

INTRODUCING A “NEW” HUMAN RIGHT: LEARNING FROM OTHERS, BRINGING LEGAL CAPACITY HOME

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INTRODUCTION

The human right of legal capacity, most recently enunciated in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD),¹ potentially transforms the way we see, understand, and treat people with a wide range of intellectual, developmental, and cognitive disabilities. This Article considers how the human right of legal capacity, specifically for persons with disabilities, can be incorporated into legal discourse and practice in the United States. It recognizes the many challenges such an endeavor confronts. As well, it notes opportunities to enhance and improve the dignity, autonomy, and self-determination of persons who are routinely deprived of the right, most commonly through systems of substituted decision-making, like guardianship and conservatorship,² or, in the

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

2. The legal process by which a person's right to makes decisions is removed and placed in a third party is usually referred to as guardianship and the legally recognized decision-maker is called the guardian. *See, e.g., Guardianship*, N.Y. STATE UNIFIED COURT SYS., <http://www.nycourts.gov/courthelp/guardianship/index.shtml> [<https://perma.cc/F29S-F8GB>] (defining guardianship as "a legal arrangement where a court gives a person the legal right to make decisions for another person who is unable to make decisions for themselves") (last visited Feb.

case of persons with psychosocial disabilities, forced treatment or confinement.

This Article also looks at the ways in which legal capacity and the corresponding practice of supported decision-making (SDM) have been introduced in countries around the world and draws on those countries' experiences. Some countries have focused exclusively on legislative reform; others have utilized pilot projects demonstrating that protecting legal capacity through the use of SDM can constitute an effective and rights-enhancing alternative to guardianship. Incorporating references to some of these efforts in Europe, Africa, and Australia, this Article focuses on two of the longest-standing and most-developed efforts—those in Canada and Bulgaria—for lessons that might be learned. It considers efforts in the United States, which have, thus far, concentrated on SDM to the exclusion of the specific right of legal capacity. This Article concludes with some observations about what it will take to bring this critical human right "home."

I. UNRESOLVED ISSUES

There are many unresolved issues that will almost surely arise in legal capacity work in the United States.³ These issues are complex and, as our knowledge and practice increase, they continue to evolve. This Article is not intended to provide answers, but rather to lay out some of the questions that call for our best thinking and constructive engagement. But precisely because a move toward legal capacity necessarily involves a true paradigm shift, these questions invite us to think in unfamiliar, and sometimes uncomfortable, ways.

First, just what is legal capacity? And why is it a "new" right? The short answer is that the *right* of legal capacity derives from a

21, 2018). However, some states, like California and Connecticut, use the term conservatorship (with the legally recognized decision-maker called the conservator). *Conservatorship*, CAL. COURTS, <http://www.courts.ca.gov/selfhelp-conservatorship.htm> [<https://perma.cc/EZL6-R8Q7>] (last visited Feb. 21, 2018); *Conservatorships*, CONN. PROB. COURTS, <http://www.ctprobate.gov/Pages/Conservatorships.aspx> [<https://perma.cc/YV2Z-3AGM>] (last visited Feb. 21, 2018). For consistency and brevity, guardian and guardianship will be used to refer to both forms of substitute decision-making.

3. For an excellent beginning to the conversation, from a primarily European and Australian perspective, see Piers Gooding, *Navigating the Flashing Amber Lights of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns*, 15 HUM. RTS. L. REV. 45 (2015) [hereinafter Gooding, *Flashing Amber Lights*].

number of human rights instruments, beginning with the Universal Declaration of Human Rights (UDHR), Article 6;⁴ the International Convention on Civil and Political Rights (ICCPR), Article 16;⁵—in an expanded definition—the Convention to End All Discrimination Against Women (CEDAW), Article 15;⁶ and most recently the Convention on the Rights of Persons with Disabilities (CRPD), Article 12.⁷

Legal capacity includes not only the right to “recognition . . . before the law,”⁸ understood as every person’s position as a rights holder, but also the right to legal agency. This involves the right to be a recognized legal actor, therefore to have “the power to engage in transactions and create, modify, or end legal relationships.”⁹ Gerard Quinn, one of the leading thinkers in this area, has a more expansive definition: “legal capacity . . . provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe—a web of mutual rights and obligations voluntarily entered into with others. . . . Legal capacity opens up zones of personal freedom.”¹⁰ More to the point, legal capacity is the right that makes so many others possible, including living in the community, working, marrying, or otherwise engaging in

4. G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948) [hereinafter UDHR].

5. International Covenant on Civil and Political Rights, *opened for signature* Dec. 16, 1966, art. 16, S. TREATY DOC. NO. 95-20, 999 U.N.T.S. 171, 177 (entered into force Mar. 23, 1976).

6. Convention on the Elimination of All Forms of Discrimination Against Women, *opened for signature* Dec. 18, 1979, art. 15, 1249 U.N.T.S. 13, 19 (entered into force Sept. 3, 1981).

7. CRPD, *supra* note 1, at 9.

8. *Id.* Beginning with the UDHR, this recognition meant at a most basic level that when a person was born, she or he was entitled to be registered so as to be visible to, and protected by, the legal system. In many societies, for example, children born with severe disabilities are not registered, and so there is no way to know of and protect their lives or to note and record their deaths. *See* Human Rights Council, Rep. of the Office of the High Comm’r of Human Rights, U.N. Doc. A/HRC/27/22, ¶¶ 67–68 (June 17, 2014).

9. Convention on the Rights of Persons with Disabilities, General Comment No. 1 (2014) ¶ 11, U.N. Doc. CRPD/C/GC/1 (May 19, 2014) [hereinafter General Comment No. 1].

10. Gerard Quinn, *Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD* 10 (HPOD Conference, Harvard Law Sch., Concept Paper, Feb. 20, 2010), <https://www.inclusionireland.ie/sites/default/files/attach/basic-page/846/harvardlegalcapacitygqdraft2.doc> [<https://perma.cc/SHL8-8R36>].

family and intimate relations, among others.¹¹ It is the essential prerequisite for what one of the founders of disability rights famously denominated “the right to live in the world.”¹²

Legal capacity is a “new” right for U.S. jurisprudence because, as a *human right*, it is inalienable—that is, it cannot be taken away.¹³ The United States, with all other common law jurisdictions, assumes legal capacity for all adults.¹⁴ However, because legal capacity is inextricably tied to *mental* capacity, it can be—and routinely is—curtailed by courts on a finding of *incapacity*.¹⁵ To the contrary, the *human right* of legal capacity is understood to be separate and distinct from mental capacity, and therefore independent of it.¹⁶ The right of legal capacity is also, as a *human right*, indivisible, so it cannot be

11. In a different paper, Quinn states, “legal capacity . . . is a continuum that connects with everything needed to enable the person to flourish—a right to make decisions and have them respected, a place of one’s own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings.” Gerard Quinn, *Rethinking Personhood: New Directions in Legal Capacity Law & Policy’ or How to Put the ‘Shift’ Back Into ‘Paradigm Shift’* 4 (University of British Columbia, Idea Paper, Apr. 29, 2011), https://cic.arts.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf [<https://perma.cc/3K58-EYPA>].

12. Jacobus tenBroek, *The Right to Live in the World: The Disabled and the Law of Torts*, 54 CAL. L. REV. 841, 841 (1966).

13. “Human rights are universal and inalienable. . . . They are universal because everyone is born with . . . the same rights. . . . [i]nalienable because people’s rights can never be taken away.” *Human Rights Principles*, U.N. POPULATION FUND (2005), <http://www.unfpa.org/resources/human-rights-principles> [<https://perma.cc/RU6Z-7872>] [hereinafter *Human Rights Principles*].

14. This has not always been the case. Until the late nineteenth and early twentieth centuries, adult women “lost” their legal capacity by virtue of the status of marriage when their “personhood” was deemed subsumed into that of their husbands. African-Americans born into slavery were seen as less than human, and so accorded no rights, much less *legal* capacity. See Cliona de Bhailís & Eilionóir Flynn, *Recognizing Legal Capacity: Commentary and Analysis of Article 12 CRPD*, 13 INT’L J.L. CONTEXT 6, 10 (2017); see also General Comment No. 1, *supra* note 9, at 2 (stating that “[l]egal capacity has been prejudicially denied to many groups throughout history, including women (particularly upon marriage) and ethnic minorities”).

15. See, e.g., Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision-Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 164–65 (2010) (discussing the Western tradition of States assuming protection over those it has deemed incapacitated).

16. See General Comment No. 1, *supra* note 9, at 3–4.

sliced and diced.¹⁷ Accordingly, the common practice of guardianship, whether plenary or limited,¹⁸ or of involuntary medication or hospitalization of persons with psychosocial disabilities, is incompatible with and violates the right of legal capacity.¹⁹ As a human right, legal capacity is also inter-connected with and inter-related to all other human rights.²⁰ Finally, as a *human right*, legal capacity is premised on dignity,²¹ a value²² nowhere reflected in the U.S. Constitution and seldom mentioned in rights-based conversations in the United States.

The precise meaning of and limitations, if any, on the right of legal capacity, especially as it has now been explicated in the General Comment,²³ are highly contested. A frequently cited example involves

17. *Human Rights Principles*, *supra* note 13 (“Human rights are *indivisible* . . . [they] are inherent to the dignity of every human person. Consequently, all human rights have equal status and cannot be positioned in a hierarchical order.”).

18. Guardianship reform has stressed the use of limited guardianships—that is, guardianships tailored to the specific “incapacities” of the subject of the proceeding rather than a wholesale removal of rights. *See, e.g.*, Salzman, *supra* note 15, at 173–74 (discussing narrow tailoring of guardianship and its continuing inadequacies). However, this still amounts to a denial of legal capacity.

19. *See* Robert Dinerstein et al., *Emerging International Trends and Practices in Guardianship Law for People with Disabilities*, 22 ILSA J. INT’L & COMP. L. 435, 443 (2016) [hereinafter Dinerstein et al., *Emerging Int’l Trends*] (“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.”). This is the position taken by the CRPD Committee in the First General Comment. General Comment No. 1, *supra* note 9, at 2–3.

20. *See, e.g.*, Eilionoir Flynn & Anna Arstein-Kerslake, *Legislating Personhood: Realizing the Right to Support in Exercising Legal Capacity*, 10 INT’L J.L. CONTEXT 81, 87 (2014). (“[L]egal capacity is the backbone of a plethora of other human rights . . . [which] demonstrates the inter-connectedness of human rights concerns with deep moral questions about the nature of personhood—a contentious issue that . . . cannot be ignored in the context of legal capacity.”).

21. UDHR, *supra* note 4, pmb1.

22. *See, e.g.*, Oscar Schachter, EDITORIAL COMMENT, *Human Dignity as a Normative Concept*, 77 AM. J. INT’L L. 848, 848 (1983) (discussing human dignity as a “basic value accepted in a broad sense by all peoples”); *cf.* AHARON BARAK, HUMAN DIGNITY: THE CONSTITUTIONAL VALUE AND THE CONSTITUTIONAL RIGHT (2015) (noting the complexity of the concept and different purposes it serves).

23. General Comment No. 1, *supra* note 9, ¶¶ 11–12.

Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing)

the so-called "hard cases" of persons with severe and persistent impairments. These issues are discussed in Section I.A, below.

Legal capacity is *not*, however, the same as or coterminous with supported decision-making,²⁴ although, for people with intellectual, psychosocial, and cognitive disabilities, the latter may be essential to the former. This distinction becomes critical when we consider, later in this Article, how SDM has already entered U.S. legal, academic, and service provision worlds, and how confusion between the two may affect recognition of the right of legal capacity.

SDM has been 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."²⁵ At a practical level, this reflects our common understanding that no one makes decisions in a vacuum, that everyone uses some kind of support or supports in making decisions,²⁶ and that the same holds true for people with a whole range of intellectual disabilities, although they may need more or different kinds of supports.²⁷ Unquestionably, SDM operates informally for many people with intellectual disabilities who

and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. . . . Under article 12 of the Convention, perceived or actual defects in mental capacity must not be used as justification for denying legal capacity.

Id. ¶ 13.

24. SDM may be practiced in all domains of life, from deciding what to eat or to wear, to whether to sign a contract or give consent to a medical procedure. It is only as to the latter, where there are legal consequences, that the right of legal capacity specifically applies.

25. Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision Making*, 19 HUM. RTS. BRIEF 8, 10 (2012).

26. Broadly understood, supports may include, among others, conversations with others; expert opinions; and use of research materials, the press, the internet, and communication devices, such as phones and computers.

27. These are commonly described as support in gathering the information necessary to make a decision, weighing the pros and cons of a decision, considering the possible or likely consequences of the decision, communicating the decision to third parties, and implementing the decision. *See, e.g.*, BIZCHUT, SUPPORTED DECISION-MAKING FOR PERSONS WITH DISABILITIES SERVICE MODEL 19–22 (2017) (describing types of support a supporter may provide a decision-maker).

might otherwise be subject to a regime of substituted decision-making.²⁸

More recently, however, SDM has come to include more formalized processes, generally involving written agreements that confer legal recognition on the arrangement. At the same time, these agreements attempt to ensure that a decision made with SDM is

28. There is a stunning lack of factual and statistical information about guardianship. See, e.g., ERICA WOOD, A.B.A. COMM'N ON LAW & AGING, STATE-LEVEL ADULT GUARDIANSHIP DATA: AN EXPLORATORY SURVEY 33-34 (2006), <https://ncea.acl.gov/resources/docs/archive/State-Level-Guardianship-Data-2006.pdf> [<https://perma.cc/YE2M-G4GB>] (finding that nearly two-thirds of responding state court administrative offices did not collect data on the number of personal or property guardianship cases). Unfortunately, there are no statistics that would enable us to measure the extent to which such informal supports exist or whether, in the absence of such supports, persons with I/DD would be subject to guardianship. We can note, however, the disparity between estimates of the number of persons with I/DD, consistently described as three percent of the population, or approximately 3.2 million persons. See, e.g., PRESIDENT'S COMM. FOR PEOPLE WITH INTELLECTUAL DISABILITIES, KEEPING THE CHARGE: PERSONAL AND ECONOMIC FREEDOM FOR PERSONS WITH INTELLECTUAL DISABILITIES (2006), https://www.acl.gov/sites/default/files/programs/2017-03/pr_2006_asset_development.pdf [<https://perma.cc/EE5S-JJLP>] (estimating the population with I/DD at three percent); see *United States Population*, WORLD POPULATION REVIEW, www.worldpopulationreview.com/countries/united-states-population [<https://perma.cc/M5SK-ELFX>] (showing the U.S. population in 2017 as 324,963,048). This figure is missing, *inter alia*, persons with Alzheimer's, estimated at more than five million, see *2017 Alzheimer's Disease Facts and Figures*, ALZHEIMER'S ASS'N, www.alz.org/facts/ [<https://perma.cc/8GMS-PGQF>], who are also among those subject to guardianship. The best undifferentiated estimates of persons currently under guardianship, including both people with I/DD and older persons with cognitive disabilities including Alzheimer's, is approximately 1.5 million. Brenda K. Uekert & Richard Van Duizend, *Adult Guardianship: A "Best Guess" National Estimate and the Momentum for Reform*, NAT'L CTR. FOR STATE COURTS, <https://ncsc.contentdm.oclc.org/digital/collection/ctadmin/id/1846/> [<https://perma.cc/8WV3-2P8Z>] (last visited Mar. 10, 2018). Another intriguing set of facts from which the inference can be reasonably drawn is the wide variation from state to state in the percentage of adults with I/DD receiving publicly-funded services who are subject to guardianship. National Core Indicators (NCI) data show the extent of variation across forty-one states, with eighty-four percent of the relevant population in Missouri under full guardianship, as opposed to seven percent in South Carolina. NAT'L CORE INDICATORS, ADULT CONSUMER SURVEY: 2014-15 FINAL REPORT (2015), http://www.nationalcoreindicators.org/upload/core-indicators/ACS_2014-15_Final1.pdf [<https://perma.cc/6FMV-E3MQ>]. Unless we were to assume that people with I/DD in Missouri are twelve times more impaired than those in South Carolina, it is likely that many South Carolinians with I/DD who would be under guardianship in other states are functioning in their communities with an unexamined variety of supports.

actually the decision of the person with intellectual and developmental disabilities (I/DD), and not of her or his supporters.²⁹ Although the CRPD nowhere uses the term "SDM," Article 12(3) requires States parties to "provide *such supports as are required* to allow the exercise of the right."³⁰

The body responsible for interpreting the CRPD, the Committee on the Rights of Persons with Disabilities (the CRPD Committee), has adopted the term SDM and acknowledged the critical part SDM plays in achieving exercise of the right of legal capacity.³¹ The recent and rapid³² introduction of SDM into the United States in scholarly literature³³ and, to a somewhat lesser extent, policy,³⁴

29. For example, most supported decision-making agreements (SDMAs) require supporters to sign, attesting to their agreement to "support," rather than impose their own views. *See, e.g., Texas Statutory Supported Decision-Making Agreement*, NONOTUCK RES. ASSOCS. & CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/wp-content/uploads/2015/09/Texas.Simplified-Supported-DecisionMaking-Form.pdf> [<https://perma.cc/BJL6-84AT>] (last visited Mar. 10, 2018); *Supported Decision-Making Agreement*, NONOTUCK RES. ASSOCS. & CTR. FOR PUB. REPRESENTATION, <http://supporteddecisions.org/wp-content/uploads/2015/09/SDM-Representation-Agreement-pdf.pdf> [<https://perma.cc/D6RP-RBDU>] (last visited Mar. 10, 2018).

30. CRPD, *supra* note 1, art. 12(3) (emphasis added).

31. *See* General Comment No. 1, *supra* note 9, ¶ 29.

32. Arguably the first national meeting to consider SDM was held in October 2012 when two American Bar Association Commissions (Disability Rights and Aging) convened an interdisciplinary roundtable in New York City. *See* A.B.A., BEYOND GUARDIANSHIP, https://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf [<https://perma.cc/9K9S-EMF2>] (last visited Mar. 10, 2018).

33. There are scores of articles on SDM in legal and other professional journals and treatises. *See, e.g.,* Jonathan Martinis, "The Right to Make Choices": *How Vocational Rehabilitation Can Help Young Adults with Disabilities Increase Self-Determination and Avoid Guardianship*, 42 J. VOCATIONAL REHABILITATION 221 (2015); Eilionoir Flynn, *Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality Before the Law*, 17 INT'L J. HUM. RTS. 491 (2013); Nandini Devi, *Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities*, 41 J.L. & MED. ETHICS 792 (2013).

34. *See, e.g., Supported Decision Making Program*, ADMIN. CMTY. LIVING, <https://www.acl.gov/programs/consumer-control/supported-decision-making-program> [<https://perma.cc/Z5VJ-HV5C>] (last visited Mar. 10, 2018) (detailing the adoption of SDM as an alternative to guardianship by the Agency for Community Living (ACL), the federal agency within the Department of Health and Human Services (HHS) that encompasses both the Agency for Intellectual and Developmental Disabilities (AIDD) and the Administration on Aging (AOA)).

legislation,³⁵ and case law,³⁶ will be discussed in Section I.B. At the same time, the Article will note how a single-minded emphasis on SDM may potentially undercut understanding and acceptance of the broader right of legal capacity.

The diversity and distinct characteristics of the groups to which legal capacity applies is another salient issue that is critical to any serious consideration of how the right might be incorporated into U.S. law and policy.³⁷ Although the CRPD covers people with a wide range of disabilities, including sensory, mobility, and intellectual disabilities, the majority of scholarly, legislative, and policy attention to legal capacity and, especially, to SDM has involved people with I/DD and, less frequently, people with psychosocial disabilities. Older persons with progressive cognitive decline and dementia, a large and ever-growing portion of the population, are virtually invisible.³⁸ The same is true of persons with traumatic brain injuries (TBIs), who may be subsumed in the I/DD category despite significant dissimilarities.³⁹ Section I.C of this Article considers the applicability of legal capacity, and the special issues presented by these three generally under-theorized groups.

35. See, e.g., TEX. EST. CODE ANN. § 1002.031 (West 2015); Supported Decision-Making Act, DEL. CODE ANN. tit. 16, § 94A (West 2016).

36. See, e.g., *In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848, 854–55 (N.Y. Sur. Ct. 2012) (terminating the guardianship of a woman with I/DD because she had a functioning supported decision-making network of family and other community members in place).

37. Of course, as a human right, legal capacity is a right held by everyone. For purposes of this discussion, however, the emphasis is on those whose claim to the right is all too commonly contested or denied by virtue of disability, and who are the direct subjects of Article 12.

38. See Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URBAN L.J. 495, 498 (2016) (noting the lack of attention paid to older persons in SDM discussions). Although the National Resource Center on Supported Decision Making is charged with including older persons with cognitive disabilities, it has few materials on, or discussion about, that population. To the Author's knowledge, there has never been a pilot project anywhere in the world that has applied SDM to older persons with cognitive decline or dementia.

39. For adults with TBIs, there is generally a more robust picture and history of their personhood, capabilities, and preferences "before" the accident that caused their disability than for people with I/DD whose disabilities usually (and by definition) began at birth or before adulthood. There is also, for many, a greater chance for improvement or "recovery," which further separates them from most older persons with progressive cognitive decline.

There is one final consideration about the right itself that raises questions about, and might significantly hinder acceptance of, the right. In addition to *what* it is and to *whom* it applies, is the question of *which* existing institutions or legal practices are at risk if the right of legal capacity were fully honored. The primary focus of attention under Article 12 has been on SDM and the institution of guardianship or other similar substitute decision-making regimes. The CRPD Committee's country-specific "Concluding Observations"⁴⁰ have uniformly found fault with the failure to abolish guardianship. In fact, much of the Committee's First General Comment is devoted to an explication of how any form of substituted decision-making for people with I/DD violates Article 12 and how incorporation of SDM into existing guardianship regimes is unacceptable.⁴¹

However, the implications of applying a universal right of legal capacity to criminal proceedings were virtually invisible in the enactment of Article 12 and have almost entirely escaped attention thus far. Generally, these include the capacity to stand trial, the insanity defense, and, more specifically, legally-defined notions of consent in rape and other sexual assault crimes. Section I.D of this Article discusses this issue.

Discussions about legal capacity or SDM in the context of law reform inevitably point to the lack of evidence upon which legislative choices can be made.⁴² Not only is there a dearth—if not an actual lacuna—of empirical evidence on how a legal system embracing legal capacity might look in practice, but there are also fundamental questions about the validity of support in advancing legal capacity. For

40. The Committee has two mechanisms for enforcing/advancing the right of legal capacity: (1) "Concluding Observations" or periodic reports regarding compliance submitted by state parties that have ratified the Convention; and (2) General Comments that further explicate the meaning of, and obligations under, the CRPD. Significantly, the First General Comment issued by the Committee dealt with Article 12. General Comment No. 1, *supra* note 9.

41. *Id.* ¶ 3 ("Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making."); *id.* ¶ 28 ("State parties' obligation to replace substitute decision-making regimes by supported decision-making . . . requires . . . the abolition of substitute decision-making regimes.").

42. See, e.g., MICHAEL BACH & LANA KERZNER, LAW COMM'N ONTARIO, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY (2010) [hereinafter BACH & KERZNER, A NEW PARADIGM] (addressing the major challenges of law reform without significant evidence).

example, how do we know whether decisions made with support, especially decisions by persons with more significant impairments, are really *their* decisions?⁴³ Issues around research, including the need to involve persons with intellectual, psychosocial, and cognitive disabilities in such research,⁴⁴ are discussed in Section I.E.

