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Emerging International Trends and Practices in Guardianship Law for People with Disabilities

Robert Dinerstein

EMERGING INTERNATIONAL TRENDS AND PRACTICES IN GUARDIANSHIP LAW FOR PEOPLE WITH DISABILITIES

Robert Dinerstein,[*] *Esmé Grant Grewal,*[**] *& Jonathan Martinis*[***]

* Professor of Law and Associate Dean for Experiential Education, American University, Washington College of Law.

** Senior Director of Government Relations, American Network of Community Options and Resources (ANCOR).

*** Senior Director for Law and Policy, The Burton Blatt Institute at Syracuse University.

I. INTRODUCTION

A. Definition and Background of Adult Guardianship Law

The concept of adult guardianship has existed for hundreds of centuries in the international sphere and dates back to ancient Greek and Roman times and English common law.[1] An example of this concept is the legal terminology of *parens patriae*, which is Latin for "father of his country" and represents the doctrine that government is the ultimate guardian of people who cannot care for themselves, including people with disabilities. As a result of the longstanding principle that adults could have other adults legally appointed to make legal decisions on their behalf, countries across the globe have integrated the concept of adult guardianship into their national and provincial legal systems with a focus on adults with disabilities of all ages as well as a growing class of elderly adults.[2]

The legal construct of adult guardianship allows a court system to appoint decision-making powers to another person on behalf of an individual with a disability or elderly person to provide protections to that individual based on a theory of their inability to make sound legal decisions. In recent decades, the system of guardianship has been challenged for its ability to effectively protect and fulfill the rights of the individual whom it serves, and further for its lack of oversight and broad coverage. In countries like the United States, the adult legal guardianship system is managed individually by its fifty states, with various standards and legal processes in place.[3] These complicated variances are further challenged by emerging disability rights law that has developed globally at a rapid pace in the past several decades. On the other hand, guardianship law has in many circumstances played an important role in achieving its goal of protecting an individual's rights when that individual may not be fully aware of the consequences of a legal decision to be made.

This article seeks to explore the recent history of guardianship in international law as well as developments that have occurred as a result of international diplomacy and discourse. Using the United States as an example, we will explain how international advancements and concepts have influenced one country's approach to adult guardianship law. Although this article does not seek to take a position on legal guardianships nor their alternatives, we aim to promote additional dialogue and thought on this topic in the hopes that it will have a positive impact on international policy and

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1. MARY JOY QUINN, GUARDIANSHIPS OF ADULTS: ACHIEVING JUSTICE, AUTONOMY, AND SAFETY 18 (2005).

2. *Id.* at 19.

3. *Id.* at 22.

development for the more than one billion people with disabilities around the world.[4]

B. Recent International Developments in Adult Guardianship Law

Although, as aforementioned, adult guardianship has existed in legal frameworks around the world for centuries, it is only within the past several decades that there have been proposals to make significant changes to its application. In fact, many of the formal conversations concerning altered approaches to adult guardianship have occurred in the 21st century alone. In order to understand current legal developments in adult guardianship, it is important to understand three key international agreements that have set the tone for evolution in future lawmaking regarding guardianship law.

1. The Hague Convention on the International Protection of Adults

The 2000 Hague Convention on the International Protection of Adults sets out standards, for the first time in modern history, for how nation states handle issues of adults and their property in international disputes when the adult may not have the legal capacity to protect his or her interests.[5] Guardianship is one key scenario that the Hague Convention lays out in Article 3 as a primary reason for its coverage.[6] The treaty was enacted in January 2000, but its origins are more than a century old, based on the 1905 Convention Relating to Deprivation of Civil Rights and Similar Measures of Protection.[7] The Hague Convention updates and replaces this previous treaty and establishes clear boundaries determining which nation state's laws are in play when a specific international situation arises concerning an individual with established incapacity and guardianship.

One example, *In re PO*, describes the case of a woman who moved from England to Scotland due to the decisions several of her children made on her behalf.[8] Although three of her children agreed to her move to Scotland, a

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4. *Disability and Health Fact Sheet,* THE WORLD HEALTH ORG. [hereinafter WHO] (2015), http://www.who.int/mediacentre/factsheets/fs352/en/.

5. *35: Convention of 13 January 2000 on the International Protection of Adults: Status Table*, HAGUE CONF. ON PRIV. INT'L LAW, https://www.hcch.net/en/instruments/conventions/status-table/?cid=71 (last visited Feb. 1, 2016).

6. Hague Conference on Private International Law: Convention on the International Protection of Adults art. 3, Jan. 13, 2000, 39 I.L.M. 7.

7. *Id.* at art. 48.

8. Alexander Ruck Keene, *The 2000 Hague Convention on the International Protection of Adults Five Years On*, 39 ESSEX CHAMBERS, Mar. 2014, at 8, www.39essex.com/docs/.../the_2000_convention_-_five_years_on.pdf.

fourth child filed suit arguing that their mother should remain in England.[9] In order to determine whether English or Scottish law applied, the court looked at the question of habitual residence described in Article 5 of the Hague Convention. Section 5(2) of the Hague Convention establishes that in the case of a change of the adult's habitual residence to another contracting state to the Convention, the authorities of the state of the new habitual residence have jurisdiction.[10] Thus, in the case at hand, Scottish law applied as to determinations of the validity of the guardianship decisions.[11]

Interestingly, habitual residence is not defined by the Convention. But in making the determination that Scottish law applied, the Court considered that the mother, PO, was happily settled in her current residence and that she did not express an interest in moving back to England.[12] Such considerations preview the process of supported decision-making ("SDM") that will be discussed in forthcoming sections of this article.

In sum, the Hague Convention not only established international jurisdiction as to guardianship laws, but also began to apply a new set of considerations and a modern approach when making such determinations.

2. The Convention on the Rights of Persons with Disabilities

Perhaps the most well-known instrument of disability rights law in the world, the Convention on the Rights of Persons with Disabilities ("CRPD") established a roadmap for implementing disability rights within a national legal framework.[13] The drafting of the CRPD began in the United Nations in 2001 with participation of various states parties and civil societies, including leading members of the disability community from around the globe. The content of the treaty ranged broadly to include, among other things, access to transportation, employment, community living, recreation, health, voting, and education.[14] The CRPD ultimately entered into force on May 3, 2008, and has been ratified by 162 countries, with its impact ranging from development of new laws meeting the treaty's rule of law standard to inclusion of disability rights in national constitutions for the first time.[15]

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9. *Id.*

10. Hague Conf. on Priv. Int'l Law: Convention on the Int'l Prot. of Adults, *supra* note 6, at art. 5.

11. Keene, *supra* note 8, at 8.

12. *Id.*

13. G.A. Res. 61/106, U.N. Doc. A/61/611, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006) [hereinafter CRPD].

14. *Id.* at arts. 9, 27, 19, 30, 25, 29, & 24.

15. *CRPD Latest Developments*, UN DIVISION FOR SOC. POLICY AND DEVELOPMENT DISABILITY, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/latest-developments.html (last visited Feb. 24, 2016).

