



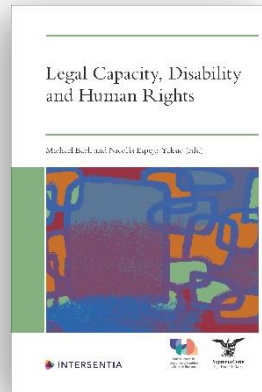
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A CRITICAL REVIEW OF LEGAL CAPACITY REFORM IN THE U.S.

Kristin Booth GLEN*

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1. INTRODUCTION

Legal capacity, generally – and mistakenly – understood as “mental capacity” is deeply ingrained in U.S. law, resulting in the denial of the human right of legal capacity to people with intellectual/developmental, psychosocial, and cognitive disabilities. The most common and visible legislative manifestations of this denial are guardianship laws, which apply primarily to persons with intellectual/developmental disabilities and older persons with cognitive decline, dementia, etc., and involuntary commitment and medication laws affecting persons with psychosocial disabilities/mental illness. In addition to guardianship, there is a vast body of laws, regulations and judicial decisions that impose differing tests of mental capacity for such activities as contracting, marrying, voting, serving as a witness or juror, giving consent for health care treatment, making a will, etc., allowing private and public third parties, like doctors, bankers, landlords, voting commissioners and marriage licence clerks to deny legal capacity to persons with disabilities.¹

To date there has been little U.S. attention to the ways in which denial of legal capacity discriminates against persons with disabilities, and even less attention to any affirmative *right* to legal capacity.² The U.S. has not ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), consistent with a long history of antipathy to human rights conventions, and other than an ever-growing body of legal scholarship, there is no public awareness of, or discussion about it.

Current reforms implicating legal capacity are tied to the use of supported decision-making (SDM), itself inconsistently understood and defined.³ They

¹ K. B. GLEN, “Supported Decision-Making From Theory to Practice: Further Reflections On An International Pilot Project” (2020) 13 *Albany Government Law Review* 1.

² L. SALTZMAN, “Using Domestic Law To Move Toward a Recognition of Universal Legal Capacity for Persons with Disabilities” (2017) 39 *Cardozo L. Rev* 521.

³ T. CARNEY, “Prioritising Supported-Decision-Making: Running on Empty or a Basis for Glacial-to-Steady Progress” (2017) 6(4) *Laws* 18.

take two forms: modest efforts to limit, but not repeal, guardianship laws through recognition of SDM as a “less restrictive alternative” to guardianship; and, more recently, laws recognising and regulating SDM Agreements (SDMAs) that purport to require legal recognition of decisions made pursuant to such agreements.

The impetus for even these limited efforts is mixed, resulting in the lack of any truly principled attack on substituted decision-making, and often leaving the door open for continuing imposition of mental capacity tests. In the absence of any popular movement advocates for the human right of legal capacity are almost all academic. With few exceptions, SDM advocates have pursued an incrementalist legislative strategy with few empirically based efforts to demonstrate how SDM might actually work “on the ground”.

While reform efforts around guardianship potentially affect both persons with developmental and cognitive disabilities, there is currently no viable movement for reform of the involuntary hospitalisation (commitment) and medication laws that deny people with psychosocial disabilities their right to legal capacity.

Understanding why legal capacity reforms are so limited in the U.S. requires knowledge of the context in which they exist. This includes the deeply rooted tradition of guardianship as “protection” for people with developmental and cognitive disabilities, and U.S. hostility to human rights treaties, including the CRPD.

2. CONTEXT

U.S. law is a mixture of common (judge-made) law, statutes, and regulations. As a federal system, the “police power” is largely reserved to the states, including guardianship and involuntary commitment and medication statutes, while the federal government has exclusive treaty power. The lack of interest in/commitment to any right of legal capacity in both jurisdictions reinforces the difficulty of creating significant reform, unlike countries that have ratified the CRPD and either domesticate its provisions or have responsibility for implementation.

2.1. U.S. HOSTILITY TO HUMAN RIGHTS TREATIES

Although the U.S. was a pioneer in international human rights, beginning with the aspirational Universal Declaration of Human Rights in 1948,⁴ the

⁴ Universal Declaration of Human Rights, G.A. Res. 217A (III), UN Doc. A/810 (10 December 1948).

politics of anti-communism (and, to some degree, support for continuing racial segregation) led to backlash against later conventions that might require U.S. compliance with international norms.⁵ Even when signing or ratifying, the U.S. does so only with significant formal reservations.⁶

Of four conventions that further elucidate human rights for “vulnerable groups”, the U.S. has signed three: Convention on the Rights of the Child (1989),⁷ Convention on the Elimination of Discrimination Against Women (1980)⁸ and the CRPD (2009),⁹ but has ratified only one, the International Convention on the Elimination of All Forms of Racial and Ethnic Discrimination (1994).¹⁰ Despite commitment by the Obama administration, and broad bi-partisan support, in 2012, amidst a flurry of right-wing misinformation the Senate withheld its consent to the ratification of the CRPD by just five votes.¹¹ The subsequent Trump presidency prevented any possibility of ratification and, with current hyper-partisanship in Washington, the future is not promising.¹²

Another important, somewhat perverse reason, accounts for the U.S.’s disappointing failure to ratify the CRPD. In 1990 Congress passed the Americans with Disabilities Act (ADA), often trumpeted as a model for the CRPD and cited for why the U.S. needs no further legal protections for people with disabilities. The ADA is, however, a comparatively limited, traditional anti-discrimination law, dealing primarily with employment and public accommodations; its provisions have been further narrowed by conservative judicial decisions. Originally advanced as a cost-saving measure, as the actual cost of needed accommodations has become apparent, support has diminished.¹³ This issue of cost-saving versus the need for, and cost of, increased services continues to impact legislative efforts, however modest, related to legal capacity.

⁵ A. C. HARFIELD, “Oh Righteous Delinquent One: The United States’ International Human Rights Double Standard – Explanation, Example, and Avenues for Change” (2001) 4 *N.Y. City L. Rev.* 59.

⁶ L. HENKIN, “U.S. Ratification of Human Rights Conventions: The Ghost of Senator Bricker” (1995) 89 *Am J. Int’l. L.* 341.

⁷ Convention on the Rights of the Child, 20 November 1989, 1577 UNTS 3.

⁸ Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, 1249 UNTS 13.

⁹ Convention on the Rights of Persons with Disabilities, 13 December 2006, 2515 UNTS 3.

¹⁰ International Convention on the Elimination of All Forms of Racial Discrimination, 21 December 1965, 660 UNTS 195.

¹¹ R. JONES, “U.S. failure to ratify the Convention on the Rights of Persons with Disabilities” (2013) <<https://www.awid.org/news-and-analysis/us-failure-ratify-convention-rights-persons-disabilities>> accessed 21.10.2021.

