on broad-brush assumptions about the viability or imprudence of a particular method of decision-making.

To ensure that courts consider support when considering whether to grant a petition for guardianship, two additional provisions should be added to state guardianship laws. The first is a provision requiring petitioners to identify any person currently supporting a respondent and that such persons receive notice of the guardianship proceeding. Thus, under UGCOPAA, a petitioner must list any person “known to have routinely assisted the respondent with decision making in the six-month period immediately before the filing of the petition” and provide notice of the hearing on the petition to such persons.<sup>178</sup> This alerts the court to the existence of supporters. In addition, it allows the respondent to have the benefit of such supporters in opposing a petition, advocating for limitations on any appointee's powers, and voicing preferences for an appointee.

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<sup>176</sup> TEX. EST. CODE ANN. § 1101.101(a)(1)(D)–(E) (West 2019).

<sup>177</sup> See Terry Carney, *Supported Decision-Making for People with Cognitive Impairments*, 4 LAWS 37, 38 (2015) (questioning whether supported decision-making is feasible with progressing dementia and suggesting that someone with early dementia will initially be able to utilize supported decision-making before reaching a stage where greater reliance is placed on substitute decision-making). *But see* Wright, *Dementia*, *supra* note 22 (arguing that supported decision-making accords with the preferences and interests of persons with dementia and should be widely adopted).

<sup>178</sup> See UGCOPAA, *supra* note 4, §§ 302(b); 402(b) (requiring that petitions for guardianship and conservatorship list “a person known to have routinely assisted the respondent with decision making in the six-month period immediately before the filing of the petition”); *see also id.* §§ 303(c); 403(c) (requiring that such persons be given notice, although it need not be by personal service, of a hearing to consider appointment of a guardian or conservator).

The second is a provision requiring that respondents be allowed to have a supporter assist them during the hearing process and its related functions.<sup>179</sup> Under UGCOPAA, a respondent has a right to be assisted in a hearing “by a person or persons of the respondent’s choosing, assistive technology, or an interpreter or translator, or a combination of these supports.”<sup>180</sup> This provision not only has the potential to allow the respondent to more successfully defend against the petition, but also increases the likelihood that the court will witness the supported decision-making relationship and thus take it fully into consideration when determining whether or not there is a need to impose guardianship.

Amending state guardianship law in this way would effectively make guardianship unlawful where supported decision-making would meet an individual’s needs, and would create processes which consider the existence and functioning of current supports. Thus, it would accomplish one of the key purported objectives of state supported decision-making statutes without removing any rights from individuals with disabilities or giving anyone else a right to act on their behalf.

### C. *Enable Personal Information Disclosure Authorizations*

A common argument in favor of formal supported decision-making agreements is that they allow supporters to access restricted information that would otherwise only be available to the decision-maker.<sup>181</sup> Retrieving and evaluating this information may be the tasks with which the individual most needs help. For example, an individual confronted with a decision about health treatment may need a supporter to access and review the individual’s health records in order to help the individual identify and analyze risks and benefits associated with the treatment. Similarly, to effectively support an individual who wishes to budget for household finances, a supporter may need to be able to access and review private financial information, such as government benefits information and bank account records.

Generally, in order to enable supporters to access such information, an individual would need to grant permission for access to each source of infor-

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<sup>179</sup> This is distinct from the court appointing a guardian ad litem (“GAL”) for the individual, as is sometimes done. Although a GAL may act much like a supporter, a GAL is an agent of the court whose duty is to the court.

<sup>180</sup> UGCOPAA, *supra* note 4, §§ 307(c); 408(c). UGCOPAA takes the requirement one step further, requiring the court to make efforts to provide such assistance. *See id.* (“If assistance would facilitate the respondent’s participation in the hearing, but is not otherwise available to the respondent, the court shall make reasonable efforts to provide it.”). This additional step might help certain respondents who do not yet have a supporter to avoid guardianship where supported decision-making would meet the respondent’s needs but is not essential to ensuring that those who already have support avoid guardianship.