Notably, one key provision took advocates and state parties' representatives a relatively long time to finalize during the preliminary treaty negotiations.[16] What ultimately became Article 12 in the treaty was an article addressing the right of people with disabilities to have "equal recognition before the law."[17] This section set out that "State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with other in all aspects of life."[18] It also noted that some people would need support to exercise their legal capacity, and provided that States Parties be required to provide access to such support.[19]

This article will discuss article 12 of the CRPD in greater detail in forthcoming sections. Importantly, this section of the Convention reflects a tension between the relatively new concept of SDM—one way that people with disabilities can receive support for their legal capacity—and the long-standing practice of guardianship, with the interplay between the concepts heralding a new era of thinking about adult guardianship law in the world.[20]

3. The Yokohama Declaration

One of the more recent developments in international trends in guardianship is the Yokohama Declaration. This international declaration, unlike the previous agreements discussed, was not a formal agreement between nations but exists in the hopes that individual countries will adopt its underlying principles. The Yokohama Declaration on Adult Guardianship emerged from the October 2010 First World Congress on Adult Guardianship law which took place in Yokohama, Japan.[21] The World Congress is made up of hundreds of delegates comprising academics, attorneys, court officials, judges, disability advocates, government officials, guardians and fiduciaries from twenty countries.[22]

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16. 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, 438–56 (2007).

17. *CRPD*, *supra* note 13, at art. 12.

18. *Id.* at art. 12, ¶ 2.

19. *Id.* at art. 12, ¶ 3.

20. One example of negotiations between States Parties for the CRPD on May 26, 2004, illustrates varying perspectives on the prioritization of equality before the law, the use of guardianship, and the correct language and process to be applied. Ad Hoc Comm. on the Comprehensive and Integral Int'l Convention on the Prot. and Promotion of Rights and Dignity of Persons with Disabilities, Rep. of the Third Sess., Daily Summary, U.N. Doc. A/AC.265/2004/5 (May 26, 2004).

21. First World Conference on Adult Guardianship, Yokohama Declaration, Oct. 4, 2010, http://www.international-guardianship.com/pdf/IGN-Yokohama_Declaration_2010.pdf [hereinafter *Yokohama Declaration*].

22. *World Congress on Adult Guardianship*, 34 BIFOCAL 6 (2013).

The Yokohoma Declaration affirms the principles of the Hague Convention and CRPD and was instigated by the sense that many countries had not integrated modern thinking in regards to decision-making for individuals found to lack mental capacity. It vocally supported new methods of applying guardianship law including the use of "substituted proxy decision-making"[23] or, as this article will discuss further, "supported decision-making." The declaration urges countries to enact legislation that respects and follows an adult's wishes, values and beliefs to the greatest possible extent and ultimately will not result in harm to the adult.[24] Ultimately, this declaration has emphasized the need for more dialogue on the application of adult guardianship law and development of solutions to ensure that it is being applied in a person-centered, situation-specific manner.

Together, the Hague Convention, CRPD, and Yokohoma Declaration represent a body of work by civil societies and nation states to address the need to revisit the model of adult guardianship law that has existed internationally for centuries. With the rapid development of disability rights laws around the world in the past three decades alone, paired with the growing population of people with disabilities and the aging community globally, this discussion has created an impetus for a wave of legal modification. In the following sections, this article will describe more fully the result of these interchanges, how guardianship law has changed as a result of international diplomacy, and, finally, how those changes have reverberated into domestic policies.

II. SUPPORTED DECISION-MAKING AS AN ALTERNATIVE TO GUARDIANSHIP

A. Definition of Supported decision-making and its Relationship to Guardianship

The basic problem that modern adult guardianship attempts to address is how to enable individuals who may lack mental or cognitive capacity to participate in decision-making related to critical areas in their lives, such as where and with whom to live; with whom to have a personal relationship (intimate or otherwise); what kinds of health care services use; what kinds of financial arrangements (opening bank accounts, purchasing goods) into which to enter; and what kinds of work and activities in which to engage, to name just some such areas.[25] Because it is believed that the adult cannot

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23. *Yokohama Declaration, supra* note 21, at I (1)[6].

24. *Yokohama Declaration*, INTERNATIONAL GUARDIANSHIP NETWORK (Oct. 4, 2010), http://www.international-guardianship.com/pdf/IGN-Yokohama_Declaration_2010.pdf.

25. *See e.g.*, Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN*

make these decisions on his or own, the guardian acts as a surrogate decision maker to make decisions "for" the allegedly incapacitated adult, bounded, in theory, by a standard of decision-making, called substituted judgment, that entails making the decision that the individual would make if he or she had the capacity to do so. Plenary guardianship entails the guardian making all decisions for the individual; limited guardianship seeks to identify only those specific areas in which the individual needs decision-making assistance. Because guardianship takes away a substantial liberty right of the adult individual, the right to make decisions, a court should not grant an order seeking guardianship unless it is the least restrictive alternative available to meet the person's need for decision-making assistance.

Guardianship has been the subject of significant reforms in recent years.[26] "Important as these reforms of guardianship have been, however, they still accept the predominance of a legal regime that locates decision-making in the surrogate or guardian and not in the individual being assisted."[27] Unlike guardianship, SDM (which is one way in which supports can be provided)[28] "retains the individual as the primary decision maker, while recognizing that the individual with a disability may need assistance—and perhaps a great deal of it—in making and communicating a decision."[29] The move from substitute decision-making to SDM is nothing less than a paradigm shift in the way we think about the decision-making capabilities of people with disabilities.[30]

How then should we define SDM. As one of us has written elsewhere:

> Supported decision-making can be defined as a series of relationships, practices, arrangements and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life.[31]

Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making, 19 HUM. RTS. BRIEF 8, 9 (2012).

26. *See id.* at 9–10; Kristin Booth Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, 3(1) INCLUSION 1, 3–4 (March 2015).

27. Dinerstein, *supra* note 25, at 10.

28. CRPD, *supra* note 13, at art. 12(3). Although Article 12 (3) is often assumed to call for supported decision-making, it actually provides only that states provide people with disabilities "with the support they may require in exercising their legal capacity." Thus, supported decision-making is one form of support but it is not co-extensive with it.

29. Dinerstein, *supra* note 25, at 10.

30. *Id.*; Glen, *supra* note 26, at 10.

31. Dinerstein, *supra* note 25, at 10; *see also Legal Capacity, Decision-Making and Guardianship: Discussion Paper* 122–23, LAW COMM. OF ONTARIO (2014), http://lco-cdo.org/en/

At its most general level, SDM can simply mean that an individual has a person or group of people on whom he or she can rely (if the individual so chooses) to assist the individual in making and communicating his or her decisions to others. It need not be subject to any formal written agreement nor ratified by a court or government agency. Alternatively, SDM can involve a formal relationship—such as, for example, the Representation Agreements used in British Columbia, Canada[32] or the SDM form used by the District of Columbia Public Schools to memorialize the decision-making relationship between a student receiving special education services and his supporter(s)[33]—that is filed and made available to others who may come into contact with the individual. Especially when the individual being supported has significant cognitive disabilities such that the supporter is functioning more as a facilitator than as mere advisor,[34] and is interpreting the individual's will and preferences to others, such formal acknowledgment may be necessary for third parties to be willing to rely upon the decision being communicated by the person and his or her supporters.