¹² A. S. KANTER, “Let’s try again: Why the United States should ratify the United Nations convention on the rights of people with disabilities” (2019) 35 *Touro L. Rev.* 301.

¹³ S. R. BAGENSTOS, “Disability rights and the discourse of Justice” (2020) 73(1) *SMU Law Review Forum* 26–34.

2.2. THE DEEP-ROOTED AND CONTINUING COMMITMENT TO GUARDIANSHIP AND THE BEGINNING OF REFORM

Guardianship has been a part of the common law since at least the sixteenth century, adopted by the colonies, and then by individual states after the establishment of a federal republic.¹⁴ Every state had at least one guardianship (sometimes called “conservatorship”) law, covering “incompetence” no matter the cause or population; a few had, and still have, statutes specifically for persons with developmental disabilities.¹⁵ These laws were almost entirely diagnosis-driven, plenary in nature, removing all legal capacity upon a finding of “incompetence”, lacking the most basic procedural protections, and with no time limitation.

A series of financial scandals in 1987 spurred the first round of guardianship reform, resulting in many procedural protections and a presumption of competence that, in theory, could only be overcome by clear evidence. Capacity was understood as “functional”, with removal of rights tied to specific incapacities. Although most statutes required “tailored” guardianships, enabling wards to retain all rights in areas where their specific “incapacities” were unproven, courts have continued to grant plenary guardianships in most cases, totally and permanently removing all the person’s legal capacity.¹⁶

The 1990 ADA adopted a social, rather than medical model of disability. This, despite its limitations, has resulted in shifting public perception of people with disabilities, although primarily for those with mobility, visual and hearing disabilities. Other laws, including those related to “special education” for children (through the age of 21) with intellectual/developmental disabilities also expanded possibilities for social inclusion.¹⁷ A 1997 U.S. Supreme Court decision (*Olmstead*, 1999)¹⁸ interpreted the ADA to require that persons with disabilities receive services in the least restrictive setting meeting their needs, spurring a community living movement with greater possibilities for inclusion. Finally, judicial decisions based in the Due Process clause of the U.S. Constitution have required that, when the state employs its police power civilly to “protect” individuals (rather than criminally, to protect society) it must do so by the “least restrictive means” available.¹⁹

¹⁴ F. A. JOHNS, “Ten Years After: Where is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?” (1999) 7 *Elder L. J.* 33.

¹⁵ National Council on Disability, *Beyond guardianship: Toward alternatives that promote greater self-determination*, Washington, DC: National Council on Disability 2018.

¹⁶ R. DILLER, “Legal capacity for all: Including older persons in the shift from adult guardianship to supported decision-making” (2016) 43 *Fordham Urb. L.J.* 495.

¹⁷ *Individuals with Disabilities Education Improvement Act*, 20 USC 400 et seq. 2004.

¹⁸ *Olmstead v. L.C.*, 527 U.S. 581, 595 (1999).

¹⁹ R. DILLER, “Legal capacity for all: Including older persons in the shift from adult guardianship to supported decision-making” (2016) 43 *Fordham Urb. L.J.* 495.

These social and legal changes, together with public scandals involving financial (and less frequently, personal elder abuse by guardians,) has spurred interest, if not yet commitment to, a “better way.” Primarily academic rights discourse offered the possibility that SDM could be that “better way”. Unfortunately, the recent media circus around Britney Spears’ conservatorship has re-focused the conversation almost entirely to abuse of power by guardians/conservators.²⁰ Proposals for reform, including those made in Congressional hearings, have been limited to making guardianship “better”, while reinforcing its legitimacy for people who, unlike rich, white, multi-millionaire pop stars, are clearly “disabled”.

3. THE RISE OF SUPPORTED DECISION-MAKING

SDM is not a full manifestation of the *right* of legal capacity; it is a *means* to that end. Because legal capacity requires both the right to *make* one’s own decisions and have them *legally recognised*, there is dissonance between the common practice by which everyone, including most people with developmental disabilities, use support from others in *making* decisions, and barriers to legal recognition of those decisions because of disability.²¹ This has led to significant lack of clarity in the discourse around SDM and related legislative efforts for recognition and implementation. It is also at least partially responsible for the overwhelming emphasis on SDM as a practice, rather than on legal capacity as a human right.

3.1. THE CONCEPT OF SUPPORTED DECISION-MAKING

Although persons with developmental, psychosocial and/or cognitive disabilities have, like others, always used supports in making decisions, the concept of “SDM” is relatively recent. An oft-cited definition that recognises its many manifestations states that it is “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”.²²

²⁰ J. COSCARELLI and L. DAY, “Judge frees Spears from father’s control”, *The New York Times*. <www.nytimes.com/2021/09/29/arts/music/britney-spears-court-decision-conservatorship.html> accessed 17.03.2023.

²¹ CRPD Committee: Committee on the Rights of Persons with Disabilities, *General Comment No. 1*, 11th Session, 50(a) UN Doc. CRPD/C/GC/1 (19 May 2014).

²² R. D. DINERSTEIN, “Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making” (2012) 19 *Hum. Rts. Brief* 8, 10.

The first formal meeting and exploration in the U.S. on SDM, was held in New York City in 2012, convened by two Commissions of the American Bar Association with support from the federal government's Administration for Community Living. The briefing paper for that interdisciplinary round table drew directly from the CRPD and focused on the necessity of legal recognition for decisions made by persons using SDM, while also promoting SDM as an alternative to guardianship. These distinct but related goals have informed how SDM is conceptualised and employed in legislative efforts that implicate legal capacity.

3.2. SUPPORTED DECISION-MAKING AND GUARDIANSHIP LAWS: THE FIRST REFORM EFFORT

Recognition of SDM as an alternative to guardianship has proceeded both in case law and legislation. In 2012, a New York court terminated the guardianship of a young woman with a developmental disability because she had developed a support system enabling her to make her own decisions, obviating the need for guardianship. Beside "least restrictive means", the decision explicitly cited the human right of legal capacity, CRPD Article 12, and the term SDM.²³ Since then, courts in New York and other states have employed similar reasoning, both to deny and terminate guardianships, though few have cited the CRPD.²⁴

The New York decision and 2012 meeting spearheaded efforts to amend existing guardianship laws to include SDM as a "less restrictive alternative" to be attempted before guardianship could be imposed.²⁵ The Uniform Law Commission, a highly respected national organisation that drafts model statutes, revised its model guardianship statute, to do so.²⁶ Several states including Maine²⁷ and Virginia²⁸ have since amended their guardianship statutes, incorporating this revision.

²³ *Matter of Dameris L.*, 956 N.Y.S. 2d 848 (Surr. Ct. N.Y. Co. 2012).

²⁴ For an example of a recent decision that does both, see *Matter of Grace J.*, 176 N.Y.S.3d 450 (Surr. Ct. Kings Co 2022).