<sup>181</sup> *See* Wright, *Dementia*, *supra* note 22, at 290–91 (discussing various states’ supported decision-making agreements that have individuals specify whether a supporter can see private records in order to help the individual understand information, or help communicate a decision to the individual).



mation separately.<sup>182</sup> Thus, to see an individual's health records, the supporter would likely need to have the individual fill out a release with the health institution where the individual's records are kept. This is a time-consuming process that has the potential to discourage supporters from assisting or, perhaps even worse, to encourage them to assist without the information that would enable them to do so in a high-quality manner.

States should therefore consider creating a statutory short form that an individual can use to grant another individual the ability to access personal information that would otherwise be inaccessible. That is, a state could enable a Personal Information Disclosure Agreement ("PIDA"), just as they enable powers of attorney for finances or health care, that would allow the individual to authorize access to entire categories of personal information. Unlike a power of attorney, however, the appointee would have no right to act based on that information. Thus, to the extent that consent to a PIDA might be obtained through undue influence or coercion (or simply be faked), the consequences would be limited.

PIDAs could make it feasible for individuals seeking support to grant one or more other persons broad access to information.<sup>183</sup> Alternatively, states could encourage more selective authorizations by having the individual explicitly select the categories of information that the supporter would be entitled to access.

#### D. Construct Public Systems for Support

Many individuals with disabilities have friends or family who can serve as supporters. For others, a lack of close, trusting relationships can be a substantial barrier to the use of supported decision-making.<sup>184</sup> Accordingly,

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<sup>182</sup> *See id.*

<sup>183</sup> Such a broad grant of rights to a supporter can be found in several pieces of supported decision-making legislation pending at the time this Article was written. For example, under Bill 64 in the 191st session of the Massachusetts Senate, an individual could grant a supporter access to all medical records regardless of their location. *See* S. 64, 2019 Leg., 191st Sess. (Mass. 2019) (allowing the individual to select whether or not to grant the supporter "[a] release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191)" as well as whether or not to grant the supporter "[a] release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. § 1232g)").

<sup>184</sup> *See* KERZNER, *supra* note 16, at 71 (discussing the need for the government to provide supporters).

those who are unbefriended<sup>185</sup> are currently more likely to end up subject to guardianship.<sup>186</sup>

Fortunately, although a decision-making supporter is often someone with whom the individual has a preexisting relationship, they need not be.<sup>187</sup> For example, processes used to create supported decision-making teams using individuals with preexisting relationships could also be employed to create such teams using volunteers who lack prior relationship with the individual to be supported.<sup>188</sup>

Government entities and non-profit organizations (including faith-based communities) could play an important role in making supporters available to individuals with disabilities who lack family or friends to serve. Long-term care ombudsmen programs could serve as a model for this approach. While the precise design of such programs varies significantly among the states, such programs typically are managed by professional staff and use community volunteers to provide advocacy support to nursing home residents. Similarly, a cadre of decision-making supporters composed primarily of volunteers and managed by professional staff might expand communities' capacities to provide decision-making support to those without other workable options.

Another option would be to expand the scope of work performed by existing public guardian programs to include provision or facilitation of decision-making support. Almost all states have publicly funded guardianship programs,<sup>189</sup> and the majority of those are statewide.<sup>190</sup> Public guardianship programs are funded by state or county appropriations, Medicaid, fees from

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<sup>185</sup> Such individuals appear to be a small minority, but nevertheless appear to exist in significant numbers. See Stephanie A. Chamberlain et al., *Incapacitated and Alone: Prevalence of Unbefriended Residents in Alberta Long-Term Care Homes*, 9 SAGE OPEN 1, 1 (2019) [hereinafter Chamberlain et al., *Incapacitated*] (finding that over four percent of residents in long-term care facilities in Alberta, Canada were unbefriended). That said, there is still minimal research on the prevalence of "unbefriended" individuals. See Stephanie Chamberlain et al., *Going It Alone: A Scoping Review of Unbefriended Older Adults*, 37 CAN. J. ON AGING 1, 1 (2018) (reporting that there is a "stark scarcity" of studies on unbefriended adults).

<sup>186</sup> See Chamberlain et al., *Incapacitated*, *supra* note 185, at 1 (stating that older adults who have reduced decision-making capacity and no family or friends to compensate for these deficiencies are known as "unbefriended" and require a public guardian without considering the possibility of state-provided decision-making supporters).