B. Supported decision-making in Practice

For a concept that has taken the disability world by storm, SDM is still in its infancy in terms of its adoption and use.[35] Canada, specifically the province of British Columbia, was the first state entity to adopt the concept. (Other Canadian provinces have followed.)[36] Prior to the CRPD's adoption in 2006 (and its entry into force in 2008), Sweden and certain states in

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capacity-guardianship-discussion-paper (last visited March 19, 2016); Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1120–21, fn. 32–35 (2013) [hereinafter "Kohn, et al."]; MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY, Prepared for the Law Commission of Ontario 22 (October 2010); U.N. DEP'T OF INT'L ECON. & SOC. AFFAIRS, U. N. OFFICE OF THE HIGH COMM. FOR HUMAN RIGHTS, & INTER-PARLIAMENTARY UNION, FROM EXCLUSION TO EQUALITY: REALIZING THE RIGHTS OF PERSONS WITH DISABILITIES, HANDBOOK FOR PARLIAMENTARIANS ON THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND ITS OPTIONAL PROTOCOL, at 89–91, U.N. Doc. HR/PUB/07/6 (2007), http://www.ipu.org/PDF/publications/disabilities-e.pdf.

32. *See, e.g.*, Dinerstein, *supra* note 25, at 73.

33. District of Columbia Public Schools, Office of Teaching and Learning, *Supported decision-making Form, Revised 3/2015*, DCPS.DC.GOV, http://dcps.dc.gov/sites/default/files/dc/sites/dcps/publication/attachments/Supported%20Decision%20Making%20Form.pdf (last visited March 28, 2016).

34. *See* BACH & KERZNER, *supra* note 31, at 163.

35. See *infra* Part IV., for its adoption in portions of the US.

36. Dinerstein, *supra* note 25, at 10; BACH & KERZNER, *supra* note 31, fn. 132 at 53 (listing provinces of Manitoba, the Yukon Territories, and Alberta as having supported decision-making legislation).

Germany also had adopted their own versions of SDM as an alternative to guardianship.[37] Subsequently, States (or provinces or pilot projects within) such as Israel, Ireland, parts of Australia and New Zealand, the Czech Republic, Norway, and Bulgaria among others, have either adopted or have indicated an intention to explore adoption of, SDM.[38]

In many of these countries, the recognition of SDM is closely tied to CRPD Article 12's ringing declarations that "persons with disabilities have the right to recognition everywhere as persons before the law," and that they "enjoy legal capacity on an equal basis with others in all aspects of life."[39] The inherent legal capacity of all individuals provides a critical underpinning to the concept of SDM, and a clear challenge to guardianship and other forms of surrogate decision-making that focus on mental capacity and its limitations rather than legal capacity.

III. THE CRPD'S APPROACH TO GUARDIANSHIP AND SUPPORTED DECISION-MAKING

A. Article 12

"As Amita Dhanda and others have documented, Article 12 was one of the most hotly contested articles to be considered during the treaty deliberation process."[40] Although Article 12's focus on universal recognition

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37. *See generally,* Dinerstein, *supra* note 25.

38. Dinerstein, *supra* note 25, fn. 58 at 12 (Czech Republic); Glen, *supra* note 26, at 7 (noting legislation proposed or enacted in Ireland, Australia, Czechoslovak (sic) Republic, and India); Government of South Australia, Dep't for Communities and Soc. Inclusion, *Safeguarding People with Disability Supported Decision-Making and Consent Policy*, SA.GOV (Oct. 30, 2015), *https://www.dcsi.sa.gov.au/__data/assets/pdf_file/0014/13415/safeguarding-people-with-disability-supported-decision-making-and-consent.pdf* (last visited on March 28, 2016); Eilionoir Flynn & Anna Kerstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT'L L. 124, 133–36 (Ireland, Canada and India); Marcia Boundy and Bob Fleischner, Fact Sheet: Supported decision-making Instead of Guardianship: An International Overview 6–9 (Training and Advocacy Support Center (TASC) April, 2013)(Canada, Sweden, Australia, Germany, Norway, Scotland, England, Ireland)(on file with the authors); Suzanne Cannon, *Bizchut Leading Legislation*, BIZCHUT (Isr.) (Feb. 17, 2016), http://bizchut.org.il/en/555 (last visited March 23, 2016) (noting organization's advocacy for supported decision-making legislation in Israel); The Bulgarian Center for Not-for-Profit Law, *New "formula" for capacity to act—opportunity for everyone to exercise their rights: Statement on the paradigm shift of article 12 of CRPD*, BCNL.ORG (2014), http://www.bcnl.org/uploadfiles/documents/osi%20researches/statementdraftupdatedeng.pdf (last visited March 28, 2016).

39. CRPD, *supra* note 13, at art. 12 (1), (2).

40. Dinerstein, *supra* note 25, fn. 5 & 6 at 8 (citing 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, 438–56 (2007) ((covering the deliberations over what was first called Article 9 extensively) [hereinafter Dhanda], and Tara J. Melish, *An Eye Toward Effective Enforcement: A*

of legal capacity did not come out of whole cloth—it had antecedents in The Montreal Declaration on Intellectual Disabilities, issued in 2004, prior United Nations treaties, and the practices of countries mentioned above, among other sources[41]—deliberation over its provisions raised profound questions regarding the meaning of legal capacity, its distinction from mental capacity, and the role of supports in assisting people in their decision-making. After much discussion and debate, over several Ad Hoc Committee sessions, Article 12 emerged in its final form. It acknowledged the importance of legal capacity as an inalienable right of a person; recognized that some people might need support in exercising their legal capacity; and provided for safeguards (which were to be proportional and tailored) designed to make sure that a person's legal capacity was not abused.

Significantly, Article 12's focus on the importance of individual choice—which is the hallmark of the autonomy that underlies legal capacity and serves to give it expression—resonates with other salient provisions of the Convention, including the Preamble, Article 3 (General Principles), Article 5 (Equality and non-discrimination), Article 19 (Living independently and being included in the community), Article 23 (Respect for home and the family), Article 25 (Health) and Article 26 (Habilitation and rehabilitation). Nor was Article 12's call for supports to enhance a person's functioning a concept confined to Article 12: Articles 19, 20 (Personal mobility), and 24 (2)(d)(e)(Education) all provide for supports in one form or the other.[42]

As Amita Dhanda has noted, Article 12, by its terms, does not necessarily eliminate guardianship as an option that can co-exist with SDM, though a contextual reading of the Article and its provenance certainly calls into question the continued viability of surrogate decision-making arrangements such as guardianship.[43] Different organizations, including United Nations bodies, have weighed in with their views on the subject,

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Technical-Comparative Approach to the Drafting Negotiations, *in* HUMAN RIGHTS AND DISABILITY ADVOCACY 70, 84–88 (MAYA SABATELLO & MARIANNE SCHULZE, EDS., 2014) (discussing views of one non-governmental organization involved in the drafting of Article 9)).