In addition to difficulties arising from the definition and applicability of the right of legal capacity itself, is the long history of “American exceptionalism,” resulting in unwillingness to ratify human rights treaties and resistance to the use of human rights norms.⁴⁵ Although the CRPD was signed by the administration shortly into President Barack Obama’s first term,⁴⁶ subsequent efforts at ratification have proven unsuccessful.⁴⁷ Under the current administration of President Donald J. Trump, the possibility of

43. See generally Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111 (2013) (describing the various questions that arise with supported decision-making, due in large part due to the lack of research on the subject).

44. See, e.g., ANNA ARSTEIN-KERSLAKE, *RESTORING VOICE TO PEOPLE WITH COGNITIVE DISABILITIES: REALIZING THE RIGHT TO EQUAL RECOGNITION BEFORE THE LAW* 216–19 (2017) [hereinafter *RESTORING VOICE*] (calling for “co-production” in “rights-based research”).

45. See, e.g., Harold Hongju Koh, *On American Exceptionalism*, 55 STAN. L. REV. 1479, 1483 (2003) (noting “four somewhat different faces of American exceptionalism,” which he ranks “in order of ascending opprobrium” as “distinctive rights, different labels, the ‘flying buttress mentality’, and double standards”); David Sloss, *The Domestication of International Human Rights: Non-Self-Executing Declarations and Human Rights Treaties*, 24 YALE J. INT’L L. 129 (1999) (detailing the history of United States involvement in human rights treaties); Mark C. Rahdert, *Exceptionalism Unbound: Appraising American Resistance to Foreign Law*, 65 CATH. U. L. REV. 537, 548 (2016) (noting the long history and prevalence of exceptionalist thinking in the United States).

46. Kareem Dale, *Valerie Jarrett & Ambassador Rice at the U.S. Signing of the UN Convention on the Rights of Persons*, WHITE HOUSE OFF. OF PUB. ENGAGEMENT (July 30, 2009, 7:26 PM), <https://obamawhitehouse.archives.gov/blog/2009/07/30/valerie-jarrett-ambassador-rice-us-signing-un-convention-rights-persons> [http://perma.cc/77BU-NX72].

47. S. TREATY DOC. NO. 112-7 (2012). The ratification document failed on a vote of sixty-one yeas and thirty-eight nays. Ramsey Cox & Julian Pecquet, *Senate Rejects United Nations Treaty for Disabled Rights in a 61-38 Vote*, HILL (Dec. 4, 2012, 5:29 PM), <http://thehill.com/policy/international/270831-senate-rejects-un-treaty-for-disabled-rights-in-vote> [https://perma.cc/8QRH-GQTT]. In 2014, the U.S. Senate again declined to act on a report from the Senate Committee on Foreign Relations favoring CRPD ratification. See LUISA BLANCHFIELD & CYNTHIA BROWN, CONG. RESEARCH SERV., *THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: ISSUES IN THE U.S. RATIFICATION DEBATE* 5 (2015).

ratification appears nonexistent. Thus it appears the right of legal capacity is highly unlikely to enter our jurisprudence through treaty incorporation.⁴⁸ Section I.F briefly discusses American exceptionalism.

The Article concludes with a prediction that although the right of legal capacity is unlikely to be accepted or adopted in legislation or judicial determinations, at least in its “purest” form, in the United States, an understanding of this right can serve as a valuable tool for changing beliefs and practices that limit people with intellectual disabilities from leading inclusive and admirable lives.⁴⁹ At the same time, the right of legal capacity can reinforce other work about vulnerability and relationships that challenge the current liberal notion of capacity and autonomy. Further, it can create and nurture solidarity with other individuals and organizations around the world for whom the right is worth the struggle.

A. The Meaning of Legal Capacity

Since the CRPD’s entry into force in 2008,⁵⁰ many States parties have submitted reports to the CRPD Committee. However, during that time, as the Committee noted in the First General Comment:

[T]here has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making The present general comment reflects

48. Of course, even when the United States ratifies a treaty, it usually does so with “reservations and understandings” (RUDs) that limit or undermine the rights guaranteed by the treaty or convention; in domains constitutionally reserved to the states, despite the Supremacy Clause, treaty rights do not automatically apply. See, e.g., David Cole, *The Idea of Humanity: Human Rights and Immigrants’ Rights*, 37 COLUM. HUM. RTS. L. REV. 627, 632 (2006) (“Congress has often . . . adopt[ed] reservations in ratifying international human rights conventions providing that the treaties not be read as anything more than what American constitutional law guarantees.”).

49. I credit my friend Arlene Kanter, Laura J. and L. Douglas Meredith Professor of Law and Director of the Disability Law and Policy Program at Syracuse University College of Law, for her insistence that we should aspire for people with disabilities to live not only good, but *admirable* lives.

50. The Convention on the Rights of Persons with Disabilities entered into force with ratification by twenty Member States in 2008. *Entry into Force*, U.N. DIV. SOC. POLICY & DEV. DISABILITY, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html> [<https://perma.cc/W4XV-EAM2>] (last visited Feb. 21, 2018).

an interpretation of article 12 which is premised on the general principles of the Convention . . . namely, respect for inherent dignity, [and] individual autonomy—including the freedom to make one’s own choices⁵¹ All practices that in purpose or effect violate article 12 must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.⁵²

This failure is largely ascribable to an inability or unwillingness to appropriately interrogate the concept of “capacity.” In an interpretation fraught with opportunities for debate, the Committee stated:

Legal capacity and mental capacity are distinct concepts. Legal capacity . . . is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person which naturally vary Article 12 . . . makes it clear that “unsoundness of mind” and other discriminatory labels are not legitimate reasons for the denial of legal capacity Under [A]rticle 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.⁵³

The law generally defines persons as having or lacking *mental* capacity, and so having or being denied *legal* capacity, through a “functional assessment.”⁵⁴ The General Comment unequivocally rejects functional assessment⁵⁵—and all modes of assessment of mental

51. General Comment No. 1, *supra* note 9, ¶¶ 3–4.

52. *Id.* ¶ 9.

53. *Id.* ¶ 13. This formulation has been referred to as the “strong” interpretation of legal capacity. See, e.g., Jillian Craigie, *Against a Singular Understanding of Legal Capacity: Criminal Responsibility and the Convention on the Rights of Persons with Disabilities*, 40 INT’L J.L. & PSYCHIATRY 6, 6–7 (2015) (“Strong interpretations suggest that Article 12 leaves very limited room for restricting legal capacity on the basis of mental incapacity.”).

54. The movement to functional assessments of “capacity” was significant in guardianship reform efforts in the 1980s and 90s. This transition was a significant advance over earlier models in which “capacity” was determined by status or medical diagnosis, or through an “outcomes” approach. See Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 109–13 (2012) [hereinafter Glen, *Changing Paradigms*].

55. General Comment No. 1, *supra* note 9, ¶ 15 (“[The functional] approach is flawed for two key reasons. . . . [I]t is discriminatorily applied to people with

capacity or “decision-making skills”—as “legitimate grounds for denying [a person’s] legal capacity and lowering his or her status as a person before the law.”⁵⁶

The separation of mental and legal capacity and the apparent rejection of functional assessment⁵⁷ undermines millennia of laws that use substitute decision-making for the “protection” of persons lacking mental capacity. This separation requires a new conceptual framework and major changes in the legal system, and simultaneously engenders significant political opposition. This has resulted, to date, in the uniform failure of states that have ratified the Convention to reform their legal capacity laws in light of Article 12.⁵⁸

In a recent article, Michael Bach, one of the preeminent theorists of legal capacity, has suggested that, in this failure, “[t]hree types of intersecting conflicts seem to be at play—conceptual/philosophical, legal and political.”⁵⁹ This Article takes this framework as a useful way to think about the issues and arguments raised, in particular about “hard cases” that need resolution if the right of legal capacity is to enter our jurisprudence, and perhaps more fundamentally, our understanding of the world.

1. Conceptual/Philosophical

A question inevitably raised about “hard cases” is whether it is possible to either attribute or actualize legal capacity for persons with profound intellectual or cognitive impairments, or who are in a coma

disabilities; and it presumes to be able to accurately assess the inner-workings of the human mind.”).

56. *Id.*

57. *But see infra* note 72 (noting when and where functional assessment may be employed for a different, non-prohibited purpose).

58. Many countries or states, including the United Kingdom, have not changed their guardianship laws at all. *See* RESTORING VOICE, *supra* note 44, at 90–96 (discussing and critiquing the reformist but pre-CRPD Mental Capacity Act of 2005). Others, like Ireland—with the Assisted Decision-Making (Capacity) Act 2015—continue to retain some forms of substitute decision-making. *Id.* at 65 n.5. For additional examples of various countries’/states’ guardianship laws, see, for example, Adult Capacity and Decision-making Act, S.N.S. 2017, c. 4 (Can.) (providing a legal framework for guardianship for adults “whose capacity is impaired”). *See also* discussion *infra* Section I.A.2.

59. Michael Bach, *Inclusive Citizenship: Refusing the Construction of “Cognitive Foreigners” in Neo-Liberal Times*, 4 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 4, 12 (2017) [hereinafter Bach, *Inclusive Citizenship*].

or persistent vegetative state. How can we talk about honoring the choices of persons with whom it appears no communication is possible? How can we honor their “inherent dignity”? This is both a theoretical and a practical question.

As a theoretical matter, this question implicates issues of moral philosophy as to whether people with severe cognitive impairments should be viewed as moral agents and, consequently, whether moral agency and attention can be ascribed to them and their actions.⁶⁰ It challenges liberal political theory and the dominant Enlightenment belief in human reason and rationality.⁶¹ It also suggests engagement with feminist theories of relationship as the basis of personhood.⁶²

As a practical matter, it calls into question whether there are ever circumstances in which someone should be given the power to make decisions *for* a person who is so impaired that it is not possible to ascertain her or his “will and preference.”⁶³ There are some who take an absolutist position that substitute decision-making should never be permissible.⁶⁴ Others, for whom that may be at least theoretically the

60. See, e.g., EVA FEDER KITTAJ & LICIA CARLSON, EDs., *COGNITIVE DISABILITY AND ITS CHALLENGE TO MORAL PHILOSOPHY*, 183–260 (Wiley-Blackwell, 2010) (discussing issues of moral philosophy with regard to agency).

61. Oliver Lewis, *Advancing Legal Capacity Jurisprudence*, 6 EUR. HUM. RTS. L. REV. 700, 702 (2011). Gerard Quinn writes,

The Enlightenment . . . probably had the largely accidental effect of narrowing down our understanding of the ‘essence’ of personhood . . . that telescoped narrowly into cognitive ability Understanding the essence of personhood as cognitive ability is not true Hard science is demonstrating daily the importance of emotion and intersubjectivity. Even economics is warming to the idea of irrationality is the prime basis for human action. RESTORING VOICE, *supra* note 44, at xi.

62. See generally Yael Brauo-Bahat, *Towards a Relational Conceptualization of the Right to Personal Autonomy*, 23 AM. U. J. GENDER, SOC. POL’Y & L. 111 (2012) (rejecting a liberal construction of autonomy in favor of a more complex account that perceives autonomy as a fluid and dynamic competency that evolves and flourishes through a web of relationships).

63. This phrase appears in CRPD Article 12(4) and is prominent in the First General Comment where it is employed to explicate the obligations of States Parties to safeguard the exercise of legal capacity. General Comment No. 1, *supra* note 9, ¶ 29.

64. See, e.g., Tina Minkowitz, *CRPD Article 12 and the Alternative to Functional Capacity: Preliminary Thoughts Towards Transformation* (Dec. 25, 2013), <https://ssrn.com/abstract=2371939> [<https://perma.cc/7BUF-RQMJ>] (arguing for an “inclusive legal capacity” that conclusively presumes contractual capacity

case, understand that to insist on it is to risk undermining the claim for legal capacity as a human right. Gerard Quinn has written:

Now, what about those whose will is undetectable or for whom it is not possible to ascribe a will or preference? . . . I think the hard reality is that sometimes decisions will be made ‘for’ and not ‘with’ does not mean that ‘substituted decision making’ *as usual* is the correct response But what’s worse: stretching a fiction (100% support) to the point that it is visibly at odds with reality . . . or admitting the obvious and then using our talents to lock in the exception and transform how decisions are ‘made for’ people?⁶⁵

Quinn explains the “exception” as limited to only those persons for whom no amount of supports is enough, while simultaneously emphasizing the obligation to explore all possibilities.⁶⁶ He proposes drawing lines to identify “toeholds on the slippery slope” in which the new exceptions—decisions “for”—could, without vigilance, revert to the existing paradigm of substitute decision-making.⁶⁷

Michael Bach and Lana Kerzner take on the challenge in their oft-cited paper, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities Through Law, Policy and Practice*.⁶⁸ Utilizing the concept of “capabilities,”⁶⁹ rather than “capacity,” they develop a three-

and rejects any functional assessment that would remove decision-making). It is possible to ascribe this position to the fact that Minkowitz primarily represents people with psychosocial disabilities, for whom it is intuitively more plausible, rather than people with severe cognitive impairments.

65. Quinn, *supra* note 10, at 15–17.

66. *Id.* at 17.

67. *Id.* at 18; see also Glen, *Changing Paradigms, supra* note 54, at 166 n.319 (discussing Quinn’s analysis).

68. This paper was prepared for the Law Commission of Ontario. BACH & KERZNER, *A NEW PARADIGM, supra* note 42. Much of the scholarly literature around legal capacity or SDM draws on their work. See, e.g., Dinerstein et al., *Emerging Int’l Trends, supra* note 19, at 442 (citing Bach & Kerzner in a discussion of SDM); Flynn & Arstein-Kerslake, *Legislating Personhood, supra* note 20, at 82 n.2 (explicitly building on the work of Bach & Kerzner).

69. Their capabilities approach is derived, in part, from the work of Amartya Sen. See MICHAEL BACH, *AN INTERNATIONAL DIALOGUE ON IMPLEMENTING ARTICLE 12, UN CRPD: LEGAL CAPACITY AND EQUAL RECOGNITION BEFORE THE LAW: A BACKGROUND PAPER 19 & 24 n.i* (2011) [hereinafter Bach, *A Background Paper*].

part model of decision-making status: (1) legally independent status,⁷⁰ (2) supported decision-making status,⁷¹ and, for Quinn's "exception," (3) facilitated decision-making.⁷²

Supported decision-making status is expected to include the vast majority of people with intellectual, developmental, psychosocial, and cognitive disabilities (Quinn's 95%). In Bach and Kerzner's typology, it has a low "minimum threshold for exercising legal capacity," requiring only that:

[a]n individual can act in a way that at least one person who has personal knowledge of the individual: can reasonably ascribe to the individual's actions, personal will and/or intentions consistent with the person's identity; and can take reasonable consequential actions to give effect to the will and/or intentions of the individual, which respects the individual's dignity of risk[.]⁷³

Their third category, facilitated status, includes the "hard cases,"⁷⁴ described as "a status in which others facilitate the making of needed decisions"⁷⁵ envisioned for use for persons "with significant disabilities who are not able to act legally independently, and who have no other people in their lives who have personal knowledge about them sufficient to understand their ways of communicating, their will and/or

70. They write, "This is the status usually articulated in moral philosophy and the law, essentially the 'freely contracting agent.'" BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 83–84. Capacity for this status is the standard "understand and appreciate" test. *Id.* at 84.

71. Persons in this status "need[] support from others to communicate, express and represent themselves to third parties or to process information." *Id.* at 85.

72. This is the space in which honest functional assessment has a place; not to determine who has or should be afforded legal capacity, which the General Comment prohibits, but rather to determine *which supports* people need in order to exercise their legal capacity. *Id.*; *see also* General Comment No. 1, *supra* note 9 (focusing primarily on the normative content of Article 12 of the Convention on the Rights of Persons with Disabilities and the State obligations that emerge therefrom).

73. BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 86.

74. Flynn & Arstein-Kerslake, *Legislating Personhood*, *supra* note 20, at 98 (discussing "hard cases" and proposing a support model of legal capacity as a universal answer).

75. BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 91.

intentions⁷⁶ as the basis for decision-making (as in a supported status).⁷⁷ Facilitated status also includes persons

who do have others in their lives who know them well and are committed to acting for them, but where these supporting others are unable to discern the person's current will and/or intentions sufficient to guide decision-making—for example, people who have experienced traumatic injury, illness or a dementia which has left them in a coma, or with dramatically impaired cognitive and communication function.⁷⁸

A person in "facilitated status" would not be defined as "legally incapable," and the status would not represent a statement or judgment about their cognitive status or abilities.⁷⁹ The "facilitator" would be "duty-bound to facilitate the making of needed decisions on the basis of any knowledge they may have or could reasonably be expected to acquire, about the person's will and/or intentions previously expressed."⁸⁰ Although Bach and Kerzner suggested that, in the absence of any such knowledge or the inability to obtain it, the standard "best interest" test would apply.⁸¹ Four years later, the CRPD Committee wrote:

[w]here, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the 'best interpretation of will and preferences' must replace the 'best interests' determinations. This respects the rights, will and preferences of the individual . . . [and] ensure[s] that

76. The relevant language in the First General Comment is "will and preferences," and that is the phrase that is utilized by most commentators discussing "facilitated decision making." General Comment No. 1, *supra* note 9. Bach has, for some time, been working on a theoretical grounding for the exercise of legal capacity by those persons who have the most severe impairments in which he employs the ability to form an "intent" as the core capability necessary for legal capacity. See Michael Bach, "Will and Preference" as a Non-Cognitive Ground for Recognizing Legal Capacity (unpublished manuscript) (on file with author). The Bach and Kerzner decisional status typology preceded the General Comment by 4 years. See BACH & KERZNER, A NEW PARADIGM, *supra* note 42.

77. BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 91.

78. *Id.*

79. *Id.* at 92.

80. *Id.*

81. *Id.* at 93.

persons with disabilities enjoy the right to legal capacity on an equal basis with others.⁸²

What, precisely, this means in practice remains to be seen. Many will question whether it is only substitute decision-making in another form.⁸³ Yet, there is arguably a real value to this insistence on “will and preference,” however difficult to ascertain, as the basis for a conception of legal capacity that is truly universal. Here it is worth considering the “expressive” value of the law,⁸⁴ which depicts how laws and legal instruments can change social perceptions and actions. When the *law* ascribes legal capacity, and thus personhood, to a person, however severely impaired, it is more likely that others will perceive her or him not as an object—to be managed or pitied—but rather as the subject of her or his own life.⁸⁵

2. Legal

Of what use is the right of legal capacity if third parties need not honor nor accept transactions with persons with intellectual, developmental, and cognitive disabilities?⁸⁶ If the landlord will not allow a person with I/DD to sign a lease, if a healthcare professional will not accept the decision of such person as “informed consent,” or if the banker will not permit her to create an account on her own, where is her legal capacity? Even though she may have a well-functioning support network and even a well-crafted SDM agreement, in our

82. General Comment No. 1, *supra* note 9, ¶ 21.

83. The General Comment’s explication of Article 12(4) is hardly a model of clarity, and leaves room for several conflicting interpretations which may be relied upon by commentators and lawmakers seeking to retain substitute decision-making. See Gooding, *Flashing Amber Lights*, *supra* note 3, at 53–70. These claims, and potential responses to them, are beyond the reach of this Article.

84. See, e.g., Michael Ashley Stein, *Under the Empirical Radar: An Initial Expressive Law Analysis of the ADA*, 90 VA. L. REV. 1151, 1155 (2004) (arguing that the law can affect individual behavior by changing social perceptions).

85. See Flynn & Arstein-Kerslake, *Legislating Personhood*, *supra* note 20, at 85 (arguing “the moral danger in excluding individual human beings from the framework of human rights” as leading to “the treatment of those individuals as *objects* to be pitied or cared for rather than as *subjects* before the law”) (emphasis added).

86. Bach, *A Background Paper*, *supra* note 69, at 21 (stating that “third parties to decision-making processes must be confident that they are entering a contract or obtaining informed consent or being directed in legal proceedings with a person with a disability in a manner that ensures the integrity of the agreement between them”).

liability-conscious society, the likelihood is small that most third parties will accept and honor that agreement.⁸⁷

To the extent that legal capacity involves legal recognition of a person's right and power to "engage in transactions and . . . create, modify or end legal relationships,"⁸⁸ it is necessary to invoke the power of the state to enforce such transactions and relationships.⁸⁹ The CRPD suggests as much in Article 12(5), which requires States parties to take "all appropriate and effective measures" to "ensure the equal right of persons with disabilities" to engage in financial and property transactions.⁹⁰

This means, in the United States and elsewhere,⁹¹ that there must be legislation that relieves third parties from liability when they rely upon supported decision-making agreements (SDMAs) in good faith, requires them to honor SDMAs, or both.⁹² Such legislation would be similar to that which commonly attaches to Powers of Attorney.⁹³ At

87. Of course, private third parties *may* accept the agreements without legislation, which might be the situation in a smaller community where everyone knows everyone and fear of litigation is nonexistent. And, where SDM is being piloted with state support, state entities like schools or agencies that provide benefits, may agree to accept SDMAs informally or by regulation. See Kristin Booth Glen, *Piloting Personhood: Reflections on the First Year of a Pilot Supported Decision Making Project*, 39 CARDOZO L. REV. 495, 518 (2017) [hereinafter Glen, *Piloting Personhood*].

88. General Comment No. 1, *supra* note 9, ¶ 12.

89. See, e.g., Kristin Booth Glen, A.B.A. COMM'N DISABILITY RIGHTS & COMM'N LAW & AGING, BEYOND GUARDIANSHIP: SUPPORTED DECISION-MAKING BY PERSONS WITH INTELLECTUAL DISABILITIES ROUNDTABLE BRIEFING PAPER 9 (2012), <https://www.americanbar.org/groups/disabilityrights/resources/article12.html> [<https://perma.cc/8L48-DP33>] (last visited Feb. 5, 2018).

90. CRPD, *supra* note 1, art. 12(5).

91. For example, the requirement that private third parties accept SDMAs appears in Article 22 of the draft Bulgarian legal capacity law, see *infra* Section II.A.2, which reads, "The support measures entered into [in accordance with other provisions of the law] shall be binding for any third parties and for all public service providers and representatives of state authorities and organizations and local authorities." BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS 28 (2015) [hereinafter SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS].

92. Passing legislation requires political effort and acceptance. For a brief discussion of this political aspect, see *infra* Section I.C.

93. As an example, the Uniform Power of Attorney Act, drafted by the Uniform Law Commission, provides in Sections 119 and 120 (of which there are two alternative provisions) that a party may rely on a valid Power of Attorney (PoA) and *shall* accept a valid PoA or be subject to a court order and assessment of attorneys' fees and costs expended in obtaining the order. UNIF. POWER OF

present, two states, Texas⁹⁴ and Delaware,⁹⁵ have enacted SDM legislation, and at least six other states are considering doing so or have created commissions or other entities to study the possibility.⁹⁶

As discussed in Section I.B, *infra*, the existence of supported decision-making and the requirement that SDMA be legally recognized are not, in and of themselves, full incorporation of a right of legal capacity. They are, however, clearly a necessary condition.

3. Political

As commentators have noted, “[r]ecently, the professional mental health community, as well as legal practitioners and academics have come out in opposition to the strong interpretation of Article 12.”⁹⁷ There are at least three potent potential bases for political opposition to the adoption of a right of legal capacity in the United States: professional identity, an economic stake in the existing system of substitute decision-making, and the ideology of “protection.”

Arstein-Kerslake identifies professional identity as a barrier to change, writing,

Legal capacity law, substituted decision-making, and the assessment and denial of legal capacity are deeply entrenched in specific relationships and professions. These groups are likely to be resistant to change, because they may feel a change is a challenge to their

ATTORNEY ACT §§ 119–20 (UNIF. L. COMM. 2006). It would differ, however, in that a PoA requires a higher level of “mental capacity” than the SDMA, which is not dependent on “mental capacity.” *Id.*

94. The Texas statute both creates a safe haven for reliance on SDMA and requires third parties to accept and honor them. TEX. EST. CODE ANN. §§ 1357.001–1357.102 (West 2015).