<sup>187</sup> Notably, this is also true in surrogate decision-making relationships, which is important given that research has shown that there is a substantial number of older adults who do not have anyone even to appoint as an agent under a health care proxy. See Eric Widera et al., *Unbefriended: Medical Decision Making for the Incapacitated and Alone*, 51 J. PAIN & SYMPTOM MGMT. 360, 360 (2016) (reporting that an estimated 3–4% of long-term care residents, and 5% of those who die in the ICU, are "unbefriended").

<sup>188</sup> For example, Texas ran a pilot project that trained volunteers to support people with intellectual and developmental disabilities in making decisions. See *The Arc of San Angelo—Volunteer Supported Decision-Making*, TEX. COUNCIL FOR DEVELOPMENTAL DISABILITIES, <https://tcdd.texas.gov/projects/grants-completed-projects/the-arc-of-san-angelo-volunteer-supported-decision-making/> [https://perma.cc/RUF3-EWUV].

<sup>189</sup> TEASTER ET AL., *supra* note 53, at 216 (finding that 48 states have some form of state-funded public guardianship program).

<sup>190</sup> *Id.* at 218 (finding that 27 states had state-wide programs).

individuals subject to guardianship, or a combination of such funding sources.<sup>191</sup> For example, the state may look first to the individual but, if the individual is unable to pay, cover the cost with public funds.<sup>192</sup>

A jurisdiction could build on this model by expanding the duties of public guardian programs to include providing supporters for those whose needs could be met with decision-making support.<sup>193</sup> Expanding the scope of public guardianship programs to include public supporter programs would be consistent with the Americans with Disabilities Act's integration mandate requiring that public entities provide services in the most integrated setting appropriate to meet the needs of persons with disabilities.<sup>194</sup> Arguably, when a public entity provides decision-making support to individuals with disabilities only if those individuals are subject to guardianship, the entity violates the ADA by not offering a less restrictive alternative.<sup>195</sup> But regardless of whether a successful challenge could be brought to a guardianship-only form of support, certainly it is fair to characterize the exclusive approach as inconsistent with the underlying spirit and objective of the ADA's integration mandate.<sup>196</sup>

## V. CONCLUSION

Supported decision-making has the potential to empower individuals with cognitive and intellectual disabilities and improve their lives. Unfortunately, states' efforts to formalize supported decision-making through legislation may do the opposite. As this Article has shown, current supported decision-making statutes in the United States purport to enable and promote supported decision-making, but instead further a form of private family ordering that limits the civil rights of individuals with disabilities and places them at substantial risk of exploitation.<sup>197</sup>

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<sup>191</sup> *Id.* at 201.

<sup>192</sup> *Id.* at 213.

<sup>193</sup> This approach will, of course, be most effective if funding is also expanded.

<sup>194</sup> 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, 187–92 (2010) (arguing that states have a duty under the Americans with Disabilities Act to provide decision-making support to individuals who need that support due to their disabilities).

<sup>195</sup> One approach would be to argue that it is a violation of the duty to provide services in the most integrated setting appropriate. See 28 C.F.R. § 35.130(d) (2020) (“A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”). This is not a clear-cut violation by any means, as it requires broadly reading the term “setting” to include more than physical location.

<sup>196</sup> In countries that have ratified the CRPD (which the United States has not), there is at least arguably a duty for the state to affirmatively provide support. Article 12(3) of the CRPD requires nations ratifying it to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising legal capacity.” CRPD Art. 12(3); see also KERZNER, *supra* note 16, at 74 (discussing the implications of the CRPD on nation states' duty to provide support).

<sup>197</sup> Thus, as one self-advocate has warned, there is reason to be concerned that “the concept of supported decision making” is “actually being understood and practiced, as well-dis-

This Article has shown how this paradoxical result has come about and has provided an alternative set of legislative responses that could satisfy key groups lobbying for supported decision-making statutes. By adopting the alternative, person-centered approach laid out in this Article, states could reduce the use of restrictive legal interventions such as guardianship and finally realize the potential of supported decision-making to empower individuals with disabilities in practice, not just in name.