41. *See* Pan American Health Organization and World Health Organization, The Montreal Declaration on Intellectual Disabilities, ¶ 6 (a)–(c) (adopted October 6, 2004); Dhanda, *supra* note 40, at 443 (citing legal capacity language in the Convention on the Elimination of All Forms of Discrimination Against Women); Stanley S. Herr, Self-*Determination, Autonomy, and Alternatives for Guardianship*, *in* THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL 429, 429–52 (Stanley S. Herr, Lawrence O. Gostin & Harold Hongju Koh, eds. 2003) (one of the co-authors (Dinerstein) was a signatory to The Montreal Declaration).

42. *See* Dinerstein, *supra* note 25, at 9; CRPD, *supra* note 13, at art. 3, 5, 12, 19, 20, 24(2)(d)(e), 23, 25, 26.

43. Dinerstein, *supra* note 25, at 73, n. 23 (citing Dhanda, *supra* note 40, at 460–61).

arguing for elimination of guardianship under Article 12.[44] In the end, though, the most authoritative views on the subject are those expressed by the Committee on the Rights of Persons with Disabilities, which are addressed in the following section.

B. Interpreting Article 12: General Comment No 1 and the Committee on Persons with Disabilities' Consideration of States Parties Reports

The Committee on the Rights of Persons with Disabilities ("the Committee")[45] has had two mechanisms in which to address what it sees as the meaning of Article 12 and, in particular, whether guardianship is consistent with it.[46] First, States that have ratified the CRPD must submit reports to the Committee (two years after a State has adopted the CRPD, and at least every four years thereafter)[47] indicating their level of compliance with the CRPD's articles. In addition, non-governmental organizations and other entities may submit "shadow" reports providing their own perspective on the State's compliance with the Convention. After the States and any other entities submit their reports, the Committee issues a List of Issues that it wishes the State to address. The State responds to these issues and its representatives make an appearance before the Committee, which meets in Geneva. Committee members ask questions of the State representatives and may also conduct a closed session with any non-governmental organizations that wish to present their views to the Committee in person. The Committee then issues its Concluding Observations, addressing the State's compliance with each Article and, where compliance has not been shown, setting out the steps the State must take to achieve compliance. The Committee meets semi-

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44. *See* Dinerstein, *supra* note 25, fn. 61–62, at 12, 74 (citing Annual Rep. of U. N. High Comm. for Human Rights and Rep.'s to the Office of the High Comm. and the Secretary-General: Thematic Study by the Office of the U. N. High Comm. for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, Human Rights Council, Tenth Sess. Agenda item 2, U.N. Doc. A/HRC/10/48 (2009); Anna Nilsson, *Who Gets to Decide Right to legal capacity for persons with intellectual and psychosocial disabilities*, COUNCIL OF EUR. (Feb. 20, 2012), https://wcd.coe.int/ViewDoc.jsp?p=&id=1908555&direct=true (discussing the 2009 report of the UN High Comm'r for Human Rights and the International Disability Alliance, the Legal Opinion on Article 12 of the CRPD, and the European Comm'r for Human Rights 2012 report)).

45. The Committee was established by the CRPD in Article 34 and its functions and make-up are set out in Articles 35–39. *See* CRPD, *supra* note 13, at art. 34–39. As with other UN bodies, the Committee is considered a committee of experts within the subject matter of the Convention.

46. The Committee also is the adjudicatory body for individual communications or complaints that people can present if their States have ratified the Optional Protocol to the CRPD. *See* U.N. Office of the High Comm'r of Human Rights, *Human Rights Bodies, Complaint Procedures*, OHCHR.ORG, *http://www.ohchr.org/EN/HRBodies/TBPetitions/Pages/HRTBPetitions.aspx* (last visited March 28, 2016).

47. CRPD, *supra* note 13, at art. 35 (1), (2).

annually in sessions that may last from one to three weeks. To date, the Committee has conducted 14 sessions and four pre-sessional working group sessions, though it was not until the fourth session, in October 2010, that the Committee started to consider the reports from States Parties.[48]

The second mechanism available to the Committee is for it to issue a General Comment on one or more aspects of the Convention. On April 11, 2014, at its Eleventh Session, the Committee adopted General Comment No 1, Article 12: Equal Recognition before the law.[49] The General Comment is both a general response to the trends it had observed in the reporting that had occurred up to that time, and a detailed description of the kinds of practices that would and would not pass muster in the Committee's interpretation of the requirements of Article 12.

1. General Comment No 1 on Article 12 and Legal Capacity

The General Comment defines support in terms similar to the definition of SDM provided above:

> 'Support' is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication . . . Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences.[50]

In a key paragraph of the General Comment, Paragraph 29, the

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48. The listing of Committee sessions, and the States Parties that have appeared before it, can be found at U.N. Office of the High Comm'r of Human Rights, *Sessions for CRPD-Convention on the Rights of Persons with Disabilities*, OHCHR.ORG, http://tbinternet.ohchr.org/_layouts/TreatyBody External/SessionsList.aspx?Treaty=CRPD (last visited March 28, 2016).

49. Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal recognition before the law, U.N. Doc. CRPD/C/GC/1 (adopted April 11, 2014), https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement [hereinafter General Comment No. 1]. The Eleventh Session met from March 31-April 11, 2014.

50. General Comment No. 1, *supra* note 49, ¶ 17 at 4. More problematically, the General Comment also defines support to include "measures related to universal design and accessibility" that an entity might adopt. *Id.* Such measures seem better conceptualized as reasonable accommodations or modifications required of a provider, rather than support.

Committee sets out a number of elements of a SDM regime it deems required:

1) Supported decision-making must be "available to all" (and not be limited regarding people who need a high degree of support)
2) All forms of support should be based on the "will and preferences of the person" (and not on his/her presumed best interests)
3) A person's mode of communication, even if limited or non-conventional, should not be a barrier to obtaining support
4) Legal recognition of the support person(s) chosen by the person must be available and accessible, and "the state has an obligation to facilitate the creation of support," especially for those who have are isolated or do not have access to natural supports. Third parties must have the ability to verify the identity of the supporter and challenge the action of the support person if they believe that the support person is not following the will and preferences of the person.
5) "Lack of resources cannot be a barrier" to using support, and the State must make sure supports are available at no or nominal cost to the person
6) "Support in decision-making (or the need for it) cannot be used to deny other fundamental rights," such as voting, reproductive rights, parental rights, etc.
7) The person must have the "right to terminate or change the support relationship at any time"
8) Safeguards designed to respect the will and preferences of the person must be available in all processes related to legal capacity and its exercise.
9) The provision of support should "not be based on assessments of mental capacity" but on "new, non-discriminatory indicators of support needs . . ."[51]

In the General Comment, the Committee noted that on the basis of initial reports, many States parties did not appear to understand the contours of Article 12, and the need to move from substituted decision-making to SDM.[52] The Committee has taken the position that "The development of supported decision-making systems 'in parallel with the maintenance of substituted decision-making' regimes is not sufficient to comply with article 12 of the

51. General Comment No. 1, *supra* note 49, ¶ 29 at 6–7 (emphasis supplied).

52. *Id.* ¶ 3, at 1. *See* Dinerstein, *supra* note 25, at 11 (stating with regard to Tunisia and Spain, the first two countries to appear before the Committee, and based on their reports to the Committee "that those countries' governments may not truly understand the difference between substituted and supported decision-making.").