²⁵ American Bar Association, Commission on Disability Rights, Section of Civil Rights and Social Justice, Section of Real Property Trust and Estate Law, Commission on Law and Aging, "Report to the House of Delegates and Resolution 113" (14 August 2017), online: <https://www.americanbar.org/content/dam/aba/administrative/law_aging/supported-decision-making-resolution-final.pdf> accessed 31.03.2023.

²⁶ National Conference of Commissioners On Uniform State Laws, "Uniform Guardianship, Conservatorship, and other Protective Arrangements Act" (2017), online: <<https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=de9bae9e-0b4e-0781-12b5-f5305569bf19&forceDialog=0>> accessed 31.03.2023.

²⁷ 18-C M.R.S. §5-102(14).

²⁸ VA ST §37.2-1200.

3.3. SUPPORTED DECISION-MAKING “IN PRACTICE”

The 2012 round table also led to official support for SDM by the federal Administration for Community Living, including a five-year grant to the National Resource Center on SDM (NRCSDM). That entity took a broad view of SDM, embracing it as “everyone’s right to make their own decisions,” without requiring written agreements by which a key component of legal capacity, legal recognition of decisions, could be achieved. Nor did it interrogate what supports might be necessary to ensure an authentic decision-making process.

Unlike countries like Bulgaria,²⁹ the Czech Republic,³⁰ and some Australian states,³¹ there was no effort to create empirical pilot projects to experiment with models for making SDMA that reflect a learned process of using and giving support. Instead, most energy and resources were directed toward legislative reform, lacking any evidentiary base of how to actually “do it.” One critic of SDMA legislation notes the false comparison between a “descriptive account of guardianship with an idealized, normative account of supported decision-making.”³²

3.4. SUPPORTED DECISION-MAKING AGREEMENT (SDMA) LAWS

Since 2012, 16 states (Texas,³³ Delaware,³⁴ Indiana,³⁵ Wisconsin,³⁶ Alaska,³⁷ Nevada,³⁸ Rhode Island,³⁹ North Dakota,⁴⁰ Louisiana,⁴¹ Washington,⁴² Colorado,⁴³

²⁹ Bulgarian Center for Not-for-Profit Law, Supported Decision-Making or How People with Intellectual Disabilities or Mental Health Problems Can Live Independent Lives, Bulgarian Association for Persons with Intellectual Disabilities, Sofia 2014.

³⁰ I. LEMANE-VELDMEIJERE, *Study Visit to Czech Republic Was Carried Out, to Explore Supported Decision Making Model in the Czech Republic*, ZELDA (2 September 2015), <<http://zelda.org.lv/en/arh%C4%ABvi/2150>> accessed 31.03.2023.

³¹ C. BIGBY et al., “Delivering decision making support to people with cognitive disability – what has been learned from pilot programs in Australia from 2010 to 2015” (2017) 52(3) *Australian Journal of Social Issues* 222–240.

³² N. KOHN, “Legislating Supported Decision-Making”, (2021) 58 *Harvard Journal on Legislation* 313, 326.

³³ TX EST §1357.001(A).

³⁴ 16 Del.C. §9405A.

³⁵ IN ST §29-3-14.

³⁶ W.S.A. §52.01-32.

³⁷ AS §13.56.150.

³⁸ N.R.S. §162C.320.

³⁹ RI ST §42-66.13-5.

⁴⁰ ND ST §14-09-31.

⁴¹ LA RS §13-4261.101.

⁴² WA ST §11.130.020.

⁴³ C.R.S.A. §15-14-801.

Oregon,⁴⁴ Virginia,⁴⁵ New Hampshire,⁴⁶ Illinois⁴⁷ and New York⁴⁸) and the District of Columbia⁴⁹ have passed some form of SDMA statutes. At the time of writing, additional statutes are pending in states including Massachusetts,⁵⁰ which like New York, is the only jurisdiction with empirical evidence to draw on.⁵¹ Most statutes involve written/form agreements that require or permit third parties to accept decisions of (or “give legal recognition to”) people who have executed SDMAs. Most also give third parties (who enter a contract or agreement with a person) immunity from liability for doing so in good faith.

In a limited way, these statutes guarantee legal capacity to some number of persons whose decisions might otherwise be questioned or ignored. As such, they advance legal capacity, although limitations on who can make valid SDMAs, who they can choose as supporters, how agreements can be terminated, etc. make that problematic. Equally concerning from the standpoint of CRPD Article 12(4) safeguards compliance, is the absence any educational or training requirements for those making SDMAs and their supporters that ensure the integrity of the process and guard against exploitation or misuse of the SDMAs.

Differing in particulars, these laws follow a similar pattern, with roughly similar components, including defining SDM, establishing a “capacity” standard, who can make an agreement, who can be supporters and what they can and cannot do, required third party recognition with corresponding immunity, and a number of more “procedural” provisions including the form of the agreement, formalities for execution and revocation, supporter access to information, alternate supporters, choice of law provisions, etc. Given space constraints, only those provisions that bear most directly on advancing legal capacity are considered here.

3.4.1. Coverage, or “who can Make an SDMA?”

Some statutes allow any adult to make the agreement, using terms including “the Principal” (Rhode Island, 2019, s.1),⁵² “the Supported Person” (District of Columbia, 2018, s. 301(13)),⁵³ the “Named Individual” (North Dakota, 2019, s. 1(2)).⁵⁴ Others are limited to persons with disabilities, variously defined.

⁴⁴ ORS 343.181-2.

⁴⁵ VA ST §37.2-1200.

⁴⁶ NH ST §563-B:17.

⁴⁷ 210 I.L.C.S. §9/5-9/99.

⁴⁸ NY CLS Men. Hyg. Art. 82 (2022).

⁴⁹ DC ST §7-761.01-13.

⁵⁰ 2019 MA S.B. 64 (NS); 2021 MA S.D. 1746 (NS).

⁵¹ C. CONSTANZO, K. GLEN and A. KRIEGER, “Supported Decision-Making in Practice: Lessons from Pilot Projects” (2022) 72 *Syracuse Law Review* 99, 154.

⁵² RI ST §42-66.13-3(7).

⁵³ DC ST §7-761.01-13.

⁵⁴ ST §14-09-31, S. 1(2).

Only New York's statute⁵⁵ is limited to persons with developmental, psychosocial and/or cognitive disabilities, whose legal capacity is most likely to be questioned. One statute refers to an adult who "doesn't need a guardian but would benefit from decision-making assistance" (Delaware)⁵⁶ raising the separate problem of capacity to make the agreement.

Use of the category "people with disabilities" also raises issues. There has been a long and unfortunate tendency in the U.S. to divide the disability rights community *by disability*, which use of this broad term avoids, intentionally or otherwise. Conversely, and linked to the issue of "capacity" to make a "supported decision-making agreement", there is potential to exclude persons with developmental, psychosocial and/or cognitive disabilities from the very protections the statute is meant to offer.