95. The Delaware statute relieves third parties from liability but explicitly tells those third parties that they may accept the agreements or may not. DEL. CODE ANN. tit. 16, § 9401A (West 2016).

96. See B22-0154, 2017 Council (D.C. 2017); S.B 264, 110th Sess. (Tenn. 2017); H.B. 941, 2017, 110th Sess. (Tenn. 2017); S. Res. 44, 2017 (Ind. 2017); S. Res. 44, 2017 (Ind. 2017); State of Me. H. of Rep. B. 900, 127th Leg. (Me. 2017); H.B 713, 2017 Gen. Assemb., Reg. Sess. (N.C. 2017); S.B.190, 2014 Va. Gen. Assemb., Reg. Sess. (Va. 2014).

97. Marie Fallon Kund & Jerome Bickenbach, *Strengthening the Voice of Persons with Mental Health Problems in Legal Capacity Proceedings Laws*, 5 LAWS 29, 1–2 (Sept. 2016).

established profession or to the way in which they have been operating for years.⁹⁸

As an example, in his discussion of political “conflicts at play,” Bach notes that,

as disability rights advocates engage with state and other actors in the politics of reform . . . [s]ome mental health experts are actively challenging [the General Comment’s interpretations on the grounds that] mental health law reform along the recommended lines would undermine the protection of informed consent, the right to the highest standard of health, to liberty, and even the right to life.⁹⁹

Bach attributes this opposition, based on the assertion of professional identity, at least in part to the failure of the Law Commission of Ontario (LCO) to adopt a robust position on legal capacity.¹⁰⁰

Several groups have a strong economic interest in continuing the present guardianship system and thus in opposing a right of legal capacity that would require its abolition. There is a considerable cohort of “professional guardians” in many states.¹⁰¹ Sectors of the bar devote all or part of their practices to bringing petitions for guardianship for

98. RESTORING VOICE, *supra* note 44, at 221.

99. Bach, *Inclusive Citizenship*, *supra* note 59, at 13. For examples of such mental health experts, see, e.g., Paul S. Appelbaum, *Protecting the Rights of Persons with Disabilities: An International Convention and its Problems*, 67 PSYCHIATRIC SERVS. 366, 366–67 (2016) (describing the Committee on the Rights of Persons with Disabilities’ views on General Comment No. 1); John Dawson, *A Realistic Approach to Assessing Mental Health Laws’ Compliance with the UNCRPD*, 40 INT’L J.L. & PSYCHIATRY 70, 73–75 (2015) (arguing for a more realistic view of the Convention on the Rights of Persons with Disabilities); Melvin Colin Freeman et al., *Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities*, 2 LANCET: PSYCHIATRY 844, 844–46 (2015) (critiquing the General Comment on Article 12 of the U.N. Convention on the Rights of Persons with Disabilities).

100. Bach, *Inclusive Citizenship*, *supra* note 59, at 13–14. For discussion of the history of the LCO project and its eventually disappointing results see *infra* at Section II.A.1.

101. See Allison Barnes, *The Virtue of Corporate and Professional Guardians*, 31 STETSON L. REV. 942, 942–44 (2002). For abuses by professional guardians, see, e.g., *Guardians of the Elderly: An Ailing System* (AP Special Report, Sept. 1987), in ABUSES IN GUARDIANSHIP OF THE ELDERLY AND INFIRM: A NATIONAL DISGRACE, H.R. COMM. PRINT 100-639 (Dec. 1987) (reporting on abuses by guardians in the United States).

persons with I/DD or for older persons with dementia and other forms of cognitive impairment.¹⁰² It should be no surprise that activists in favor of the SDM statutes in Texas and Delaware saw the organized bar as a major source of opposition to the bills.¹⁰³

Finally, there is strong, continuous, and sometimes highly emotional opposition to legal capacity in the name of protection, primarily from parents of persons with I/DD and their organizations. At numerous conferences I have attended, or events with parents and parents' groups where I have presented, I have heard again and again, without empirical support, that only guardianship can protect their children from all manner of abuse and exploitation.¹⁰⁴ For example, one such organization that has been actively opposing any recognition of SDM as an alternative to guardianship is VOR,¹⁰⁵ which has a policy of "support[ing] individual and family participation in decision-making."¹⁰⁶ VOR opposed the ABA resolution in favor of consideration of supported decision-making as a less restrictive alternative to guardianship, writing:

VOR is deeply concerned about any effort to weaken the protections of guardianship. Attempts to replace guardianship with . . . [s]upported decision-making affect not only those with severe intellectual disabilities but also people with I/DD who are vulnerable to manipulation and coercion by others as well as individuals who lack awareness of the

102. For example, there is an entire section of the New York State Bar Association devoted to Elder Law and Special Needs, with Guardianship as a significant sub-category. The program of its recent Fall meeting, attended by approximately 350 lawyers, had six of thirteen presentations over two days deal with guardianship or guardianship-related issues. N.Y. STATE BAR ASS'N, NYSBA ELDER LAW AND SPECIAL NEEDS SECTION FALL MEETING (2017) (on file with author).

103. This information comes from anonymous interviews conducted in October 14–15, 2017, and March 1, 2017 (on file with author).

104. See, e.g., *About VOR*, VOR, <https://www.vor.net/about-vor> [<https://perma.cc/VK38-A4TM>] (last visited Feb. 5, 2018) (noting the organization's mission to advocate for high quality care and human rights for all people with I/DD).

105. The organization was formerly known as Voices of the Retarded. See *Voices of the Retarded*, NAT'L ARTS & DISABILITY CTR., UCLA, <http://www2.semel.ucla.edu/nadc/resource/voices-retarded-vor> [<https://perma.cc/TT3A-WKVZ>] (last visited Feb. 5, 2018).

106. *About VOR*, *supra* note 104.

consequences of their own actions which may cause harm to themselves or others.¹⁰⁷

VOR makes similar arguments in its Policy on Guardianship.¹⁰⁸ While this may appear to be an extreme example, the power of the "protection" argument and the political power of many parents' organizations should not be underestimated.

Rebuttal of their position, sincerely held as it may be, is beyond the scope of this article, though it is at least equally likely that enhancing autonomy and self-determination through legal capacity can enhance the abilities of people with I/DD to identify and resist abuse. Similarly, community inclusion and the existence of a trusted support network ensures many "eyes" that can serve to prevent abuse, exploitation, and undue influence.

The experience of Bizchut, the Israeli organization for people with disabilities, teaches that concerns about protection should not be ignored. Based on its supported decision-making pilot project for financial decisions, Bizchut recommends that concerns about the need for protection from exploitation should be acknowledged¹⁰⁹ and that appropriate protective measures should be developed for all people who might be subject to such exploitation or undue influence in their

107. *VOR Comments to Proposed Guardianship, Conservatorship, and Other Protective Arrangement Act*, VOR, https://www.vor.net/images/stories/2017-2018/VOR_Comments_to_Draft_Guardianship_Conservatorship_and_Other_Protective_Arrangements_Act.pdf [<https://perma.cc/36NP-HXVU>] (last visited Feb. 21, 2018); see also Letter from VOR to Robert Gonzales, Chair, A.B.A. Comm'n on Disability Rights, VOR (July 26, 2017), <https://www.vor.net/images/stories/2017-2018/Letter-to-ABA-about-Resolution-Regarding-Guardianship.pdf> [<https://perma.cc/WV99-T567>] (expressing opposition to SDM).

108. *VOR Policy Statement on Guardianship and Supported Decision Making*, VOR, <https://www.vor.net/images/stories/pdf/VOR-OnGuardianshipandSDM.pdf> [<https://perma.cc/WV99-T567>] (last visited Feb. 21, 2018).

109. YOTAM TOLUB, ALTERNATIVES TO GUARDIANSHIP IN FINANCIAL MATTERS, BIZCHUT REPORT 18, <http://bizchut.org.il/en/wp-content/uploads/2014/12/Alternative-to-Guardianship-report.pdf> [<https://perma.cc/Q98U-4R8H>] ("[C]oncern about harm and the need to develop protection need to be seriously taken into account; first, because the concern is based on incidents that have actually occurred; second, it is one of the primary reasons for appointing a guardian; and third, because people with disabilities may also be concerned about harm.").

financial dealings.¹¹⁰ Bizchut points out that this is consistent with the call for “universal design” in Articles 2 and 4(1)(f) of the CRPD.¹¹¹

This is an important point, and not only for financial exploitation. It also resonates with concerns about the vulnerability of people with I/DD to sexual abuse and exploitation and to issues of self-harm or harm to others by people with psychosocial disabilities. In each instance, the work should not be to deny the concerns, but to find and actualize universal solutions that protect those with and without disabilities equally.

B. Supported Decision-Making (SDM)

SDM as a practice, described as an *alternative* to guardianship,¹¹² has proven a much easier sell than the human right of legal capacity from which it is derived. Indeed, much of the now copious literature about SDM pays short shrift to legal capacity or omits it altogether.¹¹³ Legislation passed after the CRPD may include a form of SDM even as it continues to deprive some people who lack

110. *Id.* (“People with disabilities are not the only ones who have to cope with concerns about financial harm. Concerns for [all kinds of people] have led to the development of various means of intervention or prevention of harm in the financial sphere. These solutions are universal in that they are not meant solely for people with disabilities. Universal solutions that apply to the population at large are not only clearly preferable in considering alternatives, but they are consistent with the CRPD . . .”).

111. *Id.* at 18; see also CRPD, *supra* note 1, art. 2 (“‘Universal design’ means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design”); *id.* art. 4(1)(f) (calling on States Parties to undertake or promote research and development of universal design). In the area of financial exploitation, for example, this would involve doctrines of fraud, duress, undue influence, and coercion that already exist in the contractual and probate spheres.

112. By this I mean where SDM is understood or advanced as an alternative, or even a “least restrictive alternative,” see discussion *infra* at 26–27, within a continuing system of substituted decision-making. This understanding accepts the validity of a system the CRPD Committee has found violates Article 12.

113. See, e.g., Terry Carney, *Supporting People with Cognitive Disabilities with Decision-Making: Any Australian Law Reform Contributions?*, 2 RES. & PRAC. INTEL. & DEVELOPMENTAL DISABILITIES 6, 6 (2012) [hereinafter Carney, *Supporting People with Cognitive Disabilities*] (“There is limited agreement about basic concepts and principles, but it is useful to distinguish between support for decision-making and supported decision-making that engages legal capacity.”) (citations omitted).

mental capacity, however defined, of their right to legal capacity.¹¹⁴ Pilot projects risk supporting people with intellectual disabilities with their choices rather than insisting on these individuals' rights to be legal actors.¹¹⁵ Providers may co-opt SDM as yet another billable service even as their practice discourages clients from exercising legal capacity.¹¹⁶ The introduction of SDM in the United States provides a potentially cautionary tale.

The Administration for Community Living (ACL)¹¹⁷ was an initial motivating force in introducing SDM to the United States. It was one of the funders of the first interdisciplinary roundtable on SDM in the country.¹¹⁸ Within a year of that event, ACL issued a request for proposals for a five-year grant to create a National Resource Center on

114. For example, Ireland's Assisted Decision Making (Capacity) Act which, despite the strong efforts of advocates for the right of legal capacity, ended up with a mix of supports, "includ[ing] the option of entering binding assisted decision making agreements and co-decision making agreements" but also "was still premised on the individual reaching a certain standard of mental capacity as a prerequisite for having their legal capacity respected." See RESTORING VOICE, *supra* note 44, at 173.

115. This is what Michelle Browning and her colleagues refer to as the difference between supports *with* decision-making and supported decision-making. While the former "offers people with disabilities more involvement in their own lives through preference and choice making," certainly a good in itself, it is not directed toward empowering them to exercise the right of legal capacity. Michelle Browning, Christine Bigby & Jacinta Douglas, *Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice*, 1 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 34, 37 (2014) [hereinafter Browning et al., *Supported Decision Making*].

116. See Anna Arstein-Kerslake et al., *Future Directions in Supported Decision-Making*, 37 DISABILITY STUD. Q. (2017) at 11, <http://dsq-sds.org/article/view/5070/4549> [<https://perma.cc/4R39-F7E3>] [hereinafter Arstein-Kerslake et al., *Future Directions*] ("Without close attention to the mechanics of how supported decision-making is implemented, there is a risk that it will become another tick box exercise, more to serve a bureaucratic purpose than to provide genuine choice and control for people with disability."); Glen, *Piloting Personhood*, *supra* note 87, at 508 (reflecting a similar concern by self-advocates).

117. ACL is a division of the U.S. Department of Health and Human Services. It includes both the Agency for Intellectual and Developmental Disabilities (AIDD) and the Administration on Aging (AOA). *Organizational History*, ACL, <https://www.acl.gov/about-acl/history> [<https://perma.cc/B5VD-UDGS>] (last visited Feb. 6, 2018).

118. *Supported Decision Making Program*, ADMIN. CMTY. LIVING, <https://www.acl.gov/programs/consumer-control/supported-decision-making-program> [<https://perma.cc/5ADM-CEGF>] (last visited Feb. 6, 2018).

Supported Decision Making (NRCSDM).¹¹⁹ The grant was awarded to a consortium including Quality Trust, a Washington, D.C., provider organization that had litigated the now-famous Jenny Hatch case,¹²⁰ the Burton Blatt Institute at Syracuse University (BBI), and the Beach Center on Disability, University of Kansas Center on Developmental Disabilities.¹²¹ While NRCSDM has done, and continues to do excellent and important work,¹²² references to the right of legal capacity are notably missing.¹²³

BBI received a subsequent ACL grant to fund research on “Understanding and Increasing Supported Decision Making’s Positive Impact on Community Living and Participation Outcomes.”¹²⁴ That project also focuses on the benefits to, and the process of, assisting people with disabilities in making choices, with little or no reference to their legal agency or lack thereof.¹²⁵ Again, this work is important and the omission of research on legal capacity is understandable given the lack of statutory authority requiring acceptance of an individual’s agency by third parties.¹²⁶ However, the narrow focus on SDM also suggests the need for concern that the means of SDM may swallow its human rights end.

Furthermore, the limited legislation passed to date suggests that in promoting SDM, advocates may actually be undermining legal capacity by connecting enforceability of SDMA’s to at least some level

119. Grant # HHS-2014-ACL-AIDD-DM-0084.

120. Ross et al. v. Hatch, Case No. CWF-120000-426-P-03 (Va. Cir. Ct. 2013); see also *The Justice for Jenny Trial*, JENNY HATCH JUSTICE PROJECT, <http://jennyhatchjusticeproject.org/trial> [<https://perma.cc/D3HX-JCLZ>] (last visited Feb. 20, 2018) (documenting and providing court submissions and materials from the Jenny Hatch case).

121. *About*, NAT’L RES. CTR. FOR SUPPORTED DECISION-MAKING, <http://www.supporteddecisionmaking.org/about> [<https://perma.cc/27AF-X6H2>] (last visited Feb. 6, 2018).

122. As a disclosure, I am a member of NRCSDM’s Advisory Board.

123. For example, NRCSDM’s home page repeatedly refers to “making choices,” but never once mentions legal capacity. NAT’L RES. CTR. FOR SUPPORTED DECISION-MAKING, <http://www.supporteddecisionmaking.org> [<https://perma.cc/3K4Y-UXUM>] (last visited Feb. 6, 2018).

124. Grant #90DP0076-01-00.

125. *Project Overview: Understanding and Increasing Decision-Making’s Positive Impact on Community Living and Participation Outcomes*, BURTON BLATT INST.: CMTY. LIVING AND SUPPORTED DECISION MAKING, http://bbi.syr.edu/projects/Community_Living_DRRP/index.html [<https://perma.cc/AWE4-P7D3>] (last visited Feb. 21, 2018).

126. See discussion *supra* Section I.A.2.

of mental capacity. Thus, while the Texas statute¹²⁷ nowhere defines the level of "capacity" necessary to enter into an SDMA, the advocates responsible for its passage appear to believe that the traditional test of "understand and appreciate" applies.¹²⁸ The more recent Delaware law¹²⁹ seems to require some degree of mental capacity for SDM¹³⁰ and, in a real step backward, relies on a medical model in determining capacity.¹³¹

The few U.S. pilot projects to date have also focused almost exclusively on the practice of supporting persons with I/DD in making choices or decisions in order to avoid guardianship or to restore rights to persons already subject to guardianship. The very first pilot, in San Angelo, Texas, was designed to utilize volunteers to support individuals with I/DD. However, in addition to experiencing difficulty in recruiting and training volunteers, the pilot quickly bumped up against the unwillingness of private third parties even to consider accepting decisions made by persons with questionable mental capacity.¹³²

127. TEX. EST. CODE ANN. §§ 1357.001–.102 (2015).

128. See Tresie Weeks, The Weeks Law Firm, *Presentation at 13th Annual Changes and Trends Affecting Supplemental Needs Trusts in Austin, Tex.: Representing Parties in Supported Decision-Making Agreements* (Feb. 9–10, 2017), https://www.disabilityrightstx.org/files/Representing_Parties_in_Supported_Decision-Making_Agreements.pdf [<https://perma.cc/8XRJ-ZNNE>] (noting that a supported decision-making agreement "is not available for someone who is totally incapacitated, thereby requiring a guardianship, but may be signed by someone who can make rational decisions with assistance").

129. Supported Decision Making Act, DEL. CODE ANN. tit. 16, §§ 9401A–10A (2016).

130. "All adults should be able to live in the manner they wish and to accept or refuse support, assistance, or protection, as long as they do not harm others *and are capable* of making decisions about those matters." *Id.* § 9402A(b)(1) (emphasis added).

131. Under Delaware law, capacity assessments are made by physicians and then utilized by the Chancery Court to remove legal capacity through the imposition of guardianship. See Del. Ch. Physicians Affidavit, <https://courts.delaware.gov/Forms/Download.aspx?id=15108> [<https://perma.cc/3DZJ-HHL3>].

132. ARC OF SAN ANGELO, EVALUATION SUPPLEMENTAL REPORT II (2012), <http://sdmny.org/download/arc-of-san-angelo-evaluation-supplemental-report-ii-2012> [<https://perma.cc/M2YJ-PTWH>]. Although not specifically designed to effectuate legal capacity, that project and its subsequent extension were, in fact, partly responsible for the Texas law that makes it possible for people with intellectual and cognitive disabilities to exercise the right by requiring private third parties, like medical providers, to honor SDMAs.

An early pilot, a partnership between the Center for Public Representation (CPR) and Nonotuck Resource Associates, a provider agency in Northampton, Massachusetts, at least mentions the CRPD and legal capacity as the premise from which its work derives.¹³³ Without SDM legislation, however, the SDMA into which its participants and their supporters enter cannot provide legal agency “on an equal basis with others in all aspects of life” in accordance with Article 12.¹³⁴ The largest pilot to date, Supported Decision Making New York (SDMNY) is, by virtue of its funding through New York’s Development Disability Planning Council, focused on utilizing the practice of SDM to divert persons with IDD at risk of guardianship and to restore rights to persons currently subject to guardianship,¹³⁵ although it attempts to explicitly relate that work to the CRPD and Article 12.¹³⁶

Smaller projects, often originating out of state Protection and Advocacy agencies (P&As)¹³⁷ and funded by the NRCSDM, are incorporating SDM into their practice with websites,¹³⁸ manuals,¹³⁹ videos,¹⁴⁰ and the like. As with other efforts, the focus is on offering an alternative to guardianship, not a rights-based argument for its

133. *About SDM: What is Supported Decision-Making?*, SUPPORTED DECISION-MAKING PILOT PROJECT, <http://supporteddecisions.org/about-sdm/> [<https://perma.cc/626B-S5SP>].

134. CRPD, *supra* note 1, art. 12(2).

135. See Glen, *Piloting Personhood*, *supra* note 87, at 502.

136. See, e.g., *Transformation*, SDMNY, www.sdmny.org/transformation [<https://perma.cc/C8GA-EXBP>] (last visited Jan. 31, 2018).

137. The P&As exist in every state to provide representation to people with disabilities, including especially representation in de-institutionalization for people with IDD and psychosocial disabilities. They are funded by ACL pursuant to statute. See 42 U.S.C. §§ 15041–45 (2012).

138. See, e.g., *Supported Decision-Making*, SUPPORT MY DECISION: A PROJECT OF DISABILITY RIGHTS MAINE, <http://www.supportmydecision.org/> [<https://perma.cc/V9XC-YP4D>] (last visited Feb. 6, 2018) (describing SDM and its relation to the Maine disability rights community).

139. A pilot in South Carolina has developed manuals for service providers, attorneys, and families of persons with IDD. *Resources*, S.C. SUPPORTED DECISION-MAKING PROJECT, <http://scsupporteddecisionmaking.org/resources/> [<https://perma.cc/B8D5-7HJJ>] (last visited Feb. 6, 2018).

140. See Disability Rights Tex., *Supported Decision Making in Action – Dawn and Belinda (ASL/English Subtitles)*, YOUTUBE (Oct. 20, 2016), <https://www.youtube.com/watch?v=OTDsbAMwFDO> [<https://perma.cc/LNY5-8WUN>]; Disability Rights Tex., *Supported Decision Making in Action: Timberley and Tonya’s Story*, YOUTUBE (June 29, 2016), <https://youtu.be/DwnJ1nRR0Hs> [<https://perma.cc/B3Q7-DD8Q>].

abolition.¹⁴¹ This is not to say that there is no value to such work but, as Browning and colleagues note, we should

not lose sight of the fact that the broader goal of supported decision making is to help people to exercise their legal capacity. This will entail the exploration and introduction of alternative legal mechanisms that give people legal standing and recognise their need for support to act within the framework of the law.¹⁴²

There has also been work promoting SDM in professional associations¹⁴³ and in the Uniform Law Commission's (ULC)¹⁴⁴ recent revision of the Uniform Guardianship and Protective Proceedings Act (UGPPA), now the Uniform Guardianship, Conservatorship and Protective Proceedings Act (UGCPPA).¹⁴⁵ In a three-year process at the ULC, the UGPPA was revised to specifically require consideration of SDM as a less restrictive alternative to guardianship, and to require consideration of a successful supported decision-making regime in

141. See Browning et al., *Supported Decision Making*, *supra* note 115.

142. *Id.* at 42.

143. For example, in 2015 the National Guardianship Association (NGA) issued a position paper on guardianship and SDM, concluding, perhaps oxymoronically, that, "supported 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." NAT'L GUARDIANSHIP ASS'N, POSITION STATEMENT ON GUARDIANSHIP AND SUPPORTED DECISION MAKING (formatted Sept. 20, 2017), <https://www.guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf> [<https://perma.cc/5J5F-K9PT>].

144. The Uniform Law Commission is a highly regarded independent body established in 1892 that "provides states with non-partisan, well-conceived and well-drafted legislation that brings clarity and stability to critical areas of state statutory law." *About the ULC*, UNIFORM LAW COMM'N, <http://www.uniformlaws.org/Narrative.aspx?title=About%20the%20ULC> [<https://perma.cc/F852-E8E9>] (last visited Feb. 6, 2018). The "draft" UGCPPA was adopted by the ULC in July, but then, under ULC's processes, went to the style committee for small changes to make it conform to all their other products. The most recent version is NAT'L CONFERENCE COMM'RS UNIFORM STATE LAW, UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT (July 19, 2017) [hereinafter UGCPPA], http://www.uniformlaws.org/shared/docs/Guardianship%20and%20Protective%20Proceedings/2017AM_UGCOPPA_AsApproved.pdf [<https://perma.cc/L9MD-4LY7>].