Convention."[53] Many countries disagree with this interpretation, including some that have been leaders in promoting SDM.[54] But for the Committee, existing tests of mental capacity—whether based on status, outcome, or functional ability—are problematic in that they conflate mental capacity with legal capacity and are thus, in its view, inconsistent with Article 12.[55]

2. The Committee's Consideration of States Parties Reports

Consistent with its view that Article 12 requires SDM in lieu of substituted decision-making, the Committee in its Concluding Observations (COs) has cited all thirty-four (34) States that have appeared before it for practices that violate Article 12 because of the retention in whole or in part of a substitute decision-making regime.[56] Interestingly, the Committee's COs equate the Article 12(3) requirement of supports to translate into SDM, even though, as noted above,[57] Article 12 itself does not use the term.

To provide a sense of how the Committee has addressed States Parties' compliance with Article 12, we discuss briefly the COs for several states that span a range of practices regarding substituted and supported decision-making.

a. Sweden

Sweden is a country that has long advocated the use of alternatives to guardianship and is one of the most advanced States in its recognition of legal

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53. General Comment No. 1, *supra* note 49, ¶ 28 at 6 (emphasis supplied).

54. Both Canada and Australia filed Declarations (and Canada a Reservation) indicating that they believed that both supported decision-making and substitute decision-making were acceptable under Article 12, and that there were some circumstances in which substituted decision-making would be called for. *See* U.N. Treaty Collection, *Convention on the Rights of Persons with Disabilities*, UN.ORG (March 28, 2016, 5:00 E.D.T.), https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec (last visited March 28, 2016). Both Germany and Denmark also submitted comments on the draft Comment indicating their views that there was a place for substituted decision-making in some circumstances. *See* Federal Republic of Germany, *German Statement on the Draft General Comment on Article 12 CRPD*, OHCHR.ORG (Feb. 20, 2014), *http://www.ohchr.org/Documents/HRBodies/CRPD/GC/FederalRepublicOfGermanyArt12.pdf* (last visited March 28, 2016); *see also* Government of Denmark, *Response from the Government of Denmark with regards to Draft General Comment on Article 12 of the Convention: Equal Recognition before the Law*, OHCHR.ORG, http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx (last visited March 28, 2016).

55. General Comment No. 1, *supra* note 49, ¶ 13 at 3.

56. For a listing of the States Parties that have reached the Concluding Observation stage, and the Concluding Observations themselves, *see* U.N. Office of the High Comm'r of Human Rights, *CRPD: Human Rights Bodies*, OHCHR.ORG, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5 (last visited March 28, 2016).

57. CRPD, *supra* note 13, at art. 12(3).

capacity for people with disabilities. It has banned findings of incapacity since 1989, and has made use of alternatives to guardianship, such as the ombudsperson (or good man), but still has court-ordered deputyship (consensual) and administratorship (imposed) for some people. In response to Sweden's submission, the Committee concluded:

> Even though declarations of incapacity have been completely abolished, the Committee is concerned that the appointment of an administrator is a form of substituted decision-making.
> The Committee recommends that the State party take immediate steps to replace substituted decision-making with supported decision-making and provide a wide range of measures which respect the person's autonomy, will and preferences and are in full conformity with article 12 of the Convention, including with respect to the individual's right, in his or her own capacity, to give and withdraw informed consent for medical treatment, to have access to justice, to vote, to marry and to work.[58]

b. New Zealand

New Zealand is a country that is taking steps to address SDM. In its States Report, it indicated that the Protection of Personal Property Rights Act (1988) provided for a presumption of competency (capacity). There is a high threshold to overcome before capacity can be found lacking, and any intervention must be the least restrictive.[59] In response to the State's initial submission, the Committee inquired as one of its List of Issues whether the State planned to replace substituted decision-making regimes with SDM ones.[60] New Zealand responded by indicating that its Office of Disability Issues, in consultation with Disabled Persons Organizations ("DPOs"), was working on SDM. The government went on to report:

> This will include promoting a wider understanding of legal

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58. U.N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Sweden, ¶ 33–34 at 5, U.N. Doc. CRPD/C/SWE/CO/1 (May 12, 2014), *http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5.*

59. U.N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Implementation of the Convention on the Rights of Persons with Disabilities, Initial Reports submitted by States parties under Article 35 of the Convention, New Zealand, ¶ 65–69 at 15–16, U.N. Doc. CRPD/C/NZL/1 (Oct. 1, 2013), *http://tbinternet.ohchr.org/_layouts/treatybody external/Download.aspx?symbolno=CRPD%2fC%2fNZL%2f1&Lang=en.*

60. U. N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, List of issues in relation to the initial report of New Zealand, ¶ 13 at 2, U.N. Doc. CRPD/C/NZL/Q/1 (May 12, 2014), *http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fQ%2f1&Lang=en.*

> capacity consistent with article 12, examining the use of supported decision-making regimes, and ensuring that policies support it in practice. Supported decision-making is relatively new in New Zealand, and we will need to consider how our unique cultural and social context can be reflected in its recognition. The work will also seek to understand experiences in other countries and learn from current experience domestically.[61]

In response, although the Committee took note of the State's recent efforts to explore SDM, it concluded:

> The Committee recommends that the State party take immediate steps to revise the relevant laws and replace substituted decision-making with supported decision-making. This should provide a wide range of measures that respect the person's autonomy, will and preferences, and is in full conformity with article 12 of the Convention, including with respect to the individual's right, in his or her own capacity, to give and withdraw informed consent, in particular for medical treatment, to access justice, to marry, and to work, among other things, consistent with the Committee's general comment No. 1 (2014) on equal recognition before the law.[62]

c. Republic of Korea

South Korea (Republic of Korea) is a country that had addressed guardianship legislatively but in a manner that the Committee found wanting. It noted:

> The Committee is concerned that the new adult guardianship system, which was introduced in July 2013, permits guardians to make decisions regarding the property and personal issues of persons deemed persistently incapable of managing tasks due to psychological restrictions caused by disease, disability or old age. The Committee notes that such a system continues to promote

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61. U.N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, List of issues in relation to the initial report of New Zealand, Addendum, Replies of New Zealand to the list of issues, ¶ 69–69 at 11, U.N. Doc. CRPD/C/NZL/Q/1/Add.1 (June 27, 2014), https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/067/76/PDF/G1406776.pdf?OpenElement.

62. U.N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of New Zealand, ¶ 22 at 3–4, U.N. Doc. CRPD/C/NZL/CO/1 (Oct. 31, 2014), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fCO%2f1&Lang=en.

> substituted decision-making instead of supported decision-making, contrary to the provisions of article 12 . . .