The New York⁵⁷ statute refers to the person making an agreement as the "Decision-Maker", recognising their centrality to the process. That term is now widely used in the U.S., and will be employed here.

3.4.2. "Capacity" to Make an Agreement?

This is obviously a critical issue, at least as the UN Committee sees it, since almost any effort to define capacity, including a "functional test", is deemed to violate Article 12.⁵⁸ The various approaches of most U.S. statutes are, at best, problematic, and at worst, simply a continuation of the old "mental capacity" standard.

Some statutes are silent, some begin with a presumption of capacity for all adults, (e.g., Rhode Island,⁵⁹ New Hampshire);⁶⁰ "unless otherwise determined by "a court" (Illinois⁶¹) or "legal proceedings" (Colorado⁶²) or may permit the presumption to be rebutted by clear and convincing evidence (North Dakota).⁶³ Texas limits those who can make agreements to "adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship" (Texas).⁶⁴ Others require that the agreement must be entered into voluntarily, without coercion, and that the adult must understand the nature and effect of the

⁵⁵ NY CLS Men. Hyg. Art. 82 (2022).

⁵⁶ 16 Del.C. §9401A(1).

⁵⁷ 2021 NY S.B. 7107(B) (NS).

⁵⁸ UN Committee on the Rights of Persons with Disabilities, "General Comment No. 1 – Article 12: Equal Recognition Before the Law," UN Doc. No. CRPD/C/GC/1 (April 2014) [General Comment No. 1], para. 15 <https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en> accessed 11.11.2022.

⁵⁹ RI ST §. 33-15.3-4(a).

⁶⁰ NH ST §464-D:3.

⁶¹ 210 I.L.C.S. §9/5-9/99, S. 15(a).

⁶² C.R.S.A. §15-14-801(1)(c).

⁶³ ND ST §30.1-36-04(1).

⁶⁴ TX EST §1357.003.

agreement (Nevada,⁶⁵ Rhode Island,⁶⁶ Delaware⁶⁷). A few, like New York and Alaska, require that “capacity” be judged not in a vacuum, but with support(s), (“a person is considered to have capacity even if the capacity is achieved by the person receiving decision-making assistance”) (Alaska⁶⁸).

To the contrary, as in Nevada,⁶⁹ the traditional legal standard seems still to apply (“an adult should be able to live in the manner in which he or she wishes and to accept or refuse support, assistance for protection as long as the adult does not harm others *and is capable of making decisions about such matters*”⁷⁰ (emphasis added)). The initial presumption disappears in states where a court may subsequently abrogate an agreement based on a finding that the person lacked capacity to make the agreement (Indiana⁷¹) or decision “despite the existence of a supporter (Delaware).⁷²

3.4.3. *Definition of SDM*

With minor variations, most statutes have followed the Texas definition:

Supported decision-making means a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without Impeding the self-determination of the adult.⁷³

3.4.4. *Effect of Agreement on Other Capacity Determinations*

Several states specifically provide that existence of an SDMA may not be used as evidence of the adult’s incapacity (e.g., Rhode Island,⁷⁴ Delaware,⁷⁵ Indiana,⁷⁶ Nevada,⁷⁷ Alaska⁷⁸ Colorado,⁷⁹ New York⁸⁰) or in a “proceeding” (Illinois;⁸¹

⁶⁵ N.R.S. §162C.320, S. 12(b).

⁶⁶ RI ST §42-66.13-10.

⁶⁷ 16 Del.C. §9405A.

⁶⁸ AS §13.56.160(d).

⁶⁹ N.R.S. §162C.320, S. 11.2(a).

⁷⁰ N.R.S. §162C.320, S. 11.2(a).

⁷¹ C.R.S.A. §15-1.5-110.

⁷² 16 Del.C. §9405A(i).

⁷³ TX EST §1357.002.

⁷⁴ RI ST §42-66.13-4(c).

⁷⁵ 16 Del.C. §9405A(c).

⁷⁶ IN ST §29-3-14, S. 4(c).

⁷⁷ N.R.S. §162C.320, S. 15.

⁷⁸ AS §13.56.160(d).

⁷⁹ C.R.S.A. §15-14-803(4).

⁸⁰ NY Men, Hyg. L. S. 82.01(e).

⁸¹ 210 I.L.C.S. §9/5-9/99, S. 15 (c).

New Hampshire⁸²). As a separate and potentially significant matter, an SDMA does not preclude the adult from acting independently of the agreement (e.g., Rhode Island,⁸³ Delaware,⁸⁴ Indiana,⁸⁵ Nevada⁸⁶)

3.4.5. *Other Protections for those who Make SDMAs*

To avoid negative and unintended consequences, statutes may provide that a SDMA does not relieve an entity otherwise legally obligated to provide services and required accommodations (e.g., North Dakota,⁸⁷ New York⁸⁸).

3.4.6. *Who can be Supporters: Statutory Disqualifications*

Although critical for the Decision-Maker's autonomy, virtually all statutes limit who can be chosen by imposing statutory disqualification on various classes of persons, including employees and employers of the Decision-Maker (e.g., Rhode Island,⁸⁹ Delaware,⁹⁰ Alaska⁹¹), service providers (Delaware,⁹² Alaska,⁹³ District of Columbia⁹⁴) and employees of governmental agencies with financial responsibility for the person's care (Illinois⁹⁵), although there is often an exception for the Decision-Maker's relatives.

Most statutes disqualify persons who might present a danger to the Decision-Maker, including persons against whom there is an order of protection (Rhode Island,⁹⁶ Delaware,⁹⁷ Alaska⁹⁸); governmental finding of abuse (Wisconsin⁹⁹); abuse, neglect, or exploitation of the supported person (District of Columbia);¹⁰⁰ convictions based on such findings (Wisconsin);¹⁰¹

⁸² NH ST §464-D:3.

⁸³ RI ST §42-66.13-4(c).

⁸⁴ 16 Del.C. §9404A(c).

⁸⁵ IN ST §29-3-14, S. 4(c).

⁸⁶ N.R.S. §162C.320, S. 15.

⁸⁷ ND ST §14-09-31, S. 1, p.4 (5).

⁸⁸ NY Men. Hyg. L. 82.01(c).

⁸⁹ RI ST §42-66.13-6, b(1).

⁹⁰ 16 Del.C. §9405A(e)(2).

⁹¹ AS §13.56.020(1).

⁹² 16 Del.C. §9406A(b)(1).

⁹³ AS §13.56.020(2).

⁹⁴ DC ST §7-761.01-13, S. 302(a)(1).

⁹⁵ 210 I.L.C.S. §9/5-9/99, S. 20(3).

⁹⁶ RI ST §42-66.13-6(b)(3).

⁹⁷ 16 Del.C. §9406A(b)(3).