145. Nearly twenty states have enacted one or another version of the UGPPA. *Guardianship, Conservatorship, and Other Protective Arrangements Act*, UNIFORM LAW COMM'N, <http://www.uniformlaws.org/Committee.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act> [<https://perma.cc/U3PU-HRQ6>] (last visited Feb. 6, 2018).

proceedings to restore rights to persons currently under guardianship.¹⁴⁶

The American Bar Association (ABA) has recently adopted a resolution requiring consideration of SDM as a less restrictive alternative to guardianship.¹⁴⁷ Entities within the ABA also created a “PRACTICAL” tool for attorneys, guardians ad litem, and others to utilize when guardianship is sought.¹⁴⁸ The tool encourages promoting the autonomy and self-determination of persons at risk of guardianship and promotes the use of SDM as a less restrictive alternative.¹⁴⁹ As the New York legislature considers revising its statute providing guardianship for persons with I/DD,¹⁵⁰ committees of the New York City Bar Association have issued a report suggesting the use of a “human rights lens” that explicitly cites Article 12 and the right of legal capacity.¹⁵¹

Efforts directed to SDM in the United States demonstrate that such work can be a double-edged sword. On one hand, pilot projects, in particular, have the potential for increased public awareness of the capabilities of people with intellectual disabilities. Changing hearts and minds is ultimately essential for the many changes that will be necessary to fully realize the right to legal capacity for all. And, of course, whenever SDM is utilized to avoid or terminate guardianship,

146. UGCPA, *supra* note 144, § 102(13) (“Less restrictive alternative’ means an approach meeting an individual’s needs which restricts fewer rights than would the appointment of a guardian or conservator. The term includes supported decision making”); *id.* § 301(a)(1)(A) (appointment of guardianship requires finding by clear and convincing evidence that the respondent is “unable to receive and evaluate information or make or communicate decisions, even with . . . supported decision making”); *id.* § 302(b)(4) (petition for guardianship must explain which less restrictive means were considered and implemented and why less restrictive means were not considered, implemented, or effective); *id.* § 319(d) (termination required where grounds would not exist to appoint a guardian or conservator).

147. *House of Delegates Resolution 113*, A.B.A. (2017), <https://www.americanbar.org/content/dam/aba/images/abanews/2017%20Annual%20Resolutions/113.pdf> [<https://perma.cc/ZV7A-WC5M>] (last visited Feb. 6, 2018).

148. *PRACTICAL Tool*, A.B.A., https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html [<https://perma.cc/DLB8-4UQ5>] (last visited Feb. 6, 2018).

149. *Id.*

150. N.Y. SURR. CT. PRO. ACT, CH.59-A, ART. 17-A (MCKINNEY).

151. Karen Andreasian et al., *Report: Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. REV. 287, 325–31 (2015).

an individual's right of legal capacity is protected, if not explicitly affirmed. On the other hand, SDM may be "at risk of being co-opted by service providers and others in positions of disproportionate power,"¹⁵² including guardians¹⁵³ and their organizations.¹⁵⁴ Without insistence on the connection between SDM and legal capacity, it could become "just another service," as self-advocate Tony Phillips recently told an audience at the United Nations.¹⁵⁵

C. "Vulnerable Groups" Who Are the Subjects of Article 12

In addition to persons with IDD, Article 12 and the right of legal capacity apply, at least in theory, to persons with psychosocial disabilities, older persons with progressive cognitive decline, dementia, Alzheimer's, etc., and persons with traumatic brain injuries. These three large populations¹⁵⁶ create particular and distinct problems in

152. Arstein-Kerslake et al., *Future Directions*, *supra* note 116.

153. See, e.g., A. Frank Johns & Melinda Coulter, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 UTAH L. REV. 1541, 1543–44 (2012) (noting passage of the CRPD and suggesting that "it is not clear that there is a difference between this concept of person-centered decision making and the concept of supported decision making, and encouraging some variation of the two in the guardian's interactions with her or his 'ward'").

154. The National Guardianship Association (NGA) has incorporated, or one might say co-opted, the term SDM as a possible "best practice" in guardianship, ignoring the obvious contradiction that asking someone under guardianship what choices she or he would like to make, and then making them for her or him is the very antithesis of legal capacity. See *Standards of Practice*, NAT'L GUARDIANSHIP ASS'N (2013), https://www.guardianship.org/wp-content/uploads/2017/08/Standards_of_Practice_2017.pdf [<https://perma.cc/ZYY3-PTGX>].

155. See *Tony Phillips Speaks at UN Conference of State Parties Side Event on Article 12*, SDMNY (June 15, 2017), <http://sdmny.org/tony-phillips-un-cosp-2017/> [<https://perma.cc/GS88-F52E>]. A similar sentiment was expressed by participants at a symposium in Melbourne, Australia. Arstein-Kerslake et al., *Future Directions*, *supra* note 116, at 12.

156. For example, 45.1 million U.S. adults are believed to have psychosocial disabilities. *Data on Behavioral Health in the United States*, AM. PSYCHOL. ASS'N, www.apa.org/helpcenter/data-behavioral-health.aspx (on file with the *Columbia Human Rights Law Review*). Among persons sixty-five and older, 5.3 million are estimated to have Alzheimer's Disease. *2017 Alzheimer's Disease Facts and Figures*, ALZHEIMER'S ASS'N 19 (last visited Jan. 28, 2018), www.alz.org/documents_custom/2017-facts-and-figures.pdf [<https://perma.cc/9JS8-XGCZ>]. Approximately 1.7 million Americans suffer traumatic brain injuries every year. *Get the Stats on Traumatic Brain Injury in the United States*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/traumaticbraininjuries/pdf/bluebook_factsheet-a.pdf [<https://perma.cc/8BBN-ZLVT>] (last visited Feb. 6, 2018).

thinking about how to fully incorporate and achieve their members' rights to legal capacity.

1. People with Psychosocial Disabilities

What are the specific issues that concern people with psychosocial disabilities and what debates do those issues engender? What is the consequence of the move, uniquely with regard to this group, from protection *for* its members to protection *from* them? What practices have been developed that work particularly well to provide support and might ameliorate those concerns?

Organizations of persons with psychosocial disabilities, like the World Network of Users and Survivors of Psychiatry (WNUSP), played a critical role in drafting Article 12.¹⁵⁷ For WNUSP, the issues of forced hospitalization and forced treatment were paramount.¹⁵⁸ WNUSP's position is essentially an absolute one—any hospitalization or treatment imposed over or against the will of a person with a psychosocial disability, regardless of the reason, violates Article 12 and

157. The representative of WNUSP, Tina Minkowitz, was especially important in the drafting and conceptualization process and is credited by many with ensuring that legal capacity includes both the right to recognition and the right to activity or agency. For a description of the participation of WNUSP and other Disabled Persons' Organizations (DPOs) in framing the conversation and ultimately in drafting Article 12, see Sheila Wildeman, *Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities*, 41 J. MED. & ETHICS 48, 54, 58–60 (2014).

158. *Id.* at 56. There is other support in the Convention for this position, most notably Article 14 (the right to liberty and security of the person), Article 17 (the right to respect for one's physical and mental integrity), Article 25 (the right to healthcare on the basis of free and informed consent), and Articles 15 and 16 (freedom from torture, inhumane and degrading treatment and violence, exploitation, and abuse) which "users groups" have previously argued under the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, *opened for signature* Dec. 10, 1984, art. 1, S. TREATY DOC. No. 100-20, 1465 U.N.T.S. 85 (entered into force June 26, 1987), www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx [<https://perma.cc/X6P5-NCKU>] (last visited Feb. 6, 2018). A focus on Article 12, however, demonstrates the inter-relatedness and indivisibility of human rights, since the other rights necessarily depend on the right to make a legally recognizable decision about treatment or the lack thereof.

is impermissible under the CRPD.¹⁵⁹ The First General Comment also adopts this position, noting that

Forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention.¹⁶⁰

The Committee goes on to state, unequivocally, “States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems.”¹⁶¹

The reality on the ground is quite different, owing in large part to the continued stigma of¹⁶² and fear about psychosocial disability or, as it continues to be known, mental illness.¹⁶³ And, while the entire focus of the CRPD involves movement away from an “outcomes”¹⁶⁴ or

159. Cf. GOV'T OF CAN., FIRST REPORT OF CANADA ON THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, http://publications.gc.ca/collections/collection_2014/pc-ch/CH37-4-19-2013-eng.pdf [<https://perma.cc/X6P5-NCKU>] (last visited Feb. 6, 2018) (“Court approval is required to compel persons to accept services under the Adult Protection Act or to receive treatment against their will, including hospitalization, under the Involuntary Psychiatric Treatment Act.”).

160. General Comment No. 1., *supra* note 9, ¶ 42.

161. *Id.*

162. The CRPD’s move to a social model of disability also “throws the spotlight on stigma, which is well understood to contribute to the ill health of those with psychiatric disorders.” Rowena Daw, *The Case for a Fusion Law: Challenges and Issues*, in COERCIVE CARE: RIGHTS, LAW AND POLICY 92, 97 (Bernadette McSherry & Ian Freckleton eds., 2013) [hereinafter COERCIVE CARE].

163. Professor Michael Perlin has famously coined the term “sanism” to describe a “largely invisible and socially acceptable” set of attitudes and perceptions “based predominantly on stereotype, myth, superstition and de-individualization” that “reflect societal fears and apprehensions about mental disability [and] persons with mental disabilities” and that “infect our jurisprudence.” Michael L. Perlin & Naomi Weinstein, *Said I, “But You Have No Choice”: Why a Lawyer Must Ethically Honor A Client’s Decision About Mental Health Treatment Even If It Is Not What S/He Would Have Chosen*, 15 CARDOZO PUB. L. POL’Y & ETHICS J. 73, 81 (2016) [hereinafter Perlin & Weinstein, *Said I*].

164. See, e.g., RESTORING VOICE, *supra* note 44, at 84 (“[T]he ‘outcome approach’ in denying legal capacity removes the individual’s decision-making power

medical model, in favor of a social model,¹⁶⁵ the outcomes and medical models still hold particular sway when it comes to psychosocial disabilities such as schizophrenia, depression, and bipolar disorder.¹⁶⁶

Although, as previously noted, there has been considerable movement around the world in at least reconsidering,¹⁶⁷ if not actually abolishing substituted decision-making as contained in guardianship laws, there is a notable lack of movement in the area of civil commitment or involuntary medication. Numerous coercive laws and practices remain unchanged since the enactment of the CRPD.¹⁶⁸

if it is perceived that the outcome of the decision will be negative or bad. This is commonly witnessed in mental health law.”)

165. In a recent article, however, the authors argue that “[t]he social model does not wholly abandon medicine; instead, its focus emphasizes the importance of persons with psychosocial disabilities being granted equal access to society and having control over any needed medical treatment.” Steven J. Hoffman, Lathika Sritharan & Ali Tejpar, *Is the UN Convention on the Rights of Persons with Disabilities Impacting Mental Health Laws and Policies in High Income Countries? A Case Study of Implementation in Canada*, BMC INT’L HEALTH & HUM. RTS., Nov. 11, 2016, at 3 [hereinafter Hoffman et al., *Canada Case Study*], <https://bmcinthealthhumrights.biomedcentral.com/track/pdf/10.1186/s12914-016-0103-1?site=bmcinthealthhumrights.biomedcentral.com> [<https://perma.cc/NSC3-VN2G>].

166. MENTAL HEALTH EUR., AUTONOMY, CHOICE AND THE IMPORTANCE OF SUPPORTED DECISION-MAKING FOR PERSONS WITH PSYCHOSOCIAL DISABILITIES: MHE POSITION PAPER ON ARTICLE 12 UNCRPD ON LEGAL CAPACITY 5 (2017) [hereinafter MHE REPORT] (criticizing the continuing and contested “biomedical approach to psychiatry” that “can reduce persons with psychosocial disabilities to [their] ‘disorders’”).

167. Many countries have directed relevant Ministries or government agencies to study or propose changes to guardianship laws with some significant reforms, though no outright abolition, and civil society has been especially active in this area. See, e.g., *Comparison of Legal Systems in the Following Countries: Bulgaria, Finland, France, Hungary, Ireland*, ACCESS TO JUSTICE FOR PERSONS WITH INTELLECTUAL DISABILITY (2015), <http://www.firah.org/centre-ressources/upload/notices3/2015/ajupid-final-research-report-may-2015.pdf> [<https://perma.cc/QS7M-XU6W>] (discussing the efforts in five European Countries to change guardianship law). WAYNE MARTIN, ET AL., THE ESSEX AUTONOMY PROJECT, THREE JURISDICTIONS REPORT: TOWARDS COMPLIANCE WITH CRPD ART. 12 IN CAPACITY/INCAPACITY LEGISLATION ACROSS THE UK 11 (2016), <https://autonomy.essex.ac.uk/resources/eap-three-jurisdictions-report/> [<https://perma.cc/4UTJ-F2FN>] (identifying areas in which statutory arrangements in the United Kingdom still fall short of compliance with the CRPD and discussing an alternate framework to substituted decision-making).

168. Canada is an example; despite mention of the CRPD in five federal and provincial statutes, “the explicit implementation of the Convention’s provisions in specially devised state and territorial legislation [relating to mental health]

The literature around the applicability of Article 12 to persons with psychosocial disabilities reflects tensions between an absolutist position and deference to concerns about individual and public safety. Two of the leading proponents of a literal view of legal capacity as a right of *all* persons, regardless of disability, nonetheless have suggested limitations that may be placed upon that right, particularly in the case of psychosocial disabilities, when there is an assessment of “risk of imminent and serious harm to the person’s life, health or safety.”¹⁶⁹ That same language is familiar in many existing statutory schemes where, in the guise of “imminent harm” or danger, persons with psychosocial disabilities can be hospitalized or forced to take medications against their will.¹⁷⁰

Tina Minkowitz responds that such a formulation constitutes an “outcome-based deprivation of legal capacity,”¹⁷¹ “often associated with a sense of crisis or emergency (‘imminent risk’)”¹⁷² that is clearly prohibited by the CRPD. She notes that

[b]oth General Comment No. 1 and the Guidelines on Article 14 take pains to point out that responders must respect “the individual autonomy and capacity to make decisions of persons with disabilities” “at all times, including in crisis situations.” The Guidelines call on states parties to “ensure that support is provided to persons with disabilities, including in emergency and crisis situations” and remind them to “ensure that persons with disabilities are not denied the right to

remains to be seen.” Hoffman et al., *Canada Case Study*, *supra* note 165, at 11. For a similar experience in Australia, see MCSHERRY ET AL., *infra* note 252, at 174–75. For a comprehensive chart of laws relating to substituted decision-making, supported decision-making, and forced placement and treatment in mental health legislation in all the EU member states, see MHE REPORT, *supra* note 166, at 13–18.

169. Eilionoir Flynn & Anna Arstein-Kerslake, *State Intervention in the Lives of People with Disabilities: The Case for a Disability Neutral Framework*, 13 INT’L J.L. CONTEXT 39, 39 (2017) [hereinafter Flynn & Arstein-Kerslake, *Disability Neutral Framework*] (arguing that acts of self-harm in particular can be the target of coercive intervention so long as the criteria are framed without reference to disability or functional assessment).

170. See, e.g., N.Y. Mental Hyg. Law § 9.39. For its Constitutional exegesis, see also *Rivers v. Katz*, 67 N.Y.2d 485 (1986) (requiring first a determination of whether the person for whom forced treatment is sought has “capacity” to decide on a course of action and, if not, imposing a “best interests” standard).

171. Tina Minkowitz, *CRPD and Transformative Equality*, 13 INT’L J.L. CONTEXT 77, 82 (2017) [hereinafter Minkowitz, *Transformative Equality*].

172. *Id.* at 83.

exercise their legal capacity on the basis of a third party's analysis of their 'best interests.'"¹⁷³

Few pilot projects have included persons with psychosocial disabilities, but at least one has bypassed these conflicting positions through successful use of peer support.¹⁷⁴ In Nairobi, Kenya, a local chapter of Users and Survivors of Psychiatry (USP-K) has regular meetings of a peer support group of persons with a variety of psychosocial disorders as well as some of their supporters and caregivers.¹⁷⁵ Members create agreements about what kinds of treatment they will and will not accept when they are in crisis, relying on other members of the group to assist in implementing their wishes when crises arise.¹⁷⁶

In a recent position paper on Article 12, Mental Health Europe reviews the current state of legislation affecting persons with psychosocial disabilities in Europe, noting that "the shift towards providing supported decision-making has been slow with many European States failing to move toward real reform."¹⁷⁷ The paper describes a number of "promising models" that may enable persons to maintain their legal capacity as well as their rights to liberty, physical and mental integrity, to live and be included in the community, and to freely consent to treatment.¹⁷⁸ These models include the Andalusian practice of Advanced Care Planning in Mental Health,¹⁷⁹ the Swedish

173. *Id.* (internal citations omitted).

174. These include Bulgaria and the Czech Republic. *See, e.g., infra* Part II.

175. USP-K has expanded to a number of counties outside Nairobi and now is facilitating eight peer support groups. They have collected a considerable amount of quantitative and qualitative data about the projects and have issued a draft report. USP Kenya, *The Role of Peer Support in Exercising Legal Capacity* (Oct. 2017) (draft) (on file with author) [hereinafter Kenya Draft Report]. *See also* Interview with Boaz Muhumuza, Open Societies Found. East Afr. (Sept. 2013); E-mails from Elizabeth Kamundia to author (Sept. 2017–Dec. 2017) (on file with author).

176. *See generally* Kenya Draft Report, *supra* note 175, at 32–33, 39 (describing use of advance directives); observation of USP-Kenya peer group meeting in Nairobi, Kenya (Aug. 2013).

177. MHE REPORT, *supra* note 166, at 3.

178. *Id.* at 9–12.

179. This model of Advance Care Planning involves "co-production" between mental health care users and professionals that enables people with psychosocial disabilities to record their wills and preferences in an advance directive, which "is included in the medical record of the person and made accessible to all healthcare professionals in order to influence the health care provided in case they may face temporary inability to make decisions (i.e. crisis situations)." *Id.* at 10.

Personal Ombudsman,¹⁸⁰ the "Circle of Friends" originally developed in Canada,¹⁸¹ the "Open Dialogue model" successfully implemented in Finland,¹⁸² and the "Soteria Model,"¹⁸³ originally developed in the 1970s, which uses an environment and community of support for persons with a diagnosis of schizophrenia or persons experiencing psychosis.¹⁸⁴

Minkowitz points out that "[u]sers and survivors of psychiatry have devoted considerable attention to the development of non-coercive and non-intrusive practices for suicide prevention and for non-judgmental support to persons who self-harm,"¹⁸⁵ and notes a successful peer support model in the United States.¹⁸⁶ This model, the "Alternatives to Suicide" program developed by the Western Mass Recovery Learning Community,¹⁸⁷ is based on the principle that "[s]uicidality and self-harm are best prevented by offering support, and

180. The Personal Ombudsman (PO) is "a highly skilled person who works on the commission of a person needing mental support services" and "no action is taken without the agreement of the client." *Id.* at 10. See also *Swedish Personal Ombudsman Service (PO) for People with Mental Health Problems*, CHOICES, www.right-to-decide.eu/2014/08/swedish-personal-ombudsman-service-po-for-people-with-mental-health-problems/ [<https://perma.cc/2P3L-23UB>] (last visited Feb. 21, 2018) (describing the personal ombudsman model).

181. This is an early and relatively informal system of supported decision-making. See MDAC, SUPPORTED DECISION MAKING, AN ALTERNATIVE TO GUARDIANSHIP 13–14 (2006) (outlining the "Circle of Friends" model of legal capacity).

182. This model "is based on therapy meetings with a network which brings together the person with a psychosocial disability, their family, other natural supports, and any professionals involved . . . enables the person to retain their legal capacity and to make the final decision on their treatment," and "maintain[s] the autonomy of persons in crisis situations." MHE REPORT, *supra* note 166, at 11. This model is alleged to be extremely successful. *Id.* at 11 nn.31–32.

183. The Sotiera Model uses peer support and services run by mostly non-medical personnel, and is based on "recovery" and non-coercive measures. *Id.* at 11–12. See also Calton et al., *A Systematic Review of the Soteria Paradigm for the Treatment of People Diagnosed with Schizophrenia*, 34 SCHIZOPHRENIA BULL. 181 (2007) (describing the Sotiera Model).

184. MHE REPORT, *supra* note 166, at 9–12.

185. Minkowitz, *Transformative Equality*, *supra* note 171, at 82.

186. *Id.*

187. Additional information on this organization and its peer support work may be found on its website. Western Mass Recovery Learning Cmty., www.westernmassrlc.org [<https://perma.cc/WPT2-BVNF>]. For information on the practice of "intentional peer support," see What is IPS?, INT'L PEER SUPPORT, www.intentionalpeersupport.org/what-is-ips/ [<https://perma.cc/RXJ6-GD24>] (last visited Feb. 6, 2018).

support is impeded by coercion, which destroys trust and self-confidence . . . [These support measures] are communitarian, built on ‘genuine human connection.’”¹⁸⁸

Use of peer support may, however, raise a separate but potentially concerning issue. As Bach and Kerzner point out:

An important reality for some people with psychosocial disabilities is that the people who support them both in personal care and in decision making, too, have psychosocial disabilities. Any decision-making model that recognizes the role of supporters . . . needs to ensure that there is no discrimination, intended or not, against some classes of decision-making supporters over others. People with disabilities who support others must be given equal respect in their roles.¹⁸⁹

Facilitating support or training or assisting supporters must, of necessity, take this concern, essentially unique to people with psychosocial disabilities, into account. This is most crucial where peer support is the chosen modality.

“Communitarianism,” or peer support, may also help resolve another issue commonly raised as the result of a characteristic that distinguishes people with psychosocial disabilities from other groups whose legal capacity is at risk. That is, “[p]sychosocial conditions are often temporary or episodic, and the individual may experience significant improvement in decision-making capabilities, or even full recovery, within a reasonably short time period.¹⁹⁰ This difference raises the possibility of advance directives that can potentially ameliorate or even override choices or decisions made during crisis. In such instances, there is a tension between the person in her or his ordinary life, including her or his “general life narrative,” and the sometimes very different choices or decisions that same person makes or attempts to make during a crisis situation.

For example, if a person with a psychosocial disability is voluntarily being treated for cancer with chemotherapy, and then goes into crisis where she or he believes, delusionally, that chemotherapy is an extraterrestrial poison, should the human right of legal capacity

188. Minkowitz, *Transformative Equality*, *supra* note 171, at 82 (internal citations omitted).

189. BACH & KERZNER, *A NEW PARADIGM*, *supra* note 42, at 36.

190. Leslie Salzman, *New Perspectives on Guardianship and Mental Illness: Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL’Y 279, 305 (2011).

require recognition of her or his refusal to continue the treatment even if cessation of treatment is life-threatening and inconsistent with her or his previously expressed wishes and general desire to live? Or, to put it another way, who is the person whose choice should be honored, the "person" in her or his ordinary life or the "person" in crisis?

Designation of supporters who can make the choice consistent with the person's "general life narrative,"¹⁹¹ is one possibility.¹⁹² Use of psychiatric advance directives¹⁹³ and so-called "Ulysses agreements"¹⁹⁴ is another option, entirely consistent with the CRPD Committee's interpretation of Article 12, which explicitly includes advance directives as a legitimate support for the right of legal capacity.¹⁹⁵

2. Older persons

In a world with a rapidly growing aging population and the corresponding increases in various kinds of cognitive decline,

191. The Author observed this in the Kenyan pilot program. See Kenya Draft Report, *supra* note 175.

192. The use of peer support groups and the creation of "anti-crisis plans" is also a feature of the Bulgarian pilot project for persons with psychosocial disabilities, which is run in conjunction with Global Initiative on Psychiatry-Sofia and the National Organization of the Users of Mental Health Services (NOUMHS). See LUBKA ALEKSANDROVA ET AL., BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, GLOB. INITIATIVE ON PSYCHIATRY, BULGARIAN ASS'N OF PEOPLE WITH INTELLECTUAL DISABILITIES & NAT'L ORG. OF MENTAL HEALTH SERV. USERS, SUPPORTED DECISION MAKING: GUIDEBOOK TO RIGHTS ENFORCEMENT 11–12 (2014).