The Committee concluded:

> The Committee recommends that the State party move from substitute decision-making to supported decision-making, which respects the person's autonomy, will and preferences and is in full conformity with article 12 of the Convention and general comment No. 1, including with respect to the individual's right to give and withdraw informed consent for medical treatment, to have access to justice, to vote, to marry, to work and to choose his or her place of residence. The Committee further recommends that the State party provide training, in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors, including civil servants, judges and social workers, on the recognition of the legal capacity of persons with disabilities and on the mechanisms of supported decision-making.[63]

d. Ecuador

Finally, Ecuador is a State where there has been no legislative movement toward SDM, nor an effort to reform guardianship, for that matter. In this case, the Committee stated:

> The Committee is concerned that the State party's civil legislation provides for a substitute decision-making model through the use of roles such as guardians and wards, and that there is no immediate plan to reform the Civil Code and the Code of Civil Procedure to include a supported decision-making model, as recommended in general comment No. 1 (2014) . . .
> The Committee recommends that the State party establish a working group with representatives of independent organizations of persons with disabilities in order to carry out a timely review of civil legislation and introduce supported decision-making mechanisms. It also recommends that the State party draw up an agenda, with a timetable, for the implementation of the new plan.[64]

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63. U.N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of the Republic of Korea, ¶ 21–22 at 4, U.N. Doc. CRPD/C/KOR/CO/1 (Oct. 29., 2014), http://tbinternet.ohchr.org/_layouts/treaty bodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKOR%2fCO%2f1&Lang=en.

64. U.N. Convention on the Rights of Persons with Disabilities, Comm. on the Rights of Persons with Disabilities, Concluding observations on the initial report of Ecuador, ¶ 24–25 at 4, U.N. Doc.

The Committee, thus, has been quite consistent in responding to States Parties' submissions that it will conclude that any approach to decision-making that does not completely eliminate substituted decision-making will not pass muster under Article 12 in its estimation. Whether this consistent stance will actually result in countries eliminating all forms of substituted decision-making remains to be seen.

IV. Supported Decision-Making in the United States[65]

A. Advancing Rights and Models First Identified in International Law

While the United States has not yet ratified the CRPD, an increasing number of American researchers, legislatures, policymakers, and courts have answered international law's call for decision-making options that are less restrictive and more supportive than guardianship. However, these developments have been slow in coming and have not yet taken full root; although many speeches and studies have decried overbroad and undue guardianship—such as Congressman Claude Pepper's famous finding that, "the typical ward has fewer rights than the typical convicted felon"[66]—the estimated number of American adults under guardianship has tripled since 1995.[67]

Nevertheless, recent research and commentary has shown that guardianship can, and too often does, deprive people of their most basic and

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CRPD/C/ECU/CO/1 (Oct. 27, 2014), *https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/192/02/PDF/G1419202.pdf?OpenElement*.

65. *ACL Discretionary Grant Product Disclaimer Notice*, ADMIN. FOR CMTY. LIVING (2016), http://www.acl.gov/Funding_Opportunities/Grantee_Info/docs/ACL_Grantee_Product_Disclaimer_REQUIRED_9-4-13.pdf.

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66. H.R. Rep. No. 100–641, at 1 (1987).

67. S.L. Reynolds, *Guardianship Primavera: A First Look at Factors Associated with Having a Legal Guardian Using a Nationally Representative Sample of Community-Dwelling Adults*, AGING AND MENTAL HEALTH, 109–12 (2002), http://www.tandfonline.com/doi/abs/10.1080/13607860220126718; W. C. Schmidt, *Guardianship: Court of last resort for the elderly and disabled*, DURHAM, NC: CAROLINA ACADEMIC PRESS (1995); Brenda K. Ukber & Richard Van Duizend, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform*, NATIONAL CENTER FOR STATE COURTS (2011), http://www.ncsc.org/~/media/Microsites/Files/Future%20Trends/Author%20PDFs/Uekert%20and%20Van%20Duizend.ashx.

fundamental rights.[68] Guardians are given "substantial and often complete authority over the lives of vulnerable [people],"[69] extending to the most basic personal and financial decisions,[70] which can lead to negative life outcomes including diminished health and independence.[71] As a result, "even when it is functioning as intended [guardianship] evokes a kind of 'civil death' for the individual, who is no longer permitted to participate in society without mediation through the actions of another if at all."[72]

As the United States Supreme Court has held, people have a fundamental right to make decisions regarding their health care, property, living arrangements, and marriage.[73] There has been a growing recognition of the need to identify and implement options for people with limitations in decision-making that protect and advance, rather than restrict, their rights.[74] In recent years, with increasing frequency and often relying upon rights and concepts first enunciated by international law, courts, policymakers, and legislators have turned to SDM to fulfill that role.[75]

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68. *E.g.*, Margaret Hatch, Samantha Crane, & Jonathan Martinis, *Unjustified Isolation is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship*, 3(2) INCLUSION 65, 65–74 (2015); Jonathan Martinis, *"The Right to Make Choices": How Vocational Rehabilitation can help Young Adults with Disabilities Increase Self-Determination and Avoid Guardianship*, 42 J. OF VOCATIONAL REHABILITATION 221, 222 (2015); Peter Blanck & Jonathan Martinis, *"The Right to Make Choices": The National Resource Center for Supported Decision-Making*, 3(1) AAID 24, 24–33 (2015).

69. David Hardy, *Who Is Guarding the Guardians? A Localized Call for Improved Guardianship Systems and Monitoring*, 4 NAELA J. 1, 7 (2008).

70. Naomi Karp, et al., *Guardianship Monitoring: A National Survey of Court Practices*, AARP, 1–2 (2006).

71. Leslie Salzman, *Guardianship for Persons with Mental Illness–A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 279, 289–93 (2011) chrome-extension://oemmndcbldboiebfnladdacbdfmadadm/http://law.slu.edu/sites/default/files/Journals/salzman_article.pdf [hereinafter "Salzman, 2011"]; Jennifer L. Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J.L. & PSYCHIATRY 350, 354 (2010), http://www.sciencedirect.com/science/article/pii/S0160252710000798; Kohn, et al, *supra* note 31, at 1119.

72. Dinerstein, *supra* note 25, at 8, 9.

73. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) (recognizing the significant liberty interest in refusing unwanted medical treatment); Turner v. Safley, 482 U.S. 78, 95 (1987), *Obergefell v. Hodges*, 135 S. Ct. 2584 (2015) (recognizing the decision to marry as a fundamental right); *Moore v. City of E. Cleveland, Ohio*, 431 U.S. 494, 503–06 (1977) (finding the Constitution protects the ability of relatives to live together); *Lloyd Corp. v. Tanner*, 407 U.S. 551, 570 (1972) (broadly interpreting the right to own and control private property).

74. *See, e.g.*, Kohn et al., *supra* note 31, at 1115–20.

75. See, *e.g.*, Brief for Amici, In Re: Guardianship of the Person and Estate of Ryan Keith Tonner, an Incapacitated Person (2015), (No. 14-0490), 2014 WL 4553192.