⁹⁸ AS §13.56.020(3).

⁹⁹ W.S.A. §52.30(1).

¹⁰⁰ DC ST §7-761.01-13, T. III, S. 302(b)(A)(i).

¹⁰¹ W.S.A. §52.14(2)(a).

or, an enumerated series of crimes, primarily involving physical violence and financial malfeasance (District of Columbia).¹⁰²

3.4.7. *What Supporters can do*

Most states provide that supporters can assist the Decision-Maker in gathering information, understanding the information, considering alternatives, weighing the consequences of a decision, and communicating the decision to third parties (i.e., Texas¹⁰³).

Other statutes include provisions that are, or are perceived as problematic because they permit supporters to actually do things *for* the Decision-Maker, rather than supporting them in making decisions, e.g., “assist[ing] in making appointments, implementing a service plan and monitoring support services” (Nevada,¹⁰⁴ Illinois¹⁰⁵) or “keep[ing] track of future necessary or recommended services” (Delaware).¹⁰⁶ Critics argue that granting more extensive powers to supporters may, or does, transform them into substitute decision-makers, or what I would refer to as “guardians on the cheap”.¹⁰⁷ That argument, has intensified as New Hampshire’s¹⁰⁸ recent statute includes, in its statement of legislative purpose, “giv[ing] legal status to supporters of . . . people[with disabilities].”

Questions about actual or assumed independent powers and legal status of supporters are troubling because of the potential for abuse or exploitation of the Decision-Maker; that potential is greatly exacerbated by the absence of any requirements for educating or facilitating Decision-Makers and supporters discussed below.

The danger of conferring legal status on supporters is not only about abuse or exploitation of the relationship. Most statutes attempt protection by imposing various kinds of responsibilities, discussed below. Those protections – whose efficacy and enforceability are problematic at best – fail to deal with a real threat to legal capacity, the possibility or likelihood that supporters, especially those with actual or assumed power, will slip back into substitute decision-making and paternalism, the very antithesis of support for the exercise of autonomy and legal capacity.

¹⁰² DC ST §7-761.01-13, T. III, S. 302(b)(B).

¹⁰³ TX EST §1357.051(1).

¹⁰⁴ N.R.S. §162C.320, S. 13.1.(c).

¹⁰⁵ 210 I.L.C.S. §9/5-9/99, S. 30(4).

¹⁰⁶ 16 Del.C. §9406A(a)(4).

¹⁰⁷ N. KOHN, “Legislating Supported Decision-Making”, (2021) 58 *Harvard Journal on Legislation* 313, 336–337.

¹⁰⁸ NH ST §464–D:1.

3.4.8. *Supporter Access to Information*

Although important to support, especially in areas of health and education, provisions concerning supporter access are primarily relevant to CRPD legal capacity in protections they provide, including imposing a duty of confidentiality, (e.g., Rhode Island,¹⁰⁹ North Dakota,¹¹⁰ Wisconsin¹¹¹) and/or requirements “properly dispose of such records when appropriate”.¹¹²

3.4.9. *Supporter Obligations, Liability, and Immunity*

Statutes impose a variety of obligations on supporters, including the traditional duty of care, (e.g., Nevada¹¹³), or, in two states, the heightened obligations of a fiduciary (Texas,¹¹⁴ New Hampshire¹¹⁵) A number require/limit supporters to acting within “the scope of the agreement” (e.g., Indiana¹¹⁶). Statutes also commonly contain prohibitions against exerting undue influence (e.g., Delaware,¹¹⁷ Indiana,¹¹⁸ Alaska¹¹⁹) but also, relevant to legal capacity, “making decisions on behalf of” the adult (Delaware,¹²⁰ Alaska¹²¹), signing agreements or binding the person to a legal agreement (e.g. Alaska,¹²² Wisconsin¹²³) or requiring supporters to “[s]upport the will and preference of the adult, and not the supporter’s opinion of the adult’s best interests” (Indiana¹²⁴). Notably, procedures for enforcing such obligation are entirely lacking. Indiana prohibits supporters from receiving a fee for services performed in the role of supporter (Indiana¹²⁵). These limitations are controversial, and bear on legal capacity because many Decision-Makers, especially older persons without natural supports, have no one *but* direct service providers, with whom they may have long and trusting relationships, to support them in their exercise of legal capacity.

¹⁰⁹ RI ST §42-66.13-8(b).

¹¹⁰ ND ST §14-09-31, Chapter 30.1-36, Code 30.1-36-06.

¹¹¹ W.S.A. §52.16(4).

¹¹² N.R.S. §162C.320, S. 14.2(c).

¹¹³ N.R.S. §162C.320, S. 13.3.

¹¹⁴ TX EST §1357.052(b).

¹¹⁵ NH ST §563-B:4(a)(2).

¹¹⁶ IN ST §29-3-14, S. 4, c, 14, s. 5(a)(1).

¹¹⁷ 16 Del.C. §9405A(a)(1).

¹¹⁸ IN ST §29-3-14, S. 4 (a)(1).

¹¹⁹ AS §13.56.110(1).

¹²⁰ 16 Del.C. §9406A(c)(1).

¹²¹ AS §13.56.110(2).

¹²² AS §13.56.110(2).

¹²³ W.S.A. §52.10(2).

¹²⁴ IN ST §29-3-14, S. 5(a)(1).

¹²⁵ IN ST §29-3-14, S. 5, (c)(2).

Finally, a few statutes provide supporters immunity against the Decision-Maker so long as they act in good faith and compliance with the SDMA (Wisconsin¹²⁶).

3.4.10. *Amending or Terminating the SDMA*

Among existing statutes, only New York provides for changing terms of the agreement such as the areas in which the Decision-Maker wishes support, or the kinds of support they wish to receive. New York speaks explicitly of the Decision-Maker's right to *amend* or terminate the agreement at any time, setting out requirements for both.¹²⁷

The fragility of legal capacity conferred by SDMA statutes is underscored by the many grounds upon which those agreements can be terminated by, or because of, the actions of others. Although lacking any stated procedure or authorisation, statutes provide for termination or revocation based on a supporter's criminal conviction (on any number of enumerated crimes) or issuance of a restraining order against a supporter (Illinois,¹²⁸ North Dakota¹²⁹); or a court finding that a supporter has used the agreement to commit financial exploitation, abuse, or neglect of the adult (Indiana,¹³⁰ Texas¹³¹), or if the named supporters withdraw their participation without naming successor supporters (Indiana¹³²). Most disturbing, one statute provides for termination on a retroactive finding that the Principal lacked capacity to enter into the agreement (Indiana¹³³).