193. Psychiatric advance directives are documents that allow persons with psychosocial disabilities to indicate the kinds of treatments they want and do not want to receive in the event of a psychiatric episode. Breanne M. Sheetz, *The Choice to Limit Choice: Using Psychiatric Advance Directives to Manage the Effects of Mental Illness and Support Self-Responsibility*, 40 U. MICH. J.L. REFORM 401, 403 (2007). For a discussion of the advantages and disadvantages of psychiatric advance directives, see Perlin & Weinstein, *Said I, supra* note 163, at 106–08.

194. See, e.g., Judy A. Clausen, *Making the Case for a Model Mental Health Advance Directive Statute*, 14 YALE J. HEALTH POL'Y L. & ETHICS 1 (2014) (describing a "Ulysses agreement" as a kind of psychiatric advance directive that is made when the person has capacity but that authorizes doctors to treat her during a future psychiatric episode when she may lack capacity, even though she refuses treatment).

195. General Comment No. 1, *supra* note 9, ¶ 17 ("For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others.").

dementia, Alzheimer's,¹⁹⁶ and other impairments related to aging, the applicability of Article 12 and the right of legal capacity is critical, yet critically under-theorized and unexplored. Shortly after the CRPD came into effect, Arlene Kanter wrote that it "marks an important step towards equality, dignity[,] and access to society for elderly people with and without disabilities."¹⁹⁷ Almost a decade later, however, there is little in the legal and human rights literature that connects the right to legal capacity directly to older persons, except to the extent that they are the majority subjects of guardianship.¹⁹⁸ So, what are the specific issues that are involved in applying legal capacity to this population? Why have older persons been so minimally engaged in the conversation?¹⁹⁹ And what are the critiques that need response?

To the extent that SDM is a proxy for legal capacity, it is only at the earliest stages of discussion regarding use with older persons in the United States.²⁰⁰ In Canada, where various forms of SDM, including the use of representation agreements, have been practiced

196. See ALZHEIMER'S ASS'N, *supra* note 28 (reporting one in ten Americans aged sixty-five or older has Alzheimer's).

197. Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Rights of Elderly People Under International Law*, 25 GA. ST. U. L. REV. 527, 527-28 (2009).

198. *Id.* at 538-39. The limited and disaggregated evidence we have on adult guardianship strongly suggests that older adults make up the majority of persons for whom guardians are appointed. See, e.g., ERICA F. WOOD, NAT'L CTR. ON ELDER ABUSE, STATE-LEVEL ADULT GUARDIANSHIP DATA: AN EXPLORATORY SURVEY 11-14 (2006). A 2012 guardianship study in Indiana may be representative of other states; it showed that, under causes for filing, dementia was the condition most frequently alleged. IND. ADULT GUARDIANSHIP SERV. PROJECT, WHO'S OVERSEEING THE OVERSEERS? A REPORT ON THE STATE OF ADULT GUARDIANSHIP IN INDIANA (2012).

199. It should, however, be noted that older persons' advocacy groups have been working for many years to obtain a Convention dealing specifically with their issues, with a Resolution to Form an Open-Ended Working Group on Ageing passed in 2010, G.A. Res. 65/182 (Dec. 21, 2010), and a number of working group meetings held since then.

200. There has been some discussion of how SDM may have been informally (and perhaps unintentionally) utilized. See NAT'L RES. CTR. SUPPORTED DECISION-MAKING, BRAINSTORMING GUIDE: HOW ARE WE ALREADY USING SUPPORTED DECISION-MAKING?. There have also been some presentations on what SDM might look like for older persons. See, e.g., JONATHAN MARTINIS & DAVID GODFREY, NAT'L AGING AND LAW CONFERENCE, SUPPORTED DECISION MAKING IN LATER LIFE, https://www.americanbar.org/content/dam/aba/administrative/law_aging/ACL%20Grant%20-%20Supported%20Decision%20Making%20in%20Later%20Life.authcheckdam.pdf [<https://perma.cc/PHJ4-ASU6>]. There are, however, no pilot projects currently directed to older persons.

for some time, reports indicate that very few older persons or their advocates have taken advantage of the option.²⁰¹ And, significantly, there appear to be no pilot projects anywhere in the world that use SDM for older persons with cognitive decline.²⁰² It seems almost self-evident that, in order to promote a right of legal capacity for older persons in light of an overwhelmingly medical model, there will need to be considerable empirical evidence, from pilots or otherwise, that legal capacity and SDM not only work,²⁰³ but are consistent with at least minimal levels of "safety" for that population.²⁰⁴

There are similarities here to issues about the need to protect people with I/DD from abuse and exploitation. Here, as with the argument for guardianship for people with I/DD, older people with cognitive decline are perceived as lacking mental capacity, and therefore unable to make decisions about their lives. Like people with

201. KRISTA JAMES & LAURA WATTS, *THE LAW COMM'N OF ONT., UNDERSTANDING THE LIVED EXPERIENCES OF SUPPORTED DECISION-MAKING IN CANADA* (2014). Bach and Kerzner attribute this in part to the relative isolation of many older persons and the comparative paucity of their natural supports. BACH & KERZNER, *A NEW PARADIGM*, *supra* note 42, at 37. *See also* ELIZABETH PELL & VIRGINIA MULKERN, *CTR. FOR PUB. REPRESENTATION & NONOTUCK RES. ASSOCS., SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE REPORT* (2015), [hereinafter *CPR/NONOTUCK PILOT PROGRAM EVALUATION YEAR 1*], www.supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf [<https://perma.cc/8MHK-K95M>].

202. Although without any conscious design, two of the nine participants in the CPR/Nonotuck pilot, otherwise directed at persons with I/DD, are older persons with advancing dementia. *See* ELIZABETH PELL & VIRGINIA MULKERN, *SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT*, PREPARED FOR THE CENTER FOR PUBLIC REPRESENTATION AND NONOTUCK RESOURCE ASSOCIATES 44, 52 (2016); *see also* Section I.E *infra*.

203. My personal experience with numerous persons who work with or are related to persons with I/DD and older persons with cognitive decline, is that the latter are even more skeptical of abandoning substituted decision-making for a relatively untested, rights-promoting regime of legal capacity.

204. It would also be useful to demonstrate that, despite assumptions that guardianship protects older persons—which are relatively unproven, as noted in Kohn et al., *supra* note 43—giving someone total power over another, including the ability to isolate her or him, actually creates the conditions for abuse, neglect, or exploitation. There have been numerous press reports of abuse, mostly financial, by guardians. *See, e.g.*, Rachael Aviv, *How the Elderly Lose Their Rights*, *NEW YORKER MAG.*, Oct. 9, 2017, at 48–57.

I/DD, we need to advocate for, and in some instances, propose “universal solutions”²⁰⁵ to protect all people, regardless of disability.²⁰⁶

In a thoughtful and provocative recent article, Rebekah Diller suggests “several differences between the situations of older adults at risk of guardianship and younger adults with disabilities that may account for the different levels of interest in supported decision-making so far.”²⁰⁷ These include the reasons that frequently lead to petitions for guardianship and the identity of petitioners:²⁰⁸ the perceived benefits of SDM for younger persons,²⁰⁹ the greater likelihood that older persons will have created advance directives,²¹⁰ and the relative disconnect between older persons’ advocacy groups and the disability rights movement, with its focus on self-determination, autonomy, and inclusion.²¹¹

As to that disconnect, Bach and Kerzner note the apparent clash between disability rights theory and the rights of older persons.²¹² They observe

[s]upported decision-making . . . is not [on the radar of older adults. Older adults’ experiences of isolation significantly influence their views on legal capacity laws. With isolation comes a lack of people with whom they interact, including people who could potentially

205. See Section I.A.3 *supra*.

206. For example, there are existing criminal laws about financial abuse and exploitation, as well as physical, sexual, and emotional abuse laws and protective proceedings that can be disability neutral.

207. Diller, *supra* note 38, at 521.

208. Parents generally petition for guardianship of their young adult children when they reach their majority because they are told to do so by schools or service providers. To the contrary, it is often adult children who bring guardianship proceedings for their older parents when an important decision has to be made, and there are issues as to whether the parent has “capacity” to do so. *Id.* at 520–21.

209. *Id.* at 521 (“[F]or young adults with intellectual disabilities and their families, supported decision-making can provide a welcome alternative [to guardianship] that permits persons with disabilities to build skills that can promote independence while developing experience with making decisions that can facilitate independent living.”). For older persons with dementia or other cognitive decline, those skills existed but have been, or are being, lost, and future growth is not generally a consideration or even considered a possibility.

210. *Id.* at 521.

211. Diller points out the greater emphasis by groups such as the Alzheimer’s Association (now CaringKind) on “research and treatment resources.” *Id.* at 523. I suggest also the importance of the far greater number of self-advocates in the I/DD community.

212. BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 37.

support them. At the same time, often with isolation also comes abuse. Thus, the significant issue for older adults is abuse and neglect.²¹³

In addition to concerns that SDM will not protect older persons with cognitive disabilities, there are fears that supporters themselves may exploit their positions and exert undue influence or otherwise cause harm to the persons they are supporting. As Bach and Kerzner note, “[a]n important component of any decision-making regime would be the inclusion of a high level of review and oversight to address . . . concerns about abuse and undue influence.”²¹⁴ The task here will be to address elder abuse “within a proactive human rights approach.”²¹⁵

Article 12(4), although less than clear,²¹⁶ provides the basis for appropriate and effective safeguards.²¹⁷ Interpreting Section 4, the General Comment implicitly highlights the need for universal design, noting that “all people risk being subject to undue influence”²¹⁸ and cautioning that, in protecting against undue influence, safeguards “must also respect the rights, will and preferences of the person, including the right to take risks and make mistakes”²¹⁹—a caution that should apply to *all* people.

3. Persons with Traumatic Brain Injuries

The last group for whom the right of legal capacity may be especially important is persons with traumatic brain injuries (TBI).

213. *Id.* This different focus has been reflected in in U.S. federal policy funding choices made by the Administration for Community Living (ACL) which incorporates both the Administration on Intellectual and Developmental Disabilities (AIDD) and the Administration on Aging (AOA). While ACL was an early funder of supported decision-making for the I/DD population, its emphasis for older persons continues to be elder abuse. *See, e.g.*, Grant #HHS-2018-ACL-CIP-MPPG-0260 (Senior Medicare Patrol Projects); Grant #HHS-2018-ACL-AOA-EJSG-0265 (Grants to Enhance State Adult Protective Services); Grant #HHS-2017-ACL-AOA-ABRC-0213 (National Center on Elder Abuse).

214. BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 37.

215. *Id.*

216. On one hand, it appears to be directed to providing safeguards for the process of providing support generally, but it also seems to both constitute and apply specific protections to the situation of facilitated decision-making.

217. CRPD, *supra* note 1, art. 12(4).

218. General Comment No. 1, *supra* note 9, ¶ 4.

219. *Id.*

The National Institute of Neurological Disorders and Stroke (NINDL) defines TBI in part as

[a] form of acquired brain injury [that] occurs when a sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain.²²⁰

It has been observed that “the cohort of persons with brain injuries remains a hidden or invisible minority.”²²¹ Although barely mentioned in CRPD Article 12 literature or in such research as exists,²²² national and international statistics suggest that persons with TBIs constitute a very large group²²³ with diverse needs, demonstrating both differences from, and similarities with, the three groups already discussed. What are those differences and similarities, and what potential resources are unique to them?

Not surprisingly, most TBIs occur in adolescence or early adulthood,²²⁴ so for persons with TBI there already exists a history of the person before her or his disability to draw upon. This is a significant difference from the situation of most persons with developmental disabilities. There is also considerable variance in the

220. *Traumatic Brain Injury Information Page*, NAT’L INST. NEUROLOGICAL DISORDERS & STROKE [hereinafter NINDL - Traumatic Brain Injury], <https://www.ninds.nih.gov/Disorders/All-Disorders/Traumatic-Brain-Injury-Information-Page> [<https://perma.cc/QMZ7-3UQH>].

221. Ian Freckelton, *Brain Injuries and Coercive Care: Human Rights Issues and Challenges*, in COERCIVE CARE: RIGHTS, LAW AND POLICY 258, 262 (Bernadette McSherry & Ian Freckelton eds., 2015). He attributes this to his belief that “they do not have the presence and cachet of those who are diagnosed with a mental illness or intellectual disability.” *Id.* While “cachet” may be relevant in the Australian context, it seems a stretch to describe a similar invisibility in the United States.

222. See Terry Carney, *Clarifying, Operationalizing, and Evaluating Supported Decision-Making Models*, 1 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 46, 49 (2014) [hereinafter Carney, *Operationalizing*] (observing the lack of research on persons with acquired or traumatic brain injury “other than to hint that existing models may be ill-suited to meeting their needs in practice”).

223. See, e.g., Lucy Knox et al., *Becoming a Decision-Making Supporter for Someone with Acquired Cognitive Disability Following Traumatic Brain Injury*, 3 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 12, 13 (2015) (stating that TBI is “a leading cause of death and disability internationally”).

224. *Id.* (noting that TBI “has its peak incidence among adolescents and young adults”).

degree or level of “recovery” possible, with many opportunities for advancement for some, and less or virtually none for those with the most severe injuries.²²⁵ This range both distinguishes *and* relates persons with TBIs from people with IDD or dementia.

Although people with TBIs have been mostly invisible, recent publicity regarding two groups who disproportionately suffer from TBIs, returning veterans²²⁶ and professional athletes—especially hockey and football players²²⁷—has begun to foreground the issue. This suggests that, in thinking about legal capacity in the U.S. context, more attention may need to be paid to persons with TBIs. It also suggests that, with appropriate outreach and education, veterans and their organizations could be a formidable ally in that work.

Since the exercise of legal capacity for people with disabilities often depends on the supports that are available to them,²²⁸ one question is whether such supports differ in the context of TBIs. This is one of the few areas in which there is some, although very limited, research. Based on the inclusion of a few people with TBIs in pilot projects, and some additional small studies, Australian researchers have been “the first to investigate the nature of support for decision-making available to people with acquired brain injury, which enables comparison to experiences of people with intellectual disabilities.”²²⁹

225. See, e.g., *Recovery*, TRAUMATICBRAININJURY.COM, <http://www.traumaticbraininjury.com/treatments-for-tbi/recovery/> [<https://perma.cc/3DZR-LL87>] (“Attempts at predicting TBI recovery remain crude.”); *Treatment*, BRAIN INJURY ASS’N AM., <https://www.biausa.org/brain-injury/about-brain-injury/treatment> [<https://perma.cc/9ZZ9-NNES>].

226. Between 2000 and 2014, 321,454 service members suffered a TBI, although many were classified as “mild.” Stacey-Rae Simcox et al., *Understanding TBI in Our Nation’s Military and Veterans: Its Occurrence, Identification and Treatment, and Legal Ramifications*, 84 UMKC L. REV. 1, 4 (2015).

227. The specific problem that has plagued the players in this violent sport is chronic traumatic encephalopathy (C.T.E), a degenerative brain disease that can be caused by TBIs. See Samuel D. Hodge, Jr. & Shilpa Kadoo, *A Heads-Up on Traumatic Brain Injuries in Sports*, 7 HEALTH CARE L. & POL’Y 155, 163–64 (2014).

228. Because people with TBI “frequently experience changes in the nature of their existing relationships, a reduction in the size of their social networks, and increased communication and interpersonal difficulties, . . . [t]hese changes may have significant implications in terms of the support available to the person to make decisions and to put his or her decisions into practice.” Knox et al., *supra* note 223, at 13.

229. Jacinta Douglas et al., *Factors that Underpin the Delivery of Effective Decision-Making Support for People with Cognitive Disability*, 2 RES. & PRAC. INTEL. & DEV. DISABILITIES 37, 39 (2015).

One interesting distinction has emerged: people with TBIs often choose or have their spouses as supporters while, to the contrary, “spouses are rarely decision-making supporters for people with intellectual disabilities; knowing a person with acquired brain injury well, involves knowledge about their life both pre- and post- injury, whereas such a significant marker is not present in the lives of people with intellectual disabilities.”²³⁰

The availability of potential supporters like spouses with a real knowledge base and personal commitment both to the autonomy of the person with TBI and to her or his continuing progress, is obviously a benefit in thinking about how to advance legal capacity for persons with TBIs.²³¹ Unfortunately, like people with psychosocial disabilities, people diagnosed with TBIs also face negative public perceptions and stereotypes about potential dangerousness.

The case of Aaron Hernandez, a former New England Patriots player who was convicted of one murder, suspected of another, and subsequently committed suicide in prison, has engendered much comment and attention²³² related to the aggression and lack of impulse control that sometimes results from TBI or its related conditions.²³³ While his fame made this a front-page story, there are tens of thousands of others with TBIs, including many veterans of the Vietnam, Iraq, and Afghanistan wars, currently incarcerated in U.S. prisons and in prisons around the world.²³⁴

230. *Id.*

231. In an in-depth study of one person who had sustained a severe brain injury in his twenties, researchers found that a well-developed relationship and a “shared vision for the future” were important factors in successful support of his legal capacity. Knox et al., *supra* note 223, at 18.

232. See, e.g., Ken Belson, *Aaron Hernandez Had Severe C.T.E. When He Died at 27*, N.Y. TIMES (Sept. 21, 2017) <https://nyti.ms/2ygNqlq> (on file with the *Columbia Human Rights Law Review*); Benedict Carey, *Yes, Aaron Hernandez Suffered Brain Injury. But That May Not Explain His Violence*, N.Y. TIMES (Sept. 22, 2017), <https://www.nytimes.com/2017/09/22/health/aaron-hernandez-brain.html> (on file with the *Columbia Human Rights Law Review*).

233. NINDL - Traumatic Brain Injury, *supra* note 220.

234. Freckelton notes a meta-analysis of prisoners in the United States, the United Kingdom, Australia, and New Zealand that identified an estimated prevalence of TBI in offender populations of sixty percent. Freckelton, *supra* note 221, at 262.

Studies in Australia indicate that persons with TBIs are significantly overrepresented in the criminal justice system,²³⁵ both as defendants and as persons who are found unfit to stand trial, often resulting in even longer periods of incarceration.²³⁶ Many are also subject to preventive civil detention.²³⁷ At the same time, advances in neuroscience raise troubling issues about criminal responsibility.²³⁸ Any sustained conversation about legal capacity in the United States will almost certainly need to include this conglomeration of criminal justice issues. Advocates must be prepared with particularized strategies and well thought out positions about the questions that may be raised about legal capacity for persons with TBI.

D. Implications for Criminal Law

One area that has received “stunningly” little attention²³⁹—perhaps because of the difficulties it presents—is the effect of the right of legal capacity on criminal law, specifically incapacity or incompetence to stand trial, the insanity defense, and consent to sexual activity and rape and other sex crimes. If legal capacity is truly disaggregated from mental capacity, what happens to the criminal law as we know it?

235. Knox et al., *supra* note 223, at 13 (“[R]elatively little is known about what ideal support looks like in practice.”); see *infra* Section I.E (discussing issues relating to legal capacity more generally).

236. Freckelton, *supra* note 221, at 263–68.

237. *Id.* at 272–77.

238. See, e.g., Lydia D. Johnson, *Guilty or Innocent? . . . Just Take a Look at My Brain—Analyzing the Nexus Between Traumatic Brain Injury and Criminal Responsibility*, 37 SYRACUSE U. L. REV. 25, 26 (2009).

239. Michael Perlin, *God Said to Abraham / Kill Me a Son: Why the Insanity Defense and the Incompetency Status Are Compatible with and Required by the Convention on the Rights of Persons with Disabilities and Basic Principles of Therapeutic Jurisprudence*, 54 AM. CRIM. L. REV. 477, 498 (2017) [hereinafter Perlin, *God Said*]. This is perhaps simply parochial—the result of lack of interest by U.S. academics who, in the absence of ratification, need not concern themselves about the effect of the CRPD on our criminal law. In the different legal contexts of the United Kingdom and Australia, there is extensive legal literature. See, e.g., Piers Gooding & Charles O’Mahony, *Laws on Unfitness to Stand Trial and the UN Convention on the Rights of Persons with Disabilities: Comparing Reform in England, Wales, Northern Ireland and Scotland*, 44 INT’L J.L., CRIME & JUST. 122 (2016) (comparing reform trends in international and domestic legal contexts regarding unfitness to participate in trials). The relative inaccessibility of this literature—at least on ordinary online legal search engines—also contributes to the lack of discussion here.

The General Comment makes no reference to these issues,²⁴⁰ but other U.N. documents have taken positions arguably inimical to continuation of incompetence to stand trial²⁴¹ and the insanity defense,²⁴² although, surprisingly, without reference to Article 12. Some advocates have celebrated those positions,²⁴³ while other commentators have responded with anger or horror,²⁴⁴ and yet others have taken a more nuanced view.²⁴⁵

240. It is important to note that these issues also implicate Articles 13 (Access to Justice), 14 (Liberty and Security of the Person), 15 (Freedom from Torture or Cruel, Inhuman, Degrading Treatment or Punishment), and 17 (Protection of the Integrity of the Person) of the CRPD.

241. See, e.g., Office of the High Comm'r on Human Rights, Statement on Article 14 of the Convention on the Rights of Persons with Disabilities (Sept. 2014) [hereinafter Committee Statement on Art. 14], www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LanfID-E [<https://perma.cc/XLP6-ZBNQ>] (“The committee has established that declarations of unfitness to stand trial and the detention of persons based on that declaration is contrary to article 14 of the convention since it deprives the person of his or her right to due process and safeguards that are applicable to every defendant.”).

242. See U.N. Human Rights Council, Annual Rep. of the U.N. High Comm'r for Human Rights and Reps. of the Office of the High Comm'r and the Sec'y Gen., U.N. Doc A/HRC/10/48, at 15 (Jan. 26, 2009) (“In the area of criminal law, recognition of the legal capacity of persons with disabilities requires abolishing a defence based on the negation of criminal responsibility because of the existence of a mental or intellectual disability.”).

243. See, e.g., Tina Minkowitz, *Some Thoughts on the Insanity Defense*, MAD IN AM. (July 12, 2014), <http://www.madinamerica.com/2014/07/thoughts-insanity-defense/> [<https://perma.cc/CBJ3-44TZ>] (expressing opposition to the insanity defense); see generally Tina Minkowitz, *Rethinking Criminal Responsibility from a Critical Disability Perspective: The Abolition of Insanity/Incapacity Acquittals and Unfitness to Plead and Beyond*, 23 GRIFFITH L. REV. 434 (2014) [hereinafter Minkowitz, *Rethinking Criminal Responsibility*] (arguing that the defenses based on mental capacity, along with other measures, are discriminatory and should be abolished).

244. Perlin, *God Said*, *supra* note 239, at 480 (“This position is wrong-headed in every possible way.”).

245. See Cliona de Bhalis & Eilionóir Flynn, *Recognizing Legal Capacity: Commentary and Analysis of Article 12 CRPD*, 13 INT'L J.L. CONTEXT 6, 12 (2017) (noting that it is possible to oppose disability-specific criminal provisions as violative of Article 12 while allowing for legal capacity to be denied “as long as it is on an equal basis between people with and without disabilities.”); see also RESTORING VOICE, *supra* note 44, at 162–65 (suggesting reassessment of the insanity defense in light of Article 12).