In 2012, a New York court terminated the guardianship of Dameris L. because she had developed an SDM network of, "family and community support that enables [her] to make, act on, and have her decisions legally recognized."[76] The court recognized that, "[t]his use of supported decision-making, rather than a guardian's *substituted* decision-making, is . . . consistent with international human rights, most particularly Article 12 of the [CRPD]."[77] Citing with respect to the CRPD's, "internationally recognized right of legal capacity through supported decision-making,"[78] the court terminated the guardianship because "Dameris has demonstrated that she is able to exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network . . . [Thus,] [t]erminating the guardianship recognizes and affirms Dameris's constitutional rights and human rights."[79]

In 2013, Margaret "Jenny" Hatch defeated a petition seeking to place her in a permanent, plenary guardianship and won the right to make her own life decisions using SDM.[80] Prior to the petition, Ms. Hatch lived in her own apartment, worked at an integrated job she chose and enjoyed, and led an active social life.[81] However, after she was struck by a car while riding her bicycle, her parents sought guardianship over her.[82] Initially, the court ordered her into a temporary guardianship and placed her in a group home—where she was not allowed to use her cell phone or laptop, could not go to her job, and was not permitted to see her friends.[83]

A psychologist called by the petitioners testified that Ms. Hatch needs, "assistance to make decisions regarding her health care, her living arrangements and such like that. She will need someone to guide her and giver her assistance."[84] In response, Ms. Hatch presented evidence that, with support and assistance from friends and professionals, she made her own decisions including whether to sign a complex power of attorney agreement, consent to surgery, and play a lead role in planning her services and

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76. *In re Dameris L.*, 956 N.Y.S.2d 848, 855 (N.Y. Sup. Ct. 2012).

77. *Id.* at 853.

78. *Id.* at 855–56.

79. *Id.* at 856.

80. *Ross and Ross v. Hatch*, Case No. CWF-120000-426-P-03 (Va. Cir. Ct., 2013). Jonathan Martinis, the third author, served as Ms. Hatch's lead counsel. Robert Dinerstein, the second author, testified as an expert witness on Ms. Hatch's behalf.

81. Hatch et al., *supra* note 68, at 65.

82. *Id.*

83. Margaret Hatch, *My Story*, *in* 3 (1) INCLUSION 34, 34 (AAIDD, 2015).

84. *See, e.g.*, *Excerpt from Testimony of Professor Robert Dinerstein*, THE JENNY HATCH JUSTICE PROJECT, at 64 (2013), http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_testimony_excerpt_dinerstein.pdf [hereinafter *Dinerstein Testimony*].

supports.[85] Experts called by Ms. Hatch testified, consistent with the CRPD and *Dameris L.*, that these were, "classic or textbook case[s] of the support that would be part of supported decision-making."[86] After a multiple day trial, the court denied the petition for permanent guardianship, instead appointing Ms. Hatch's friends as her temporary limited guardians for one year, "with the . . . goal of transitioning to the supportive [*sic*] decision-making model."[87]

State legislatures have also recognized, recommended, and implemented SDM systems for people who might otherwise be placed under guardianship. In 2009, the Texas legislature created a pilot program to, "promote the provision of supported decision-making services to persons with intellectual and developmental disabilities and persons with other cognitive disabilities who live in the community."[88] The program trained volunteers to support people in making, "life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person."[89]

In 2015, after the pilot program expired, Texas passed new laws consistent with the CRPD's recognition that all people have capacity but that some people need support to exercise it. Texas law now recognizes the availability and effectiveness of "Supports and Services"—defined as formal and informal resources and assistance that enable people to meet their needs; care for their health; manage their finances; and make personal decisions—as an alternative to guardianship.[90] The law requires courts to find by clear and convincing evidence that a person cannot make decisions using "Supports and Services" before appointing a guardian.[91]

In 2014, the Virginia General Assembly directed the state Secretary of Health and Human Services to study SDM and, "recommend strategies to improve the use of supported decision-making in the Commonwealth and ensure that individuals . . . are consistently informed about and receive the opportunity to participate in their important life decisions."[92] The resulting

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85. *See, e.g., Id.* at pp. 71–94.

86. *See, e.g., Dinerstein Testimony, supra* note 84, at 73; *Excerpt from Testimony of Dr. Peter Blanck*, THE JENNY HATCH JUSTICE PROJECT, at 123 (2013), http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_testimony_excerpt_blanck.pdf.

87. *Ross v. Hatch*, CWF-120000-426-P-03, at 5 (declaring that the temporary guardianship expired on August 2, 2014).

88. Volunteer-Supported Decision-Making Advocate Pilot Program, Tex. Gov't Code Ann. § 531.02446 (West 2009) (Expired 2013).

89. *Id.*

90. Tex. Est. Code Ann. §1002.031(2015).

91. Tex. Est. Code Ann. §1101.101(2015).

92. H.R.J. 190, Reg. Sess., at 5, 8 (Va. 2014).

report cited international efforts in Australia, Canada, Sweden, and England in making several recommendations to expand knowledge and use of SDM, including: that state law be amended to recognize SDM as a "legitimate alternative to guardianship;" that state law, policy, and procedure require anyone appointed as a substitute decision-maker to be trained in and commit to using SDM; and that Virginia develop and require a standard training on SDM for providers and professionals.[93]

SDM concepts first identified in international law have also helped shape United States policy and practice. In 2014, the Administration for Community Living in the United States Department of Health and Human Services made funding available to create, "a national training and technical assistance center on . . . supported decision-making."[94] Recognizing the importance of international law to this process, the federal agency stated:

> By declaring 'legal capacity' for all people, the CRPD separates a person's cognitive and communicative abilities from this basic right. In other words, all people regardless of their disability or cognitive abilities have the right to make decisions and have those decisions implemented. These concepts . . . inform and frame the conversation around developing the supported decision-making process.[95]

Similarly, powerful private organizations have embraced SDM. In 2012, the American Bar Association ("ABA") convened a stakeholder summit entitled "Beyond Guardianship: Supported Decision-Making by Persons with Intellectual Disabilities."[96] Citing the CRPD as its impetus and inspiration, the ABA stated that the goal of the meeting was, "to explore concrete ways to move from a model of substituted decision-making, like guardianship, to one of supported decision-making, consistent with the human right of legal capacity."[97] In 2015, an ABA-published journal article called for the increased use of SDM, stating, "[i]n contrast to overbroad or undue guardianship, Supported Decision-Making can increase self-

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93. *Id.*

94. Supported decision-making Grant Application, DEP'T. OF HEALTH AND HUM. SERV., ADMIN FOR CMTY. LIVING, HHS-2014-ACL-AIDD-DM-0084, at 9 (2014).

95. *Id.* at 7.

96. *Supported Decision-Making*, AM. BAR ASS'N, http://www.americanbar.org/groups/disabilityrights/resources/article12.html (last visited Jan. 27, 2016).