3.4.11. *Third Party Obligation under the Agreement*

The legally imposed obligation that third parties must accept decisions made pursuant to an SDMA, cannot impose their own view of a person's legal capacity, and are bound by the decision is the primary means to ensure legal capacity for persons with developmental, cognitive, and psychosocial disabilities. A typical provision reads:

A decision or request made or communicated with the assistance of a supporter in conformity with this chapter shall be recognized for the purposes of any provision of law as the decision or request of the principal and may be enforced in law or equity on the same basis as a decision or request of the principal. (N.H. 464-D:11)

¹²⁶ W.S.A. §52.30(2).

¹²⁷ NY Men. Hyg. L, 82.07.

¹²⁸ 210 I.L.C.S. §9/5-9/99, S. 70, (b)(2).

¹²⁹ ND ST §14-09-31, S. 1, p.3.3.b.

¹³⁰ IN ST §29-3-14, S. 4, c, 14, s. 9(a)(5).

¹³¹ TX EST §1357.53(b)(1).

¹³² IN ST §29-3-14, S. 4, c, 14, s. 9(a)(3).

¹³³ C.R.S.A. §15-1.5-110.

There is, however, a considerable, if unintended split in what states are actually recognising: the *agreement*, or *decisions* made pursuant to the agreement. SDMA's frequently contain a provision that the Decision-Maker is not required to use the support provided for in the agreement in making any particular decision. If the state requires recognition of a decision *because of* the use of supports, how does a third party know if the Decision-Maker actually utilised the support described in the agreement?

In requiring recognition of a decision, some statutes require third parties to rely on (presumably the existence of) the agreement (Texas,¹³⁴ Colorado,¹³⁵ Illinois¹³⁶). A common provision, requiring recognition of a “decision or request made or communicated with the assistance of a supporter in conformity with [this law]” (e.g., Delaware,¹³⁷ Rhode Island,¹³⁸ Alaska,¹³⁹ Indiana¹⁴⁰) leaves ambiguous the issue of whether or not the Principal used the support set forth in the SDMA.

Any guarantee of legal capacity is undermined by eschewing mandatory recognition, instead substituting the discretionary “may” (Delaware,¹⁴¹ Indiana¹⁴²). Furthermore, in some states, third parties may decline to recognise a decision if they believe in good faith that the agreement is “invalid” or has been terminated (e.g., Texas,¹⁴³ Wisconsin,¹⁴⁴ Indiana¹⁴⁵).

Some statutes provide “conscience” or religious belief, and “medical judgment” exceptions, like Delaware¹⁴⁶ and Alaska¹⁴⁷ which permit third parties to “declin[e] to comply with authorizations related to health care contrary to conscience, or good faith medical judgment or the provisions of a written institutional policy on conscience.”

3.4.12. *Immunity from Liability*

Because the U.S. is so litigious and liability-conscious, immunity from liability for good faith recognition of decisions is a *sine qua non* for ensuring legal capacity. If third parties see a person's disability as raising the possibility that their capacity

¹³⁴ TX EST §1357.101(a).

¹³⁵ C.R.S.A. §15-14-806.

¹³⁶ 210 I.L.C.S. §9/5-9/99, S. 55(a).

¹³⁷ 16 Del.C. §9407A.

¹³⁸ RI ST §42-66.13-7.

¹³⁹ AS §13.56.030.

¹⁴⁰ IN ST §29-3-14, S. 4, c, 14, s. 6.

¹⁴¹ 16 Del.C. §9401A(c).

¹⁴² IN ST §29-3-14, S. 4, c, 14, s. 10.

¹⁴³ TX EST §1357.101(b).

¹⁴⁴ W.S.A. §52.30(3).

¹⁴⁵ IN ST §29-3-14, S. 4, c, 14, s. 11(a).

¹⁴⁶ 16 Del.C. §9408A(3).

¹⁴⁷ AS §13.56.040(a)(3).

could be challenged later, and the transaction (including “informed consent” for medical care) undone, statutory relief from liability is essential.

Most statutes specifically relieve third parties from civil and criminal liability and/or professional discipline for good faith reliance on an SDMA or decision made pursuant to it (e.g., District of Columbia,¹⁴⁸ Texas,¹⁴⁹ Delaware,¹⁵⁰ Alaska,¹⁵¹ Illinois,¹⁵² Colorado¹⁵³), or against potential claims of medical malpractice (Wisconsin¹⁵⁴). There are exceptions: Indiana¹⁵⁵ denies immunity if the third party’s “act or omission amounts to fraud, misrepresentation, recklessness, or willful or wanton misconduct”. New Hampshire,¹⁵⁶ however, makes no provision for immunity, effectively undercutting any guarantee of legal capacity.

3.4.13. *Third Party Reporting of Abuse, Neglect, and/or Exploitation*

One important argument for SDMA statutes is that they create many “watchful eyes”, permitting third parties to disregard decisions where there may be abuse, neglect or exploitation, (Texas,¹⁵⁷ North Dakota¹⁵⁸), or the person “is in need of protective services” (District of Columbia¹⁵⁹), and permitting or requiring third parties to notify the appropriate government entities (e.g., Texas,¹⁶⁰ Rhode Island,¹⁶¹ Illinois,¹⁶² New Hampshire¹⁶³). There is, however, an unexamined confusion between the purpose of these provisions. Are they intended to protect the *decision*, and the decision-making process, as CRPD Article 12(4) requires? Or, are they a new, additional, mostly private system to protect the *person* with a SDMA? If the former, undue influence, abuse and/or exploitation may be relevant, while neglect in general is not. If the former, only persons actually asked to accept or honour a decision should be included; if the latter, anyone with knowledge that a person with a SDMA is being abused or neglected is empowered to report to the appropriate state agency and be protected for doing

¹⁴⁸ DC ST §7-761.01-13, S. 303(e).

¹⁴⁹ TX EST §1357.101(b).

¹⁵⁰ 16 Del.C. §9408A.

¹⁵¹ AS §13.56.040(a).

¹⁵² 210 I.L.C.S. §9/5-9/99, S. 55(b).

¹⁵³ C.R.S.A. §15-14-806(2).

¹⁵⁴ W.S.A. §52.30(1).

¹⁵⁵ IN ST §29-3-14, S. 4, c, 14, s.11(c).

¹⁵⁶ NH ST §563-B:17.

¹⁵⁷ TX EST §1357.053(b)(1).

¹⁵⁸ ND ST §14-09-31, S. 1, p.3(1)(a).

¹⁵⁹ DC ST §7-761.01-13, T. III, S. 303(c)(1).

¹⁶⁰ TX EST §1357.102.

¹⁶¹ RI ST §42-66.13-9.

¹⁶² 210 I.L.C.S. §9/5-9/99, S. 65.

¹⁶³ NH ST §464-D:14.

so. (e.g., Texas,¹⁶⁴ Rhode Island,¹⁶⁵ Illinois,¹⁶⁶ New Hampshire¹⁶⁷). Expansion of voluntary reporters raises real possibilities for misuse, including by vindictive former spouses who use claims of abuse or neglect to punish or control, or seek financial or other advantage, undermining or disincentivising the use of SDMA.