This subject is complex, not only because of the bewildering diversity of provisions in numerous relevant federal and state laws,²⁴⁶ but also because it implicates contested areas of morality and politics. And, it is worth noting, virtually no one who writes or thinks about legal capacity in the human rights context has any real experience in or expertise about criminal law.²⁴⁷ Thus, this Section will only briefly describe each of the three issues, primarily as placeholders for the more extensive consideration that will have to occur in any serious effort to advance the human right of legal capacity in the United States.

1. Incompetence to Stand Trial

In a Statement—of lesser worth than a General Comment—not on Article 12, but rather on Article 14, Liberty and Security of the Person, the CRPD Committee wrote:

Detention of persons unfit to plead in criminal justice systems. The committee has established the declarations of unfitness to stand trial and the detention of persons based on that declaration is contrary to article 14 of the convention since it deprives the person of his or her right to due process and safeguards that are applicable to every defendant.²⁴⁸

The principle that an “incompetent defendant” may not be put on trial is firmly embedded in our jurisprudence, with the primary purpose to “safeguard the accuracy of adjudication.”²⁴⁹ As a first issue, the dependence on “incompetence,”²⁵⁰ i.e., a defendant lacking in mental capacity, would appear to run afoul of a right of legal capacity

246. See, for example, discussion of the variety of “insanity defenses” in *Clark v. Arizona*, 548 U.S. 735, 749–53 (2006). The basic standard for competence to stand trial was set out in *Dusky v. United States*, 362 U.S. 402 (1960), but states’ codification of “competency varies, including substituting ‘mental illness’ for a competency determination.” Sara Longtain, Comment, *The Twilight of Competency and Mental Illness: A Conciliatory Conception of Competency and Insanity*, 43 HOUS. L. REV. 1563, 1574–75 (2007).

247. Although, many years ago, I did a number of criminal appeals and taught Criminal Procedure, I certainly count myself among the inadequately informed. Michael Perlin, who has both practiced and, for the past thirty years, written in the area, is a notable exception.

248. Committee Statement on Art. 14, *supra* note 241, at 3.

249. Perlin, *God Said*, *supra* note 239, at 487 (citing *Youtsey v. United States*, 97 F. 937, 941 (6th Cir. 1899)).

250. I do not here even begin to discuss the thorny issue of how, for this purpose, “incompetence” is defined or determined.

that disaggregates mental from legal capacity.²⁵¹ One obvious answer is to provide the supports necessary to enable the defendant to assist her or his lawyer and participate in the trial.²⁵² But what if there are no supports that make that possible? Perlin argues that it is “fundamentally unfair to try a defendant who may not have . . . sufficient present ability to consult with his lawyer with a reasonable degree of rational understanding [or] a rational as well as factual understanding of the proceedings against him.”²⁵³

For disability rights activists there is another important issue underlying the Committee Statement. What happens when a defendant is found incompetent or unable to stand trial? All too often she or he may be detained in conditions similar to or worse than would have been the case had she or he been convicted of the crime charged, and that detention may be, at least in some jurisdictions, indefinite.²⁵⁴ What appears initially to be a “protection” may end as a double deprivation of rights.

This indefinite and often cruel detention has been a particular issue in Australia where it is compounded by discrimination against Aboriginal defendants, generating considerable literature and commentary.²⁵⁵ Disability scholars have explored the variety of

251. It can also be seen as an impermissible attack on or diminution of the defendant’s “personhood” and, as well, arguably involves prohibited unequal treatment “on the basis of disability.”

252. In order to deal with the increasing number of defendants held in long term custody for “unfitness to plead,” as Australian law refers to it, the government has funded a multi-year project to explore the range of supports that might be effective for defendants with cognitive impairments. See generally BERNADETTE MCSHERRY ET AL., MELBOURNE SOCIAL EQUITY INITIATIVE, UNFITNESS TO PLEAD AND INDEFINITE DETENTION OF PERSONS WITH COGNITIVE IMPAIRMENTS: ADDRESSING THE LEGAL BARRIERS AND CREATING APPROPRIATE ALTERNATIVE SUPPORTS IN THE COMMUNITY 9–11 (2017), http://socialequity.unimelb.edu.au/_data/assets/pdf_file/0009/2598507/Unfitness-to-Plead.pdf [<https://perma.cc/NR6D-959N>] (summarizing results of a study regarding access to justice for those with disabilities in Australia).

253. Perlin, *God Said*, *supra* note 239, at 488 (quoting *Dusky v. United States*, 362 U.S. 402, 402 (1960) (per curiam)).

254. RESTORING VOICE, *supra* note 44, at 163; see also Warren Brookbanks, *Managing the Challenges and Protecting the Rights of Intellectually Disabled Offenders*, in COERCIVE CARE, *supra* note 162, at 219 (criticizing New Zealand’s Intellectual Disability Compulsory Care and Rehabilitation Act (IDCCRA), which covers persons found unfit to stand trial or found “legally insane” and “risk[s] becoming indefinite preventive detention”).

255. See, e.g., Piers Gooding et al., *Unfitness to Stand Trial and the Indefinite Detention of Persons with Cognitive Disabilities in Australia: Human*

procedures or "special hearings" currently used to issue "custodial orders" in lieu of trial when a defendant lacks the ability to plead, and conclude that none comply with the CRPD.²⁵⁶ They concede that it is counter-intuitive to insist that more or all people with cognitive disabilities "be pushed through typical criminal trials,"²⁵⁷ and that "greater formal equality in criminal proceedings may increase substantive inequality."²⁵⁸ However, they also argue that

UNCRPD compliance also requires a range of positive measures to be taken, including procedural accommodations and measures to alter typical criminal process to ensure accessibility. It seems premature to suggest that the *UNCRPD* requires the repeal of special hearings, and it would be misguided to position the "protective" aims of unfitness to stand trial in diametric opposition to rights-based efforts to secure equal achievement before the law.²⁵⁹

Although insufficiently fleshed out, and difficult to imagine in practice, they propose "[m]oving towards a universally accessible justice system"²⁶⁰ which, they claim, "is not only likely to benefit people with disabilities, but also others for whom participation in court proceedings may be hindered."²⁶¹

2. The Insanity Defense

At first blush, the insanity defense would seem to violate Article 12 in its denial of legal capacity *because of* disability. This is consistent with a "strong" interpretation of Article 12, such as that taken by Michael Bach, who has written that having legal capacity includes being "held legally responsible and liable for one's actions in

Rights Challenges and Proposals for Change, 40 MELB. UNIV. L. REV. 816, 850–59 (2017) [hereinafter Gooding et al., *Unfitness*] (discussing indefinite detention in Australia, in the context of persons with cognitive disabilities).

256. *Id.* at 850–63.

257. *Id.* at 865. Perlin contends that any such argument "must be rejected out of hand." Perlin, *God Said*, *supra* note 239, at 489.

258. Gooding et al., *Unfitness*, *supra* note 255, at 865.

259. *Id.*

260. *Id.*

261. *Id.*

contract, tort, property *and criminal law*.”²⁶² To deny responsibility is effectively to deny personhood.²⁶³

Tina Minkowitz echoes this interpretation, arguing that “the capacity to be held accountable for harm done to others or to the community [is] a corollary of the capacity to exercise rights, assume obligations and create legal relationships.”²⁶⁴ The insanity defense violates Article 12 “because it undermines the equal recognition of people with disabilities before the law as individuals with mutual obligations towards others and an equal right to participate in defining and negotiating those obligations.”²⁶⁵

Legally relieving someone who has committed a criminal act of responsibility because of “insanity” or other “mental defect” has other serious consequences. A leading commentator writes “granting people with mental disability a special defense stigmatizes and marginalizes them. The category of ‘criminal insanity’ perpetuates the extremely damaging myth that people with mental disability are especially dangerous or specially lacking in self-control.”²⁶⁶

Like a finding of incapacity to stand trial, an insanity acquittal does not mean that the defendant goes free. Almost inevitably she or he will then be detained for treatment, prevention, or both, possibly for longer than she or he would have been if convicted, and often under conditions at least as severe.²⁶⁷

The “abolitionist” position has been adopted by the U.N. Human Rights Council, but not the CRPD Committee, which has not addressed the issue. The Council has written that “recognition of the legal capacity of persons with disabilities requires abolishing a defence

262. MICHAEL BACH, THE RIGHT TO LEGAL CAPACITY UNDER THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: KEY CONCEPTS AND DIRECTIONS FROM LAW REFORM 3 (2009), http://irisinstitute.ca/wp-content/uploads/sites/2/2016/07/The-right-to-legal-capacity-under-the-un-convention_cr.pdf [<https://perma.cc/YL5F5-W46A>] (emphasis added).

263. See R.A. Duff, *Who is Responsible, for What, to Whom?*, 2 OHIO ST. J. CRIM. L. 441, 450 (arguing that, in the case of individuals not in touch with objective conceptions of reason, value, and emotion, “we cannot hold them responsible, since we cannot address them as fellow participants in such practices”).

264. Minkowitz, *Some Thoughts on the Insanity Defense*, *supra* note 243.

265. Minkowitz, *Rethinking Criminal Responsibility*, *supra* note 243, at 447.

266. Christopher Slobogin, *Eliminating Mental Disability as a Legal Criterion in Deprivation of Liberty Cases: The Impact of the Convention on the Rights of Persons with Disabilities on the Insanity Defense, Civil Commitment, and Competency Law*, 40 L. & PSYCHOL. REV. 297, 309 (2016).

267. See, e.g., Perlin, *God Said*, *supra* note 239, at 504.

based on the negation of criminal responsibility because of the existence of a mental or intellectual disability.²⁶⁸ Professor Perlin takes a diametrically opposing view, noting that “the [insanity] defense ‘has been a major component of Anglo-American common law for over 700 years’²⁶⁹ and “it continues to serve as a ‘surrogate for resolution of the most profound issues in criminal justice.’²⁷⁰ In response to the “abolitionists,” and particularly Minkowitz’s position, Perlin writes that “[i]f adopted, it will make a mockery of any modicum of fair-trial rights for the population in question,²⁷¹ and will likely lead to torture of the population in the jails and prisons in which it will languish.²⁷² This draws on his claim that the CRPD should be read *in pari materia*,²⁷³ a principle of statutory construction, which he applies to harmonize Article 14 and, by implication, Article 12 with other CRPD provisions²⁷⁴ to preserve the insanity defense or some variation of it.²⁷⁵

268. U.N. High Comm’r for Human Rights and U.N. Sec’y Gen., *Thematic Study by the U.N. High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities*, ¶ 47, U.N. Doc. A/HRC/10/48 (Jan. 26, 2009).

269. Perlin, *God Said*, *supra* note 239, at 492 (footnote omitted).

270. *Id.* (citing LINCOLN CAPLAN, *THE INSANITY DEFENSE AND THE TRIAL OF JOHN W. HINCKLEY, JR.* 127 (1984)).

271. *Id.* at 480. Perlin points out what he appears to see as a conflict between Article 12, or at least the “strong” position on legal capacity, and the right to a fair trial and due process, such as is laid out in Article 13. *See id.* at 497–99 (juxtaposing the endorsement by the Comment on Article 12 of eliminating the insanity defense with Perlin’s observation that Professor Christopher Slogobin’s analysis would effectively endorse non-culpability for certain crimes); *see also* ARLENE S. KANTER, *THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO RIGHTS* 222–31 (2015) (analyzing meaning and scope of Article 13 of the CPRD).

272. Perlin, *God Said*, *supra* note 239, at 480. Given the well-documented mistreatment of persons with disabilities in the prison system, this argument also relies on Article 15, the right to be free from torture or cruel, inhuman, or degrading treatment or punishment. *Id.* at 510.

273. *Id.* at 496.

274. *Id.* (cataloging separate CRPD provisions on the “[r]espect for inherent dignity; [f]reedom from torture or cruel, inhuman or degrading treatment; [f]reedom from exploitation, violence and abuse; [and] a right to protection of the integrity of the person . . .”) (alterations in original footnotes omitted).

275. This mode of statutory interpretation is consistent with Articles 31 and 32 of the Vienna Convention. Vienna Convention on the Law of Treaties, *opened for signature* May 23, 1969, arts. 31, 32, 1155 U.N.T.S. 331 (entered into force Jan. 27, 1980).

Once again, there is at least an implicit appeal to universal design. Perlin is not unsympathetic, at least in principle,²⁷⁶ to what is referred to as providing an “integrationist” approach,²⁷⁷ that is, an effort to rewrite criminal laws to “provid[e] persons with mental disabilities with ‘all of the defenses that are available to criminal defendants without mental disabilities.’”²⁷⁸ This is a variation on a U.K. scholar’s observation that “the development of non discriminatory alternative formulations must be of paramount import.”²⁷⁹ Not surprisingly, in pursuing such an agenda, the devil will surely be in the details.

Jilian Craigie suggests an alternative and provocative mode of analysis that shifts the debate. She interrogates an assumption in the “standard interpretatio[n] of the concept of ‘legal capacity’” that “these two kinds of legal capacity are two sides of the same coin” and that, because legal recognition should apply “in the context of personal decisions[, it should also apply] in the context of responsibility for criminal acts.”²⁸⁰ The result is a belief “that a need for wider recognition in the personal sphere automatically means that there is a need for wider recognition in the criminal sphere.”²⁸¹ Craigie challenges that assumption by examining three moral arguments for wider recognition of legal capacity in the personal sphere, concluding that they are less compelling, or even inapplicable to, criminal responsibility because different moral considerations apply in the two spheres.²⁸² For example,

[w]hile decisions about where to set the mental threshold for the right to make one’s own decisions must balance the value of liberty and recognition

276. Perlin is critical of the precise way in which Slobogin attempts to recast the insanity defense because it includes a requirement that the defendant must not have caused any of the exculpatory “mental states . . . by, inter alia, purposely avoiding treatment, aware that such states would occur without such treatment.” Perlin, *God Said*, *supra* note 239, at 498 (alteration and footnote omitted).

277. *Id.*

278. *Id.* at 498 (citing Slobogin, *supra* note 266, at 306).

279. Peter Bartlett, *The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law*, 75 MOD. L. REV. 752, 776 (2012).

280. Craigie, *supra* note 53, at 12.

281. *Id.* at 9.

282. These are what she categorizes as “personhood,” “growth and flourishing,” and “limited understanding.” *Id.* at 7. The latter category raises questions, given new research in psychology, neuroscience, etc., about how decisions are actually made, thus challenging the whole rationality paradigm. *Id.* at 9.

against the protection of well-being, the equivalent question in relation to criminal responsibility involves weighing the importance of punishment and holding others to account, against welfare considerations.²⁸³

Craigie posits that these differences suggest that “there may be strong moral reasons not to think of legal capacity in a singular, decontextualized way: it may well be appropriate to adopt different standards for legal capacity in different areas of law on the basis that there are different moral and political considerations in play.”²⁸⁴

3. “Consent” in Rape and Sexual Assault Crimes

Legal capacity includes the legal recognition of one’s decisions. Rape and other sexual assault crimes²⁸⁵ often have, as an essential element, the absence of consent to sexual intercourse or other sex acts.²⁸⁶ Regardless of her or his will, preference, and actual decision about engaging in sexual activity, rape statutes routinely criminalize sex with a person with a “mental disability” or similar language, or impose a “know and appreciate” test to consent or its absence,²⁸⁷ which, as a matter of law, deprives that person of legal capacity in the moment.

283. *Id.* at 14.

284. *Id.*

285. For brevity, I will include all crimes that involve consent or non-consent to sexual activity within the term “rape.”

286. In rape, the dilution of the common law requirement of “force” so as to focus entirely on non-consent was the result of decades of feminist agitation, resulting in legislative change in most states. *See, e.g.*, Joseph A. Fischel & Hillary O’Connell, *Disabling Consent, or Reconstructing Sexual Autonomy*, 30 COLUM. J. GENDER & L. 428, 435–36 (noting the efforts of “liberal and feminist legal scholars” in the “substitution of nonconsent for force as the gravamen for sexual assault” and “reforms to modern rape law”).

287. *See, e.g.*, Stephanie L. Tang, *When “Yes” Might Have Meant “No”: Standardizing State Criteria to Evaluate the Capacity to Consent to Sexual Activity for the Elderly with Neurocognitive Disorders*, 22 ELDER L.J. 449, 468–69 (2015) (discussing statutes criminalizing sexual relations with those lacking “mental capacity” and the factors courts use in analyzing an individual’s capacity). In the area of “statutory rape,” Professor Perlin argues that we “must start with the assumption that all individuals have the capacity to consent to sexual relations, and that the presence of mental disorder, in itself, does not mean the individual lacks this capacity.” Michael L. Perlin & Alison J. Lynch, “*All His Sexless Patients*”: *Persons with Mental Disabilities and the Competence to Have Sex*, 89 WASH. L. REV. 257, 263 (2014) [hereinafter Perlin & Lynch, *All His Sexless Patients*].

These statutes have a much wider effect. They are clearly intended to deter prospective sexual partners and almost certainly, to at least some extent, they do. In this way, they create barriers to intimate relationships, limit rights to sexual expression,²⁸⁸ and, in addition to Article 12, violate Article 23's prohibition on discrimination against people with disabilities "in all matters relating to marriage, family, parenthood, and relationships."²⁸⁹ These statutes stigmatize people with intellectual disabilities in the most personal areas and reduce them to "children" who also are prohibited, as a matter of law, from consenting to sex. They "outcast" them into "statutory isolation."²⁹⁰ They deprive them of basic human dignity.

While these critiques of existing law seem unassailable in a human rights context, they carry little weight in a country that has not ratified the CRPD.²⁹¹ Accordingly, to the extent that we seek to advance a right of legal capacity, we must be prepared to think deeply about the difficult issue these statutory provisions raise. We cannot simply dismiss these provisions in rape and sexual assault law as outdated protectionism when people with intellectual disabilities, especially

288. Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201 (stating that sexuality and incapacity "need not be mutually exclusive, but current sexual incapacity doctrines make them so for many"); Perlin & Lynch, *All His Sexless Patients*, *supra* note 287, at 263; see also Anna Arstein-Kerslake, *Understanding Sex: The Right to Legal Capacity to Consent to Sex*, 30 DISABILITY & SOC'Y 1459, 1463 (2015) [hereinafter Arstein-Kerslake, *Understanding Sex*] ("[T]he denial of legal capacity to consent to sex may serve to further stigmatize and remove agency from individuals with intellectual disabilities.").

289. CRPD, *supra* note 1, art. 23.

290. Fischel & O'Connell, *supra* note 286, at 485 (citing the term coined in Deborah W. Denno, *Sexuality, Rape and Mental Retardation*, 1997 U. ILL. L. REV. 315, 393 (1997)).

291. This is not to say that there is not considerable controversy about laws based on non-consent, but it is hardly premised in an argument for the right of legal capacity. It is also worth noting that, as Perlin and Lynch describe, ". . . the literature surrounding the sexual autonomy and issues of sexuality people with disabilities continue to confront remains remarkably silent on the issue." Perlin & Lynch, *All His Sexless Patients*, *supra* note 287, at 274. This is largely because of "[t]he discomfort people feel in discussing this topic." *Id.* at 259.

older people²⁹² and women,²⁹³ are, and are viewed as,²⁹⁴ disproportionately the victims of sexual assault.

We can begin with the non-controversial proposition that everyone should be protected against unwanted sexual actions. The question then becomes how to balance autonomy and protection, while ensuring that people with intellectual, developmental, and cognitive disabilities are not singled out because of their disabilities. Advocates have proposed at least two different approaches: disability-neutral statutes and a reconceptualization of “capacity” to consent to sexual activity. In addition—because the provision of supports is a necessary component of legal capacity for people with disabilities—the nature, timing, and ability to accept or refuse supports is also implicated. It is also important to notice that differences between groups for whom legal capacity is threatened may require different consideration or approaches.²⁹⁵

i. Disability Neutral Laws

Respecting legal capacity “on an equal basis” requires that when legal capacity is denied to individuals, it is done in a way that is not discriminatory.²⁹⁶ And Article 2, which must be read in conjunction

292. In general, older people are more likely to be the victims of sexual abuse. See Tang, *supra* note 287, at 463.

293. Notably the CRPD has a separate article, Article 6, on women with disabilities. CRPD, *supra* note 1.

294. Confronting popular belief about the hyper vulnerability of people with I/DD and older persons cognitive decline—including, because of the sporadic exposés, nursing home residents—is critical to persuading decision-makers that embracing the right of legal capacity in this area, as others, will not undercut the protections from sexual assault and violence that society owes to all its members.

295. For example, the meaning and importance of sexuality for older persons with severe cognitive decline may differ from that of other groups. As Tang notes, “For these individuals, ‘sexual sensations are among the last of pleasure-giving biological processes to deteriorate and are an enduring source of gratification at a time when pleasures are becoming fewer and fewer.’” Tang, *supra* note 287, at 461 (quoting Sally M. Roach, *Sexual Behavior of Nursing Home Residents: Staff Perceptions and Responses*, 48 J. ADVANCED NURSING 371, 378 (2004)).

296. General Comment No. 1, *supra* note 9, ¶¶ 25, 32–34. While this resonates with traditional U.S. notions of equal protection, constitutional equal protection is not necessarily sufficient. Discrimination based on disability is subject only to a rational relationship test. See *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 442–47 (1985) (holding that “mental retardation” is not a suspect classification requiring a more exacting level of scrutiny under the Fourteenth Amendment). In our paternalistic society, which stigmatizes, stereotypes, and

with Article 12, defines “discrimination on the basis of disability” as any “distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms.”²⁹⁷

It is beyond the purpose or space constraints of this Article to propose examples of disability-neutral sexual assault laws, especially given the myriad formulations that appear in the laws of different jurisdictions. It is useful, however, to note that it is not necessarily enough simply to delete references to “mental disability,” “mental retardation,” or other variations on the term. Any statute that requires absence of consent, but excuses that absence when, for example, the victim is unable to understand and appreciate the meaning of consent, disproportionately affects people with intellectual disabilities, and so is still a discrimination based on disability.

On the other hand, a provision excusing the absence of consent when the victim is unable to communicate her or his non-consent would be disability-neutral because it would apply to everyone who could not communicate non-consent for whatever reason—whether the person was unconsciousness, gagged, threatened, or non-verbal because of her or his disability.

ii. Reconceptualizing Capacity to Consent to Sex

A person’s agreement to engage in any particular sexual activity is seldom the result of a carefully thought out, “rational” decision, so insisting on a pure “understand and appreciate” capacity test is unrealistic, not only for people with disabilities but for everyone.²⁹⁸ Arstein-Kerslake attempts to reconcile the approach with reality by beginning to theorize an “agreement model” that requires two elements: agreement and understanding.²⁹⁹

devalues people with disabilities, this lower standard has been relatively easy to meet. *See, e.g., Heller v. Doe*, 509 U.S. 312 (1993) (ruling a Kentucky statute regarding involuntary commitment was constitutional under the rational basis test).

297. CRPD, *supra* note 1, art. 2.

298. *See* Arstein-Kerslake, *Understanding Sex*, *supra* note 288, at 1463 (“If a functional test of mental capacity to consent to sex was applied on an equal basis to all people, many people would be found to lack the requisite capacity to consent.”).

299. *Id.* at 1469. *See generally* Liz Brosnan & Eilionoir Flynn, *Freedom to Negotiate: A Proposal Extricating ‘Capacity’ from Consent*, 13 INT’L J.L. CONTEXT

Because some people with intellectual disabilities are non-verbal and use non-traditional communication methods, "the evidence for determining agreement would have to come from a holistic examination of the interaction between the two individuals."³⁰⁰ Agreement requires some level of understanding, but Arstein-Kerslake argues that the specific level "must realistically reflect sexual decision-making, which is generally quite basic This could be merely an understanding of the physiological elements of a particular sexual encounter."³⁰¹ And, she continues, "[t]he element of understanding must be present in all sexual encounters, not only those of persons with intellectual disabilities."³⁰² A "disability neutral approach," she claims, may "provide a more robust definition of sexual [offenses] generally."³⁰³

Consent can also be conceptualized as explicitly including SDM, as in Alexander Boni-Saenz's "cognition-plus" model.³⁰⁴ His "novel sexual consent capacity test"³⁰⁵ requires, first, an assessment of whether an individual has the ability to "express volition" with respect

58 (2017) (presenting a new approach, one respectful to persons with disabilities, to writing consent laws).