97. *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities* http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf: *A Short Summary from the 2012 National Roundtable*, AM. BAR ASS'N, http://www.americanbar.or/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf.

determination by ensuring that the person retains life control to the maximum extent possible."[98]

Also in 2015, the National Guardianship Association ("NGA"), an organization representing "over 1,000 guardians, conservators and fiduciaries from across the United States," committed to advancing "the nationally recognized standard of excellence in guardianship,"[99] issued a position paper on guardianship and SDM. Echoing the CRPD in recognizing that, "[m]odern day respect for individual rights dictates that we must allow each individual to make or participate to the extent possible in personal decisions," the NGA concluded, "[s]upported decision-making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary."[100]

B. The Future of Supported Decision-Making in the United States: Achieving the Promise of International Human Rights Law and Practice

Present and planned efforts to advocate for increased access to and implementation of SDM will bring American policy and practice ever closer to the ideals set forth by the CRPD and related international laws. These include the work of The National Resource Center for Supported Decision-Making, which has launched a five-year action plan to increase knowledge and implementation of SDM through:

1. Publication, outreach, and training intended to change attitudes in the legal, educational, medical, and professional fields so that families, practitioners, and providers recognize and consider SDM as an appropriate decision-making option;
2. Identifying local, state, and national policies and practices that are barriers to the use of SDM, and advocating for necessary and appropriate modifications;
3. Conducting and sponsoring research into SDM, including identifying best practices; and

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98. Jonathan G. Martinis, *Supported Decision-Making: Protecting Rights, Ensuring Choices*, 36 A.B.A COMM'N ON L. & AGING 107, 110 (2016), http://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALMay-June2015.authcheckdam.pdf.

99. *Mission, Overview, and History*, NAT'L GUARDIANSHIP ASS'N INC., http:///www.guardianship.org/overview.htm (last visited Jan. 27, 2016).

100. Position Stmt. On Guardianship, Surrogate Decision-making, & Supported decision-making, NAT'L GUARDIANSHIP ASS'N INC., http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf (last visited Jan. 27, 2016).

4. Holding annual symposia bringing together American and international experts to discuss the state-of-the-art in SDM and strategize ways to increase acceptance and use of SDM.[101]

In a separate effort, the partners in The National Resource Center for Supported Decision-Making[102] have begun a first-of-its-kind five-year project to address existing gaps in research on SDM.[103] American and international researchers and scholars have theorized that people who use SDM should show increases in self-determination and improved life outcomes.[104] However, no research currently establishes such a linkage, which is an absence noted by leading commentators.[105] This effort is the first, in America or internationally, to longitudinally study whether such connections exist and then document any benefits accruing from it. If successful in establishing a causal link between use of SDM and increased self-determination, this research will demonstrate that SDM is a demonstrably effective alternative to guardianship.

United States federal agencies continue to play a key role in encouraging less-restrictive options for decision-making. While studies show that schools are the most frequent source of referrals for guardianship,[106] the United States Department of Education has supported efforts to decrease overreliance on guardianship, calling it, "one of the most legally restrictive forms of support . . . [that] can also have negative effects on the individual."[107] Through its partners, the Department of Education has given parents and teachers information and resources that increase knowledge about and access to less restrictive, more inclusive options such as SDM.[108]

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101. Martinis, *supra* note 98, at 110. Jonathan Martinis, the third author, is co-Project Director of the National Resource Center.

102. News Staff, *Burton Blatt Institute Receives $2.5 Million Grant*, SYRACUSE UNIV. NEWS (Oct. 19, 2015), http://news.syr.edu/burton-blatt-institute-receives-2-5-million-grant-60460/.

103. *Id.*

104. Krista James & Laura Watts, *Understanding the Lived Experiences of Supported Decision-Making in Canada Legal Capacity, Decision-Making and Guardianship*, L.COMM'N OF ONTARIO 7 (Mar. 2014), http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ccel.pdf.

105. *See, e.g.*, Kohn et al., *supra* note 31, at 1115–1120.

106. J. Matt Jameson, Tim Riesen, Shamby Polychronis, Barbara Trader, Susan Mizner, Jonathan Martinis, & Dohn Hoyle, *Guardianship and the Potential of Supported decision-making With Individuals With Disabilities*, 40(1) RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 36–51 (2015).

107. *Getting Ready for Independent Living at the Age of Majority*, CTR. FOR PARENT INFO. & RES., http://www.parentcenterhub.org/repository/aom-series-independence/ (last visited Jan. 27, 2016).

108. *Id.*

Such support is key, because using SDM not only furthers the goals of the CRPD and international law, it also advances the overarching aims of United States law. For example, using and supporting SDM as a means of increasing independence and self-determination is consistent with the intent of the Americans with Disabilities Act, which was enacted, "to assure equality of opportunity, full participation, independent living, and economic self-sufficiency"[109] of people with disabilities. In the same way, SDM furthers the purpose of the Developmental Disabilities Assistance and Bill of Rights Act: "assur[ing] that individuals with developmental disabilities . . . have access to needed . . . forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."[110]

To help reach these goals, advocacy organizations have followed the lead of Canada, Sweden, and other countries by creating SDM agreements, where individuals are empowered to specify areas where they want support, who will provide it, and how it will be provided. These include the Center for Public Representation,[111] the Texas Guardianship and Supported Decision-Making Workgroup,[112] Disability Rights Maine,[113] and The Arc of North Carolina.[114]

These efforts, moving American policy and practice along the path to SDM first laid by the CRPD, will empower Americans with disabilities to direct their own lives to the maximum of their abilities, in stark contrast to overbroad or undue guardianship. Rather than, "divest[ing] the individual of the ability to make crucial self-defining decisions,"[115] as guardianship has done for hundreds of years, SDM "retains the individual as the primary decision maker, while recognizing that the individual may need some assistance . . . in making and communicating a decision."[116] In so doing, SDM can end a sad history of "marginalization and isolation from mainstream society,"[117] in favor of an empowering option that makes people with disabilities the primary "causal agents" in their lives, respected and ready to

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109. 42 U.S.C.A. § 12101 (a)(7) (2015).

110. 42 U.S.C.A. §15001 (b) (2015).

111. *See generally, Supported Decision-Making Pilot Project*, CTR. FOR PUB. REPRESENTATION, http://supporteddecisions.org/ (last visited Jan. 27, 2016).

112. *See generally*, TEX. GUARDIANSHIP REFORM AND SUPPORTED DECISION-MAKING, http://grsdm.wordpress.com/ (last visited Jan. 27, 2016).

113. *See generally,* SUPPORTED DECISION-MAKING, http://supportmydecision.org/ (last visited Jan 27, 2016).

114. *Restoration & Alt. Proj. Supported Decision-Making*, THE ARC OF N.C., http://arcnc.org/file/guardianship/SupportedDecisionMaking.pdf.

115. Salzman, 2011, *supra* note 71, at 291.

116. Dinerstein, *supra* note 25, at 10.

117. Salzman, 2011, *supra* note 71, at 293.

make their own life choices, achieving the improved life outcomes associated with increased self-determination.[118]

V. CONCLUSION

The concept of adult guardianship law has been constantly evolving in our legal systems for centuries, and perhaps even more so in this century, as we look at the recent developments in international agreements and how they have affected complex legal systems like that of the United States. The goal of this article is to provoke more discussion on this topic in the international sphere so that as our world's population of people with disabilities and older persons continues to steadily increase, we can feel confident that our legal protections for these individuals are sound and fully incorporate their human rights and decision-making powers. Equal recognition before the law can have a direct impact on a person's quality of life and protection of fundamental human rights, so it is imperative we initiate this discourse now.

118. Michael L. Wehmeyer, *Self-Determination and Individuals with Severe Disabilities: Re-examining Meanings and* Misinterpretations, 30 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 113, 119 (2005).