3.4.14. *Education/Training*

Until recently, no statute contained any provision for educating/training either Decision-Makers or supporters. Virginia and Illinois have modest provisions for creating materials and/or training opportunities, thus far undeveloped, while New York, alone, conditions legislative recognition on agreements made pursuant to a meaningful facilitation process.¹⁶⁸ See section 4.3 below.

3.4.15. *Monitoring*

Although the prototype for all SDMA statutes, the British Columbia Representation Act (B.C. 1990) provided, in considerable detail, for appointment of “monitors”, no U.S statute included any provision for such role until New Hampshire which permits Decision-Makers to “designate a monitor” to ensure that supporters are complying with statutory provisions on “Authority of Supporters” and “Duties of Supporters,” including duties deriving from a fiduciary relationship.

4. CRITIQUES OF EXISTING STATUTES

4.1. MIXED MOTIVES: THE CASE OF TEXAS

As an extensive study demonstrated, Texas, the first state to pass a SDMA statute, was driven not by human rights, but concern about courts’ ability to process and monitor the enormous influx of guardianship cases predicted to accompany an aging population. This “ma[de] supported decision-making an attractive policy to pursue for stakeholders like state legislators, judges, and court administrators ... [and] to conservatives who favor small government”.¹⁶⁹

¹⁶⁴ TX EST §1357.102.

¹⁶⁵ RI ST §42-66.13-5.

¹⁶⁶ 210 I.L.C.S. §9/5-9/99, S. 65.

¹⁶⁷ NH ST §464-D:14.

¹⁶⁸ NY Men. Hyg. L. 82.11.

¹⁶⁹ E. J. THEODOROU, “Supported decision-making in the lone-start state” (2018) 93 *NYUL Rev.* 973.

A coalition of disability rights activists and these more conservative, cost-driven stakeholders, resulted in compromises, including adoption of a “moderate position on [SDM]” and an apparent concession that a more traditional standard of mental capacity, similar to that required for a power of attorney would be necessary for a valid SDMA.¹⁷⁰ This understanding has been confirmed by the only reported judicial decision to date. An appellate court held that, in a guardianship proceeding, SDM was not an alternative because the “[Respondent was] incapacitated and cannot make important life decisions for herself.”¹⁷¹ The lesson here is that when SDMA legislation is primarily driven by prospective cost-saving, the result is unlikely to achieve legal capacity for anyone who does not already possess it.

4.2. WHAT IS (BUT SHOULD NOT BE) IN THE STATUTES

A recent article by the most prominent U.S. interrogator of SDM and critic of related legislation,¹⁷² reads existing statutes as legally empowering supporters, giving them legal status, and creating a kind of “guardianship on the cheap” that deprives people with disabilities of autonomy, and potentially subjects them to abuse and exploitation.¹⁷³ The critique relies on provisions in Alaska and Delaware statutes permitting supporters to independently enforce a decision made by the Decision-Maker (Alaska, 2017; Delaware, 2016).

Kohn also charges that, rather than expanding the rights of people with disabilities to make their own decisions, SDMA statutes limit those rights by imposing restrictions on who can be supporters, how agreements can be revoked, etc. To make clear that informal supported decision-making is *not* being curtailed, New York’s statute provides

The availability of [SDMAs] is, in no way, intended to limit the use of informal supported decision-making, or to preclude judicial consideration of such informal arrangements as less restrictive alternatives to guardianship.¹⁷⁴

¹⁷⁰ E. J. THEODOROU, “Supported decision-making in the lone-start state” (2018) 93 *NYUL Rev.* 973.

¹⁷¹ *In re Guardianship of A.E.*, 552 S.W.3d at 879, 880 (Texas S. Ct., 2018).

¹⁷² N. COHN, J. BLUMENTHAL and A. CAMPBELL, “Supported decision-making: A viable alternative to guardianship” (2013) 117 *Penn St. L. Rev.* 1111.

¹⁷³ N. KOHN, “Legislating Supported Decision-Making” (2021) 58 *Harvard Journal on Legislation* 313.

¹⁷⁴ 2021 NY S.B. 7107 (NS).

4.3. WHAT IS MISSING FROM THE STATUTES

Aside from the indeterminate, minimal education/training requirements still to be developed pursuant to Virginia and Illinois statutes, and with the exception of New York, existing statutes require neither meaningful training nor education for Decision-Makers and/or supporters. Yet every pilot project internationally¹⁷⁵ and the U.S.¹⁷⁶ has utilised a facilitation process through which trained facilitators assist Decision-Makers to understand how decisions are made, and the steps to go into them, determine areas in which they desire support and the kinds of support they wish. Similarly, supporters learn to move from their pre-existing roles with Decision-Makers, understand the “dignity of risk”, and commit to supporting Decision-Makers in making their own decisions, rather than substituting a paternalistic “best interest” test. An authentic facilitation process is the only means that has been demonstrated to “offe[r] genuine support rather than being surrogate decision-making in disguise.”¹⁷⁷

The facilitation processes already developed have been used almost exclusively for persons with developmental disabilities; there is no similar body of empirical work demonstrating what might constitute adequate supports for members of any other groups whose legal capacity is denied or at risk, including older persons with cognitive decline, dementia, etc.,¹⁷⁸ and persons with psychosocial disabilities, or traumatic brain-injuries,¹⁷⁹ yet all of them are presumptively included among those who can make SDMAs.

The experience of all these pilot projects, especially the large New York pilot (see below), has demonstrated that it takes real work, over time, to create a process by which persons with developmental disabilities come to see themselves as decision-makers, understand what goes into making a decision, and where and how they need support from others. Similarly, amplified by empirical studies in Australia,¹⁸⁰ it is clear that without training or substantial capacity-building, even the most well-intentioned supporters can quickly fall back into a more familiar and paternalistic role of substitute decision-making.

¹⁷⁵ K. GLEN, “Not Just Guardianship: ‘Supported Decision Making From Theory To Practice: Further Reflections On An Intentional Pilot Project’” (2020) 13 *Albany Government Law Review* 94.

¹⁷⁶ E. PELL and V. MULKERN, “Supported decision making pilot: Pilot program evaluation year 1 report” (2015) *Human Service Research Institute*, Boston, MS, USA.

¹⁷⁷ E. LARGENT et al., “Supported Decision-Making in the United States and Abroad” (2021) 23 *J. Health Care L. & Pol’y* 271.

¹⁷⁸ R. DILLER, “Legal capacity for all: Including older persons in the shift from adult guardianship to supported decision-making” (2016) 43 *Fordham Urb. L.J.* 495.

¹⁷⁹ K. GLEN, “Supported Decision-Making: What You Need to Know and Why” (2018) 23 *NYSBA Health L. J.* 93.