300. Arstein-Kerslake, *Understanding Sex*, *supra* note 288, at 1469. The call for a "contextual approach" that considers the situational and circumstantial criteria of the sexual encounter was first advanced almost two decades ago (which explains the unfortunate use of the now discredited term "mental retardation") in an oft-cited article by Deborah W. Denno. Denno, *supra* note 290, at 355–59. This approach has been criticized because of, *inter alia* its indeterminacy, giving judges, who may bring their own prejudices or views of what is "appropriate" sex, to bear in the analysis. See, e.g., Boni-Saenz, *supra* note 288, at 1221–22.

301. Arstein-Kerslake, *Understanding Sex*, *supra* note 288, at 1469. This is somewhat similar to the "issue specific" (as opposed to "situation specific") test adopted by the English Court of Appeals in *I.M. v. L.M.* [2014] EWCA (Civ) 37 (critiqued in Jonathon Herring & Jesse Wall, *Capacity to Consent to Sex*, 22 MED. L. REV. 620 (2014)). Herring and Wall argue that "[f]or everyone, having capacity to engage in sex is not about understanding facts (or at least not very much at all about that) it is about values such as tenderness, respect; mutuality; sensitivity. It is about having time; feeling safe; and being free to say no." *Id.* at 629–30.

302. Arstein-Kerslake, *Understanding Sex*, *supra* note 288, at 1469.

303. *Id.*

304. Boni-Saenz, *supra* note 288, at 1205 ("[T]he Article sets forth a novel sexual capacity consent test for [adults with cognitive impairments]: cognition-plus.").

305. Rather than traditional notions of cognitive *capacity*, Boni-Saenz grounds his test in a theory of sexual "capabilities" derived from the work of Martha Nussbaum and Amartya Sen. *Id.* at 1205 n.17 and accompanying text. He writes, "An individual's sexual capability is a product not only of that person's cognitive abilities, but also of her social resources and the legal treatment of those abilities and resources." *Id.*

to a sexual decision,³⁰⁶ and second, the traditional mental capacity test of “understand and appreciate” as to a given sexual decision.³⁰⁷ The novelty in Boni-Saenz’s approach, however, is a third step if this second requirement cannot be met: evaluation of whether an adequate decision-making support [SDM] network is in place.³⁰⁸ Such a network, he posits, “can provide support to an individual in formulating her purposes, connecting her desires with options, communicating with others, and creating a safe space to engage in sexual expression.”³⁰⁹ This third step can be dispositive in opening up the possibility of sexuality for cognitively-impaired persons because “[i]f the system is adequate, then the individual possesses sexual consent capacity.”³¹⁰

There are several possible criticisms of Boni-Saenz’s test. First, as with Denno’s approach,³¹¹ because the test is contextual in nature, it may require excessive judicial inquiry, with the accompanying concerns that entails.³¹² Second, as Jasmine Harris notes, Boni-Saenz applies his test to older adults within a taxonomy which defines their disability as “persistent acquired incapacity” as opposed to people who have had intellectual and developmental disabilities from birth or shortly thereafter, a situation he classifies as “persistent lifelong incapacity.”³¹³ Using the onset of incapacity “matters with respect to assessing sexual decisions”³¹⁴ because the latter group will have had

306. *Id.* (“Without this manifestation of desire, one cannot proceed to be a sexual agent.”).

307. *Id.* (“If one meets this requirement, then one has sexual consent capacity without the need for assistance.”).

308. *Id.* at 1205–06.

309. Boni-Saenz, *supra* note 288, at 1205–06.

310. *Id.* at 1206.

311. See *supra* note 300 for a critique of Denno, *Sexuality, Rape and Mental Retardation*, *supra* note 290.

312. “Assessment of the system would be contextual in nature . . . courts would evaluate whether the system is free from conflicts of interest, has adequate knowledge of the individual and the sexual decision, and has taken reasonable steps to protect the individual . . . from the threat of sexually transmitted diseases and pregnancy.” Boni-Saenz, *supra* note 288, at 1206 (explaining the evaluation of the adequacy of the network). As with other contextualized decisions, the possible intrusion of implicit or explicit bias on the part of those judges makes the proposed evaluation somewhat problematic.

313. Jasmine E. Harris, *The Role of Support in Sexual Decision-Making for People with Intellectual and Developmental Disabilities*, 77 OHIO ST. L.J. FURTHERMORE 83, 86 (2016).

314. *Id.* at 86

"no prior period of unimpaired cognitive functioning,"³¹⁵ and perhaps no opportunities for, or knowledge of, sexuality sufficient to constitute the necessary volition.³¹⁶

iii. Supports for Sexuality and Sexual Consent

It is unrealistic to expect an appropriate supporter to be present on every occasion in which a person with an intellectual, developmental, or cognitive disability may be the subject or object of sexual activity,³¹⁷ but there are many supports that can be provided in order to further such persons' sexual autonomy. Drawing on the interpretation of "support" in the General Comment,³¹⁸ Arstein-Kerslake sketches out a useful framework:

Support for the exercise of legal capacity in sexual decision-making . . . should include support that is flexible and has the individual's wishes at its core. It should enable an individual to exercise autonomy in sexual decision-making, while also providing information about how to protect against sexual abuse and resources to avail of when sexual abuse occurs. It should never present an additional barrier to sexual relationships. . . . People with intellectual disabilities should not be legally required to accept or use support in order to enjoy the freedom to have sex and to develop intimate relationships.³¹⁹

Fischel and O'Connell helpfully describe three kinds of support relevant both to consent and to sexual autonomy: greater access for sexual information and opportunities, variably tailored sexuality education, and substantive provisions for sexual assistance.³²⁰ Here the

315. *Id.*

316. *Id.*; see *infra* notes 320–24 and accompanying text (outlining necessary supports for this group).

317. This is why Boni-Saenz's work may be more useful for people in nursing homes or other confined situations, where the support network has greater control and influence, than for people with I/DD living in the community, where more spontaneous and unplanned interactions occur.

318. This includes "various support options which give primacy to a person's will and preferences and respect human rights norms. It should provide protection for all rights, including the right to autonomy . . . and rights related to freedom from abuse and ill-treatment . . . [Supports] should not over-regulate the lives of persons with disabilities." General Comment No. 1, *supra* note 9, ¶ 29.

319. Arstein-Kerslake, *Understanding Sex*, *supra* note 288, at 1462.

320. Fischel & O'Connell, *supra* note 286, at 505–23.

differences between affected groups also need to be considered. Older persons with cognitive decline, most persons with psychosocial disabilities, and persons with TBIs will likely have had knowledge and experience of sex prior to the onset or fluctuating manifestation of their disability, while persons with I/DD, especially those with the most severe impairments, will need to be taught about sexual expression and its manifestations.³²¹ However, sex education for children and young adults with I/DD is woefully inadequate.³²² Older persons may also need information about sexually transmitted diseases that was not part of whatever sex education they received growing up.³²³ Many of these supports, especially adequate and appropriate sex education, should be available to all.

E. The Need for Research

Much has been written about the normative aspects of legal capacity, but there is remarkably little concrete information about how supports can be used to further the exercise of legal capacity in the real world. As one commentator notes,

[t]he creation of appropriate legal structures is essential to implement the right to make one's own decisions and consequently much attention has been paid to developing such structures. However, in comparison the crucial issue of the actual practice of delivering support for decision-making in whatever context has been severely neglected.³²⁴

Article after article calls for “developing the research base that is so necessary to sound policymaking or law reform,”³²⁵ often quoting the former Chief Justice of the High Court of Australia, Sir Anthony Mason, who cautioned that “[a]s things currently stand, [current] proposals seem to reflect little more than ideals which have not been

321. See *id.* at 508–17 (discussing the role of sex education and sexual facilitation). Harris notes the importance of “meaningful educational and experiential opportunities” relating to sexuality. Harris, *supra* note 313, at 100 (emphasis added).

322. *Id.* at 99–100.

323. Tang, *supra* note 287, at 481.

324. Douglas et al., *supra* note 229, at 38; see also Carney, *Supporting People with Cognitive Disabilities*, *supra* note 113, at 7 (“Policy conundrums are compounded by a lack of evidence about the suitability-for-purpose or the efficacy of either legislative or informal schemes of supported decision-making.”).

325. Carney, *Operationalizing*, *supra* note 222, at 49.

carefully thought through, with the risk that they will result in experimental lawmaking."³²⁶

Australia has had the most pilot projects,³²⁷ some of which have been evaluated,³²⁸ but even in that country there is very little "gathering [of] rigorous evidence on what works in terms of ensuring that the desires of people with cognitive disabilities are *actually* at the center of decision-making."³²⁹ What empirical evidence exists from the pilot projects and "the literature on maximizing choice at a micro level for people with cognitive disabilities"³³⁰ has, it is posited, resulted in "empirically based propositions . . . that describe factors in four broad areas with implications for practice: (a) orchestration,³³¹ (b) commitment,³³² (c) support principles,³³³ and (d) strategy development."³³⁴ Exploration of what is required to realize these factors could provide a framework for further research.

326. *Id.* at 50 (citing Anthony Mason, *Foreword*, 36 U.N.S. WALES L.J. 170, 170–74 (2013)).

327. *See infra* notes 399–400 and accompanying text.

328. *See, e.g.*, NEW S. WALES DEP'T. FAMILY & CMTY. SERVS., MY LIFE, MY DECISION: AN INDEPENDENT EVALUATION OF THE SUPPORTED DECISION MAKING PILOT 10–13 (2015) (summarizing the results of the evaluation); S. AUSTL. HEALTH & CMTY. SERVS. COMM'R'S OFFICE, HCSCC SUPPORTED DECISION MAKING PROGRAM 2014–15 EVALUATION REPORT 69–70 (summarizing the results of the program as compared to the key purposes).

329. Douglas et al., *supra* note 229, at 39. The authors note that "[e]arly adopters of supported-decision making, such as Sweden and Canada, provide little evidence on the operation of mechanisms such as micro-boards, Sweden's *Godman*, or the practice of decision-making supporters." *Id.*

330. *Id.* at 40.

331. Orchestration involves the participation of a trusted primary supporter and her or his ability to recruit and orchestrate the involvement of other supporters. *Id.*

332. This refers to the level of supporters' knowledge about the person's history, preferences, the effect of her or his specific cognitive impairments on decision-making needs, and the supporters' commitment to continually learning about the person and changing expectations based on new knowledge. *Id.*

333. These can include recognition that the person's desires drive the decision-making agenda. The principles can be realized in many ways: understanding and being able to put aside one's own values and preferences, understanding risk and its costs and benefits and "us[ing] rights as a touchstone for weighing these," preserving the person's self-identity, and "be[ing] able to articulate the reasoning processes involved in supporting and reaching a decision with the person." Douglas et al., *supra* note 229, at 40.

334. "Effective supporters need to develop a repertoire of flexible strategies that they can call upon readily as personal and contextual demands vary." *Id.*

Supporter characteristics and requirements to ensure authentic decision-making by the supported person are not the only area requiring more rigorous study. In an influential 2013 article directed primarily toward a U.S. audience, Nina Kohn and her colleagues laid out a series of questions which, they argue, require further research before SDM should be wholeheartedly embraced.³³⁵ These included: how often do individuals make use of supported decision-making arrangements where they are currently available;³³⁶ what groups of people tend to or would effectively use supported decision-making;³³⁷ who are the supporters and what are their demographics;³³⁸ what is the impact of race and ethnicity;³³⁹ and what is the process by which supported decisions are made?³⁴⁰

Kohn and her colleagues also raise questions regarding the evaluation of substantive outcomes,³⁴¹ including the psychological impact on principals; congruency between what she refers to as “wishes”³⁴² and decisions; the quality of decisions made;³⁴³ the psychological impact on, and of, supporters,³⁴⁴ and the effect of

335. Kohn et al., *supra* note 43, at 1133.

336. *Id.* at 1130–31. Here the Kohn article includes “informal” supported decision-making as well as the more formalized version, which, at that time, was essentially non-existent in the U.S. *Id.*

337. *Id.* at 1132–34 (looking primarily at data on the use of representation agreements in British Columbia).

338. *Id.* at 1134–35. A focus here may be on how many supporters are family members because of “family dynamics . . . which may or may not be empowering.” Kohn et al., *supra* note 43, at 1134–35.

339. *Id.* at 1135 (noting the lack of such demographic information to date and group differences found in research on patients’ approaches to medical decision-making).

340. *Id.* at 1136–38. Understanding the dynamics of the process are, according to the authors, important not only for evaluating the impact and efficacy of supported decision-making but also the potential for abuse or undue influence. *Id.*

341. *Id.* at 1138–44.

342. Kohn et al., *supra* note 43, at 1140. In language more directly derived from Article 12 this might be better denominated “will and preferences.” CRPD, *supra* note 2, art. 12(4).

343. Kohn et al., *supra* note 43, at 1141–42. Recognizing the difficulty of evaluating decision quality, Kohn notes the need for both policy and data-driven research to establish criteria. *Id.*

344. *Id.* at 1143–44. This is relevant to, *inter alia*, the importance of training and development of safeguards.

individual differences and context on outcomes.³⁴⁵ The article concludes with a thoughtful list of “five primary areas” for future research necessary for “policy makers . . . to actually design and implement practices which effectively empower persons with intellectual and cognitive disabilities to engage to the fullest extent possible in decisions about their own lives.”³⁴⁶

Since the Kohn article, there have been several promising developments both at home and abroad. In Bulgaria in 2015, the De Pasarel Bulgarian Foundation and the Bulgarian Center for Not for Profit Law (BCNL) published thoughtful research from BCNL’s ongoing pilot projects,³⁴⁷ entitled *Study of the Effects and Economic Benefits of Supported Decision Making*.³⁴⁸ That study utilized a recognized conceptual framework for assessing quality of life in measuring changes in pilot participants’ self-determination, personal development, interpersonal relationships, and social inclusion.³⁴⁹ In addition, it calculated the economic consequences of the use of SDM in the pilots in several areas, including the use of health services and increases in employment.³⁵⁰ Going forward, the Bulgarian study provides a useful model for assessing the consequences, benefits, and costs of SDM and promoting legal capacity.

In the United States, the CPR/Nonotuck pilot project in Northampton, Massachusetts, incorporated high quality, professional

345. *Id.* at 1144–54. Here the article draws on research involving shared decision-making for medical decisions to raise issues for exploration in the supported decision-making context. *Id.*

346. *Id.* at 1155.

347. See discussion of the Bulgarian experience, *infra* Section II.A.2.

348. DE PASAREL BULG. FOUND.: BULGARIAN CTR. NOT-FOR-PROFIT LAW (BCNL), *Study of the Effects and Economic Benefits of Supported Decision-Making*, in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 138–54 (2015) [hereinafter De Pasarel, *Study on Supported Decision-Making*]; see also Haralan Alexandrov, *Intro-version: From Guardianship to Freedom*, in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 82–83 (2015), http://bcnl.org/uploadfiles/documents/pvr/booklet_eng.pdf (describing the use of “action research,” specifically designed for the purpose of studying social and cultural change within communities and organizations).

349. De Pasarel, *Study on Supported Decision-Making*, *supra* note 348, at 142.

350. *Id.* at 146–54.

evaluation³⁵¹ from the outset,³⁵² and has since generated two lengthy project evaluation reports, the first of which was issued in December 2015.³⁵³ Describing the project's first year, the initial report was primarily a process evaluation, focusing on pilot design.³⁵⁴ The second report, covering 2016, "present[ed] SDM pilot activities and findings regarding the experience of using SDM and an assessment of impacts."³⁵⁵ The overall purpose of the evaluation was "to identify challenges and recommendations to inform broader SDM adoption."³⁵⁶ Although the pilot sample was small and heterogeneous, many useful lessons were learned and many issues raised earlier began to be answered.³⁵⁷ Following the example of the CPR/Nonotuck project, the far larger SDMNY pilots are currently the subjects of a well-funded independent evaluation.³⁵⁸

351. The evaluation was done by Elizabeth Pell and Virginia Mulhern of the Human Services Research Institute in Cambridge, Massachusetts, with funding from the Open Societies Foundation.

352. As a member of the Advisory Committee, I can attest to the importance of participation by the evaluator in the earliest stages where the questions they asked had a large and salutary effect on the project's design.

353. CPR/NONOTUCK PILOT PROGRAM EVALUATION YEAR 1, *supra* note 201. The evaluation looked at the activities undertaken to establish the pilot, to choose persons with I/DD who agreed to accept support, train supporters, and assist the parties in reaching SDMAs. *Id.* at 4–5.

354. *Id.*

355. ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT (2016) [hereinafter CPR/NONOTUCK PILOT PROGRAM EVALUATION YEAR 2], supporteddecisions.org/wp-content/uploads/2016/11/Evaluation-Year-2-Report_HSRI-2016_FINAL-2-1.pdf [<https://perma.cc/BNP3-AAAC>]. The Evaluation included the number and type of SDM decisions, the understanding and experience of all pilot participants, their satisfaction with the decisions and decision assistance, the extent of risk, and provision of information as a form of safeguard monitoring and review, and whether and how SDM made a difference in adopters' lives. *Id.* at 4–5.

356. *Id.* at 4.

357. For example, concerns about whether SDM would place participants at risk of abuse or exploitation were ameliorated by a finding that "SDM adopters did not experience abuse, neglect or financial exploitation through use of SDM. Many pilot participants stated their belief that the structure of SDM, selecting people one trusts to help with decisions, and having more than one supporter, reduces risk of abuse." *Id.* at 26.

358. In a separate five-year grant, the New York State Developmental Disabilities Planning Council has engaged the Council on Quality Leadership (CQL), a well-known accrediting agency in the I/DD field. Glen, *Piloting Personhood*, *supra* note 87, at 122.

In 2015, the ACL National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) awarded a five-year, \$2.5 million grant to the Burton Blatt Institute at Syracuse University for a project on “Understanding and Increasing Supported Decision Making’s Positive Impact on Community Living and Participation Outcomes.”³⁵⁹ The project team “will test interventions using a randomized control trial approach examining whether training individuals with I/DD, their families, and support network to use a SDM approach, improves life satisfaction and integration in community living and daily life outcomes.”³⁶⁰

Thoughtful collection of information in ongoing pilots around the world,³⁶¹ creative evaluations, and independent research should begin to provide an evidence base for determining not only the efficacy of SDM regimes, but whether and how those regimes further—or limit—exercise of the right of legal capacity. In the context of legal capacity, however, simply collecting evidence, no matter how extensive or apparently relevant, is not enough. The CRPD instructs States parties to include persons with disabilities in all their policymaking and implementation measures.³⁶² Research efforts must be similarly inclusive. Arstein-Kerslake reminds us of a core tenet of the disability rights movement, “nothing about us without us.”³⁶³ She stresses the importance of effectively engaging people with intellectual and cognitive disabilities in research about legal capacity “at both the

359. See, Press Release, Burton Blatt Institute Receives \$2.5 Million from National Institute on Disability, Independent Living, and Rehabilitation Research for Increasing Supported Decision Making in Community Living (Oct. 19, 2015), http://bbi.syr.edu/news_events/news/2015/10/NIDILRR_SDM_PressRelease.html [<https://perma.cc/ZN88-8ZTE>].

360. *Id.*

361. A promising example is the data collection being done by the Peer Support Group Initiative (Experts by Experience) of Users and Survivors of Psychiatry in Kenya which is incorporated in its Draft Report. See Kenya Draft Report, *supra* note 175.

362. CRPD, *supra* note 1, art. 4(4) (“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities.”).

363. RESTORING VOICE, *supra* note 44, at 217 (citing JAMES I. CHARLTON, NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT (Univ. of Cal. Press 1998)).

design stage and at the productions and outcomes stages.”³⁶⁴ This “co-production” matters “because research can be core to influencing [policy] at all levels.”³⁶⁵

An inspiring example of such co-produced research is the 2014 report done by Inclusion International,³⁶⁶ *Independent But Not Alone: A Global Report on the Right to Decide*.³⁶⁷ Echoing the first core aspect of Arstein-Kerslake’s “rights based” model,³⁶⁸ Inclusion International explains that “our members identified legal capacity and the right to make decisions as one of four priority issues.”³⁶⁹ The Report comprehensively demonstrates their use of “a different approach”³⁷⁰ to research: “Over the last decade we have developed and enhanced a participatory action research methodology that relies on the expertise and experience of people with intellectual disabilities and their families. Each of our reports reflects the culmination of a process to hear and represent the[ir] collective voices”³⁷¹

Research that includes—and heeds—the voices of “experts by experience” is, simply, better and more effective research.³⁷² Moving

364. *Id.* (“[T]here has been a decades long discussion of what it means to include people with disabilities in research.”).

365. *Id.* (“[M]any models have emerged and continue to emerge.”). Arstein-Kerslake proposes a “rights based” model with four core aspects. *Id.* at 218.

366. Inclusion International is “the international network of people with intellectual disabilities and their families advocating for the rights of people with intellectual disabilities worldwide.” It has been in existence for more than fifty years, and represents over 200 member federations in 115 countries. *Who We Are*, INCLUSION INT’L, <https://inclusion-international.org/who-we-are/> [<https://perma.cc/4X9S-7RJJ>] (last visited Feb. 25, 2017).

367. INCLUSION INT’L, *INDEPENDENT BUT NOT ALONE: A GLOBAL REPORT ON THE RIGHT TO DECIDE* (2014) [hereinafter *INDEPENDENT BUT NOT ALONE*], <http://inclusion-international.org/wp-content/uploads/2014/06/Independent-But-Not-Along-final.pdf> [<https://perma.cc/9EC6-NK8U>] (last visited Feb. 25, 2018).

368. *RESTORING VOICE*, *supra* note 44, at 218. (“Research is instigated by the voice of people with disabilities and the disability community calling for change in a particular area.”).

369. *INDEPENDENT BUT NOT ALONE*, *supra* note 367, at xv.

370. *Id.* at 6.

371. *Id.*

372. Another example of such “co-produced” research was the evaluation of the 2011 pilot project of the South Australian Office of the Public Advocate. *See ACCESS TO JUSTICE FOR PERSONS WITH INTELLECTUAL DISABILITIES, GUIDE OF PROMISING PRACTICES 23–24* (2015) http://www.ajupid.eu/images/documents/promising_practices/BAG_AJUPID_UK_2015_BV.pdf [<https://perma.cc/7T5X-Z8WV>]. The research “included people with the lived experience of disability . . . [and] the inclusion of people with disabilities in the design, monitoring

forward, we should be mindful of, and inspired by, their active participation.

F. American Exceptionalism

Readers of this journal will be familiar with the concept of "American exceptionalism," which, though defined in many ways,³⁷³ most often encompasses U.S. hostility toward domestic adoption of international law and, in particular, human rights treaties.³⁷⁴ American exceptionalism is reflected in an unwillingness by Congress to ratify human rights conventions or, if ratification occurs, to drastically limit their use by attaching to them non-self executing (NSE) declarations.³⁷⁵ American exceptionalism "is very much a part of the prevailing national narrative"³⁷⁶ and "strongly resonates with public sentiment . . . that U.S. law is so widely different from law elsewhere in the world that any use of foreign or international sources and legal education risks corrupting U.S. justice and is a betrayal of fundamental U.S. legal values."³⁷⁷

At the same time that this anti-internationalist sentiment almost certainly precludes ratification of the CRPD or other previously-signed human rights treaties,³⁷⁸ there is a modest trend by American judges toward using human rights and human rights

and implementation of the project was . . . in keeping with the directives for participation of people with disabilities under the UNCRPD." *Id.*

373. See, e.g., Koh, *On American Exceptionalism*, *supra* note 45, at 1483 (noting "four somewhat different faces of American exceptionalism" which he ranks "in order of ascending opprobrium" as "distinctive rights, different labels, the 'flying buttress mentality', and double standards").