¹⁸⁰ C. BIGBY et al., “Delivering decision making support to people with cognitive disability – what has been learned from pilot programs in Australia from 2010 to 2015” (2017) 52(3) *Australian Journal of Social Issues* 222–240.

5. SUPPORTED DECISION-MAKING NEW YORK (SDMNY): A SUCCESSFUL EMPIRICAL MODEL ADVANCING THE RIGHT OF LEGAL CAPACITY

5.1. THE MODEL

Supported Decision-Making New York (SDMNY) is a large pilot project funded by state agencies and private foundations in New York state. Since 2016 it has drawn on legal capacity work by pilot projects around the world to develop and pilot a three-phase facilitation model to enable people with developmental disabilities to make their own decisions with the support and supporters they choose, and to memorialise that process in a SDMA.¹⁸¹ Based on its experience, SDMNY developed “Principles for Supported Decision Making Agreement Legislation”¹⁸² that has been essentially incorporated in New York’s statute; designed a cost-effective service delivery model through which the state could enable SDM facilitation for anyone who wants it;¹⁸³ and been awarded a \$4 million, three-year grant to pilot that model.

5.2. LEARNINGS FROM THE PROJECT

Although funding focused on promoting SDM as an alternative to guardianship, the project has always been based on the human right of legal capacity, and participants are inspired by being part of a world-wide movement.¹⁸⁴ SDMNY’s facilitation model is about much more than reaching a signed agreement that confers legal recognition. It is about spending the necessary time and effort to empower Decision-Makers to understand and make their own decisions, and to become agents in their own lives, entitled to dignity, equality, and non-discrimination.

While, at least in the U.S., it may be politically advantageous to characterise SDM as an alternative to guardianship, or related legislation as “civil rights” or “anti-discrimination” laws for people with developmental disabilities, SDMNY’s

¹⁸¹ K. GLEN, “Not Just Guardianship: ‘Supported Decision Making From Theory To Practice: Further Reflections On An Intentional Pilot Project’ (2020) 13(1) *Albany Government Law Review*.

¹⁸² See Supported Decision Making New York, “Principles for Supported Decision Making Agreement (SDMA) Legislation” <<https://sdmny.org/supported-decision-making-legislation/principles-for-supported-decision-making-agreements-in-new-york/principles-for-a-supported-decision-making-agreement-sdma-law-long/>> accessed 06.07.2022.

¹⁸³ STOUT RISIUS ROSS, *The Estimated Economic Impact of Facilitated Supported Decision-Making in New York*, 2022.

¹⁸⁴ K. GLEN, “Supported Decision-Making: What You Need to Know and Why” (2018) 23 *NYSBA Health L. J.* 93.

strategy and experience demonstrate and embody the necessary conditions for legal capacity as defined by the CRPD: state-provided support for *making decisions* (the facilitation process) and state-provided support (through recognition in legislation) to ensure that those decisions are *legally recognised*.

Another important learning is the importance of changing the educational system to include SDM to advance legal capacity for many people with developmental disabilities. If, from an early age, children were taught how to make decisions, where they need support, and how to get it, guardianship would disappear for the vast majority of those on whom it might have been imposed, and people with developmental disabilities would develop the self-determination, autonomy and skills to enable them to exercise legal capacity and live good, inclusive lives.

6. CHALLENGES AND BARRIERS TO ADVANCING LEGAL CAPACITY THROUGH SDM

1. There are no well-developed, empirically tested models for giving authentic decision-making support to older persons with cognitive decline and dementia, persons with psychosocial disabilities, and those with traumatic brain injuries. The extensive work done to create and pilot models for people with developmental disabilities shows that there is no “one-size-fits-all” model easily transferable to other at-risk populations. Time and resources are required to develop appropriate disability-specific supports as the New York statute specifically notes, urging government and civil society to undertake that work “... so that full legislative recognition can also be accorded to the decisions made with [SDMAs] by persons with such conditions, based on a consensus about what kinds of support are most effective and how they can best be delivered.”¹⁸⁵
2. There is enormous and pervasive scepticism about the ability of persons with severe impairments to make their own decisions with support, and no empirical models exist to disprove that scepticism or provide the basis for their credibly entering into supported decision-making agreements.
3. To the extent that full, or near-full, recognition and/or enabling of legal capacity is tied to SDM, the existence of a social network from which supporters can be drawn is critical. Yet many persons who could benefit from SDM and related agreements lack any such network or social capital sufficient to create one.

¹⁸⁵ NY Men. Hyg. L. 82.01(d).

7. THE FUTURE OF AN EQUAL RIGHT TO EXERCISE LEGAL CAPACITY IN THE U.S.

Modest changes in guardianship statutes, and/or SDMA statutes that may decrease guardianship, but lack provisions for effective decision-making supports do not meaningfully advance the right of legal capacity in the U.S.

The New York experience, however, offers a potential blueprint. It demonstrates the importance of initiating and building on incremental projects to promote SDM as an alternative to guardianship, encouraging and incentivising a facilitation model leading to SDMA, providing state funding for that model, and granting legislative recognition to decisions made pursuant to facilitation-enabled SDMA.

Substantial pent-up demand exists for a viable SDM model for older persons with cognitive disabilities and dementia.¹⁸⁶ There is more nascent attention to how SDM could address the unique issues facing persons with psychosocial disabilities. Progress in these areas depends on SDMA legislation that requires meaningful, disability-specific supports.

Such legislation can potentially limit or end denial of legal capacity to persons to whom it would otherwise be denied in numerous situations where some form of “mental capacity” is required for legal transactions.¹⁸⁷ The existence of legislation alone, however, is not enough. Comprehensive education reaching all who are potentially involved – persons with SDMA, private and public third parties with whom they deal, lawyers and judges – is also necessary.

As more people use SDM and SDMA, guardianship will presumably decline, especially for young adults with developmental disabilities. Public consciousness about their abilities should increase, as it has for persons with mobility, visual and hearing disabilities who utilise accommodations. Increased consciousness should also, albeit slowly, decrease discrimination against, and denial of legal capacity to, people with “mental” disabilities by third parties, both public and private.

Finally, a small but growing understanding that “Disability Rights are Human Rights”, together with increased attention to the rights of vulnerable populations (who are racialised, ethnically diverse, living in poverty, LGBTQ+ community members, and/or gender-diverse) provides opportunities for coalition-building that can begin to focus attention on a human rights agenda that includes legal capacity for everyone, regardless of disability.

¹⁸⁶ M. S. WRIGHT, “Dementia, autonomy, and supported healthcare decision making” (2020) 79 *Md. L. Rev.* 257.

¹⁸⁷ K. GLEN, “Not Just Guardianship: Uncovering The Invisible Taxonomy Of Laws, Regulations And Decisions That Limit Or Deny The Right Of Legal Capacity For Persons With Intellectual And Developmental Disabilities” (2020) 13(1) *Albany Government Law Review*.