374. See, e.g., Soo Jee Lee, *Note: A Child's Voice vs. a Parent's Control: Resolving a Tension Between the Convention on the Rights of the Child and U.S. Law*, 117 COLUM. L. REV. 687, 698 (2017) (noting that the United States has not adopted Article 12 from the U.N. Convention on the Rights of the Child).

375. See generally David Sloss, *The Domestication of International Human Rights: Non-Self-Executing Declarations and Human Rights Treaties*, 24 YALE J. INT'L L. 129 (1999) (delineating how the United States adopts and ratifies international treaties).

376. Mark C. Rahdert, *Exceptionalism Unbound: Appraising American Resistance to Foreign Law*, 65 CATH. U. L. REV. 537, 548 (2016).

377. *Id.*

378. These include the Convention on the Rights of the Child and the Convention to End All Discrimination Against Women (CEDAW).

documents for their “interpretive value” in explaining domestic law.³⁷⁹ One author writes of “a typology of interpretive techniques that courts are utilizing [in] incorporating human rights treaties into their work . . . [that includes] the use of treaties to gild the domestic lily.”³⁸⁰ “Gilding the lily” is a catchphrase used to describe judicial “add-ons” of references to human rights treaties to bolster a court’s already-adopted interpretation of a statute or Constitutional provision.³⁸¹ It is the primary way through which human rights instruments and principles have been mentioned in U.S. case law. Some of the best-known examples have occurred in the context of Supreme Court death penalty jurisprudence. For instance, in *Thompson v. Oklahoma*,³⁸² the Court referred to the International Covenant on Civil and Political Rights (ICCPR)³⁸³ even though, at the time, the United States had not ratified the treaty;³⁸⁴ and, in *Roper v. Simmons*,³⁸⁵ the Court cited both the ICCPR and the Convention on the Rights of the Child.³⁸⁶ Additionally, Justice Ruth Bader Ginsberg famously cited the Convention to End Racial Discrimination in her concurring opinion in *Grutter v. Bollinger*.³⁸⁷

379. *But see* Koh, *On American Exceptionalism*, *supra* note 45, at 1482 (discussing “judicial exceptionalism” and quoting Justice Scalia’s scathing critique in *Stanford v. Kentucky*).

380. Melissa A. Waters, *Creeping Monism: The Judicial Trend Toward Interpretive Incorporation of Human Rights Treaties*, 107 COLUM. L. REV. 628, 653 (2007). The examples provided by the author are all courts in countries other than the United States.

381. *Id.* at 654–59 (discussing the use of the “gilding the lily” technique in statutory interpretation).

382. *Thompson v. Oklahoma*, 487 U.S. 815 (1988) (prohibiting execution of a sixteen-year-old based on the Eighth Amendment’s bar on cruel and unusual punishment).

383. *Id.* at 831; International Covenant on Civil and Political Rights, *opened for signature* Dec. 16, 1996, 999 U.N.T.S. 171, (entered into force Mar. 23, 1976) [hereinafter ICCPR], <https://treaties.un.org/doc/publication/unts/volume%20999/volume-999-i-14668-english.pdf> [<https://perma.cc/TA8M-G98H>].

384. The United States ratified the ICCPR, with RUDS, on June 8, 1992. *See* U.N., U.N. TREATY COLLECTION, INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS, https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-4&chapter=4&lang=en [<https://perma.cc/AB2J-CVPU>] (last visited Feb. 11, 2018).

385. *Roper v. Simmons*, 543 U.S. 551 (2005) (holding that the Eighth Amendment prohibits execution of a defendant who was under eighteen at the time the crime was committed).

386. *Id.* at 567, 576.

387. *Grutter v. Bollinger*, 539 U.S. 306, 344 (2003).

State courts have also utilized human rights instruments to interpret their own constitutions.³⁸⁸ The retired Chief Judge of the Massachusetts Supreme Judicial Court, Margaret H. Marshall, has been quoted as arguing that state court judges are

“uniquely positioned to take advantage of the significant potential of comparative constitutional law” because of their expertise in drawing on the comparative experience of other American jurisdictions, their continued work “in the open tradition of the common law,” and their role as interpreters of ‘positive liberty clauses’ that have parallels in the new constitutions of other democracies.³⁸⁹

In a less hopeful mode, however, surveys have shown that, overall, state court references to human rights treaties have been few and far between.³⁹⁰

State courts may, nonetheless, present real opportunities for introducing human rights and human rights discourse into more mundane and real-life situations, precisely where the right of legal capacity arises. Johanna Kalb has noted with some optimism that “it

388. See, e.g., *In re Marriage Cases*, 183 P.3d 384, 426 n.41 (Cal. 2008) (referring to the ICCPR in deciding same-sex marriage cases and holding against differential treatment against same-sex couples wanting to get married); *Sterling v. Cupp*, 625 P.2d 123, 132 (Or. 1981) (en banc) (citing to international human rights instruments, including the U.N. Charter, UDCHR, and ICCPR in deciding that body searches for male prisoners should only be done for necessity); *Boehm v. Superior Court*, 223 Cal. Rptr. 716, 721 (Cal. Ct. App. 1986) (citing the UDHR and noting the “dignity” right to discuss state’s obligations to provide adequate subsistence allowances for clothing, transportation, and medical care to the poor); Anna Maria Gabrielidis, *Human Rights Begin at Home: A Policy Analysis on Litigating International Human Rights in U.S. State Courts*, 12 BUFF. HUM. RTS. L. REV. 139, 1, 45 (2006) (arguing that human rights litigation can be most effective in state courts).

389. Johanna Kalb, *Human Rights Treaties in State Courts: The International Prospects of State Constitutions After Medellin*, 115 PENN ST. L. REV. 1051, 1060–61 (2011) (quoting Margaret H. Marshall, “Wise Parents Do Not Hesitate to Learn from their Children”: *Interpreting State Constitutions in an Age of Global Jurisprudence*, 79 N.Y.U. L. Rev. 1633, 1641–43 (2004)). Kalb notes Justice Marshall’s use of this approach in the Massachusetts marriage equality case, *Goodridge v. Dep’t of Pub. Health*, 798 N.E.2d 941 (Mass. 2003). *Id.*

390. David Kaye, *State Execution of the International Covenant on Civil and Political Rights*, 3. U.C. IRVINE L. REV. 95, 112 (2013) (stating that as of June 2010, state courts mentioned one of the eight main leading human rights treaties only 187 times).

is not just the most high-profile and politically charged cases where international human rights law has been valuable,³⁹¹ citing two trial court decisions in New York relying on the CRC and the CRPD respectively.³⁹² She has also written about the importance of “receptive judges.”³⁹³

II. LESSONS FROM OTHER COUNTRIES

There is much to be learned from other countries’ efforts to bring their laws, practices, or service provisions into compliance with Article 12, although none have yet been entirely successful in passing legal capacity legislation.³⁹⁴ Pilot projects in the Czech Republic³⁹⁵ and Latvia³⁹⁶ have demonstrated that, with adequate and appropriate

391. Kalb, *supra* note 389, at 1059–60.

392. *Id.*

393. *Id.* at 1060–63. This brings to mind a personal experience that suggests the potential of a promising way forward. In October 2003, the National Association of Women Judges (NAWJ), of which I am a member, devoted a day of its annual conference to “the impact of international human rights in domestic U.S. courts.” Documents from Nat’l Ass’n of Women Judges, Annual Conference, Washington, D.C., (Oct. 8–12, 2003) (on file with author). NAWJ membership includes judges of all kinds, from administrative agencies and traffic courts to tribal courts and the highest state and federal appellate courts, including the U.S. Supreme Court. *About NAWJ, NAT’L ASS’N WOMEN JUDGES*, <https://www.nawj.org/about-nawj> [<https://perma.cc/U2W9-AK94>] (last visited Feb. 11, 2018). The membership also includes all political persuasions. The program was partially organized by the late Rhonda Copelon and was enthusiastically received by the more than 400 judges in attendance. See Christina D. Silva, *Outstanding 2003 Annual Conference Sets Stride for Next 25 Years of NAWJ*, 25.1 COUNTERBALANCE 1, 1 (Winter 2004), https://www.nawj.org/uploads/files/counterbalance/cb25_1.pdf [<https://perma.cc/Q72D-PNHG>]. At its conclusion, an informal survey was taken as to whether the judges in attendance were interested in or willing to use what they had learned in their own courts. While I do not recall the exact figures, I remember that well over half of the judges in attendance raised their hands to demonstrate willingness to consider using human rights norms in their decisions. Most of the remaining judges indicated enthusiasm about learning more. However, there was no meaningful follow-up, so it is unclear if any of the hoped-for results that the straw poll suggested actually materialized.

394. See MHE REPORT, *supra* note 166, at 13–18.

395. For a description of the pilot project in the Czech Republic, denominated the “Black and White Project,” see *Black and White*, QUIP, <http://www.kvalitavpraxi.cz/en/projects/current-projects/black-and-white/> [<https://perma.cc/S6TH-9Q7N>]. (last visited Feb. 11, 2018).

396. For a description of the pilot project in Latvia, see *RC Zelda Has Published “Handbook: First Steps in Implementation of Supported Decision Making in Latvia*, ZELDA (Apr. 26, 2016), <http://zelda.org.lv/en/news/rc-zelda-has->

supports, people with I/DD, and a smaller number with psychosocial disabilities, can make their own decisions and exercise legal capacity. Israel has had similar results in a pilot using trained volunteer supporters for decisions about finances and, using that experience, has enacted legislation codifying SDM as an alternative to guardianship.³⁹⁷ As a country with a federal system that ratified the CRPD (albeit with RUDs), Australia now has the varied experiences of pilot projects from five different states.³⁹⁸ Thoughtful studies and prescriptions have been prepared and disseminated.³⁹⁹

I have been privileged to visit a number of the pilot projects and to have met and continued conversations with many of the lawyers and activists in NGOs committed to advancing the right of legal capacity. For the purpose of this Article, I focus on two countries, Canada and Bulgaria, because of the length and depth of experience of

published-handbook-first-steps-in-implementation-of-supported-decision-making-in-latvia-2-2446 [https://perma.cc/428C-EZB8].

397. Suzanne Cannon, *Supported Decision-Making Law Approved by the Knesset*, BIZCHUT (Apr. 4, 2016), <http://bizchut.org.il/en/576> [https://perma.cc/UR4X-DLQK]; Dana Dimant, *My Son Will Have a Normal Life, Starting Now*, HA-MAKOM (Mar. 4, 2016), <https://www.ha-makom.co.il/post/dana-dimant-custody-english> [https://perma.cc/86C4-6ATM].

398. Carney, *Operationalizing*, *supra* note 222, at 47–49 (describing pilot programs in South Australia, the Australian Capital Territory, New South Wales, and Victoria); *see also Supported Decision Making*, OFFICE OF THE PUB. ADVOCATE, http://www.opa.sa.gov.au/resources/supported_decision_making [https://perma.cc/3TPP-XBU5] (last visited Feb. 25, 2018) (describing South Australia's two-year trial from 2010–2012 called the Supported Decision Making Project); *Respect Know Act (RKA)*, ADACAS ADVOCACY, <http://www.adacas.org.au/supported-decision-making/supported-decision-making/> [https://perma.cc/HE5Y-NDQE] (last visited Feb. 25, 2018) (ACT Disability, Aged and Care Service in preparation for the National Disability Insurance Scheme roll out); *Supported Decision Making Projects*, NEW S. WALES FAMILY & CMTY. SERVS., https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making/sdm-projects [https://perma.cc/454J-FW46] (describing a New South Wales government agency and Public Guardian project on financial decision-making, "covering ageing, disability and home care clients"); and *Supported Decision Making*, VICTORIA OFFICE OF THE PUB. ADVOCATE, <http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making> [https://perma.cc/FB7Y-VRSP] (showing how the Victoria Office of the Public Guardian focused on isolated persons who lacked natural supports).

399. *See, e.g., INDEPENDENT BUT NOT ALONE*, *supra* note 367; MENTAL DISABILITY ADVOCACY CTR., *SUPPORTED DECISION-MAKING: AN ALTERNATIVE TO GUARDIANSHIP*, https://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/MDAC.authcheckdam.PDF [https://perma.cc/JQ2C-3CD2] (last visited Feb. 25, 2018).

advocates there, and what can be learned from the notably different contexts and strategies that each group has pursued.

A. Contributions from Canada and Bulgaria

1. Canada

The disability rights movement for persons with I/DD in Canada has probably been working towards the “human right” of legal capacity longer than anywhere else.⁴⁰⁰ It “officially” began in 1991 at the inaugural national meeting of self-advocates, People First of Canada,⁴⁰¹ with an initial demand for the right of people to make their own decisions and to be free of guardianship.⁴⁰² Though there had been a 1982 judicial decision upholding the right of an individual with an intellectual disability to make her or his own decisions,⁴⁰³ earlier

400. See Tim Stainton, *Supported Decision-Making in Canada: Principles, Policy and Practice*, 3 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 8 (2015); Ravi Malhotra, *The United Nations Convention on the Rights of Persons with Disabilities in Canadian and American Jurisprudence*, 32 WINDSOR Y.B. ACCESS JUST. 1, 2 (2015) (noting the “history of disability rights in Canada has always been influenced by international developments, since at least the 1970’s”).

401. Glen, *Changing Paradigms*, *supra* note 54, at 146 n.235.

402. Resolution adopted at the founding convention of People First of Canada, Saint John, New Brunswick, April 7, 1991 (“Because guardianship and orders of supervision take away the rights of individuals: therefore be it resolved that People First of Canada oppose all legislation putting people under these acts.”); see also Michael Bach & Lana Kerzner, *History and Context of Legislative Provisions in Ontario Challenging Guardianship* 24 (unpublished manuscript) (on file with author) [hereinafter Bach & Kerzner, *History and Context*] (recounting the adoption of People First of Canada’s first resolution).

403. *Clark v. Clark*, (1983), 40 O.R. 2d 383 (Can. Ont. Matheson. Co. Ct. J.) <https://www.canlii.org/en/on/onsc/doc/1982/1982canlii2253/1982canlii2253.html?resultindex=4> [<https://perma.cc/YJL3-7EWF>]. The case involved a young man with cerebral palsy and severe physical impairments who wanted to leave the institution in which he had been confined since the age of two. In denying his father’s petition for guardianship on the basis of “mental incompetency” the court wrote that “respondent’s obvious physical and severe physical disability was irrelevant to a determination of his mental competency . . . [he] was able to communicate effectively, was fully aware of his surroundings, and knew what he wanted.” *Id.* at 383.

reforms in guardianship law had followed essentially the same timeline⁴⁰⁴ as law in the United States.⁴⁰⁵

People First's demand for an end to guardianship was soon taken up by the Canadian Association for Community Living (CACL),⁴⁰⁶ which, in 1991, appointed a "National Task Force on Alternatives to Guardianship." This "National Task Force" originally demanded meaningful alternatives to guardianship, with the supports necessary to enable them, but its work ultimately led to the proposal of a right to legal capacity.⁴⁰⁷ At the same time, research growing out of the movement for deinstitutionalization confirmed that people with substantial disabilities could make decisions with support,⁴⁰⁸ resulting in legislation⁴⁰⁹ adopting various forms of supported and co-decision-

404. See generally Sarah Birmingham, *Developments in Canadian Adult Guardianship and Decision Making Law*, 18 DALHOUSIE J. LEGAL STUD. 119, 130–32 (2008) (describing the development of adult guardianship and co-decisional law in Canada). One exception was Alberta, which adopted a functional capacity and due process model in 1976. *Id.*

405. See Glen, *Changing Paradigms*, *supra* note 54, at 98 (discussing the movement toward guardianship statutes with greater procedural protections and the possibility of, or preference for, tailoring of the guardian's powers).

406. CACL is a family-led organization that advocates for the right of inclusion for Canadians with intellectual and developmental disabilities. See *About Us*, CANADIAN ASS'N FOR CMTY. LIVING, www.cacl.ca/about-us [<https://perma.cc/9JFQ-XMJJ>] (last visited Feb. 10, 2018).

407. See Michael Bach, *Bidding Farewell to CACL-As I Embark on a New Role with IRIS*, CANADIAN ASS'N FOR CMTY. LIVING (Mar. 17, 2017), <http://cacl.ca/news-stories/blog/bidding-farewell-cacl-as-i-embark-new-role-iris> [<https://perma.cc/MZU7-UH7F>] [hereinafter Bach, *Bidding Farewell*]. Speaking of work on the CRPD, Bach wrote, "We secured recognition of a right of legal capacity and support for decision making (rooted in CACL's original proposals from its 1991 'Alternatives to Guardianship' Task Force)." *Id.*

408. Bach & Kerzner, *History and Context*, *supra* note 402, at 25–27 (discussing studies from British Columbia that showed "how people with substantial intellectual disabilities were being supported to guide decision making by their personal support networks").

409. Browning et al., *Supported Decision Making*, *supra* note 115, at 35.

making⁴¹⁰ in several provinces,⁴¹¹ including the oft-cited⁴¹² British Columbia Representation Agreement Act⁴¹³ in 1996.⁴¹⁴ Over time the movement for recognition of supports in decision-making moved to a more explicitly human-rights-based emphasis on legal capacity.⁴¹⁵ As part of that movement, People First and CACL played a major role in negotiations leading up to the CRPD and the clear enunciation of legal capacity in Article 12.⁴¹⁶

410. See The Adult Guardianship and Co-Decision-Making Act, S.S.2000, c. A-5.3 (Can.) (providing for a co-decision-maker who assists the person who is the subject of the proceeding in making decisions, but who shares decision-making authority). While the co-decision-maker must generally accede to the person's decision, she need not if no reasonable person would have made the decision, or if harm or loss is likely to occur. *Id.* §§ 17, 42. Unfortunately, it appears that, despite provisions meant to limit guardianship and promote autonomy, the vast majority of orders made under the Act result in plenary guardianships. See Doug Surtees, *The Evolution of Co-Decision-Making in Saskatchewan*, 73 SASK. L. REV. 75, 91–92 (2012) (describing review of all accessible files between adoption of the Act and 2012, and finding that 93.27 percent of applications were for guardianship and only 6.73 percent involved co-decision-making).

411. See Glen, *Changing Paradigms*, *supra* note 54, at 145–53. It is worth noting that none of the legislation is couched in the language of legal capacity, and while each includes provisions for support, and provides an alternative to guardianship, substitute decision-making remains as a significant default position.

412. The Representation Agreement Act is cited in virtually every discussion of SDM. See, e.g., RESTORING VOICE, *supra* note 44, at 204–05 (citing and discussing the Representation Agreement Act); Dinerstein et al., *Emerging Int'l Trends*, *supra* note 19, at 442–43.

413. Representation Agreement Act, R.S.B.C., 1996, c 405 (Can.).

414. The most significant aspect of that law, for purposes of the human right of legal capacity, is that, in order to make a valid representation agreement, a person need not have the mental/cognitive capacity necessary to make a valid contract or manage her or his personal or financial affairs. *Id.* § 8(1). The following section, 8(2), has been described as even more important in permitting persons with a wide range of intellectual disabilities to execute representation agreements as, in describing the incapability (notably not *incapacity*) that would preclude a valid agreement, it omits any mention of the “understand and appreciate” test so familiar in most cognitively-based capacity assessments. E-mail between Lana Kerzner and author (Sept. 23, 2017) (on file with author).

415. See, e.g., *Position on Legal Capacity*, CANADIAN ASS'N FOR CMTY. LIVING 1 (June 2010), http://www.cacl.ca/sites/default/files/CACL%20Policy%20Position%20legal%20capacity_0.pdf [<https://perma.cc/935A-79NR>] (stating that “[a]dults with intellectual disabilities must have their legal capacity . . . recognized and supported”).

416. Bach, *Bidding Farewell*, *supra* note 407 (“Our Canadian team, and the knowledge and examples we brought to the negotiating floor of the UN in New York

Canada signed the Convention in 2007 and ratified it in 2010,⁴¹⁷ albeit with a Declaration and Reservation that stated, in pertinent part, that although Canadian law presumed legal capacity, “to the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards.”⁴¹⁸ Besides the limitations expressed in the Declaration and Reservation, Canada has also failed to pass enabling legislation required to implement the Convention under Canadian law.⁴¹⁹ This is the result, in large part, of the fact that most of Canada’s obligations under the CRPD fall within provincial and territorial law.⁴²⁰

Despite this failure, CACL and its research arm, the Institute for Research and Development in Inclusion and Society (IRIS),⁴²¹ continued to advocate explicitly for the human right of legal capacity. Perhaps most notable was the critically important paper authored by Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and*

helped make major breakthroughs . . . secur[ing] recognition of a right of legal capacity . . .”).

417. BACH & KERZNER, A NEW PARADIGM, *supra* note 42, at 27.

418. *Id.* at 29. The Declaration and Reservation also placed limits on the review process of Article 12(4), stating, “Canada reserves the right not to subject [any safeguards] to regular review by an independent authority, where such measures are already subject to review or appeal.” *Id.*

419. Hoffman et al., *Canada Case Study*, *supra* note 165, at 8 (“[F]ull implementation [of the CRPD] is perhaps most acutely hindered by Canada’s reservations to Article 12 of the Convention.”).

420. *Id.* at 10; see Lana Kerzner, *Paving the Way to Full Realization of the CRPD’s Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective*, in IN FROM THE MARGINS: NEW FOUNDATIONS FOR PERSONHOOD AND LEGAL CAPACITY IN THE 21ST CENTURY 22 (April, 2011), http://cic.arts.ubc.ca/files/2014/07/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf [<https://perma.cc/5EJZ-UEVH>] (last visited Feb. 10, 2018) (“[B]ased on the current state of provincial/territorial capacity legislation, despite ratification, Article 12 does not appear to be domestically implemented.”). See *id.* at 17–28 for a fuller discussion of Canada’s domestic law implications of ratifying the CRPD, and U.N. treaties generally.

421. In 2016, IRIS became a separate, independent organization, with Michael Bach as its director. See *About*, IRIS INST., www.irisinstitute.ca/about [<https://perma.cc/CHT6-4BEM>] (last visited Feb. 10, 2018); *Staff and Associates*, INSTS. RES. & DEV. INCLUSION & SOC’Y, <http://irisinstitute.ca/about/our-staff/> [<https://perma.cc/KY5K-FK2T>] (last visited Feb. 10, 2018).

Practice,⁴²² submitted in response to a request for papers issued by the Law Commission of Ontario (LCO)⁴²³ as part of LCO's project on reform to laws relating to persons with disabilities.⁴²⁴ The initial project did not focus on intellectual disabilities, but receipt of the Bach and Kerzner paper was a factor prompting the LCO to engage in a new project—Legal Capacity, Decision-Making and Guardianship—that continued through 2017.⁴²⁵ The project, the most extensive ever conducted by LCO, included an expert Advisory Council, commissioned papers, formed thirty focus groups and, in all, initiated contacts with over 800 people and organizations.⁴²⁶

During that same period, CACL developed a “Statutory Framework for the Right of Legal Capacity and Supported Decision Making”⁴²⁷ including a “Sample Statutory Text.”⁴²⁸ This thoughtfully crafted and comprehensive model legislation anticipates many of the issues that skeptics or opponents may raise.⁴²⁹ Nevertheless, although

422. BACH & KERZNER, A NEW PARADIGM, *supra* note 42.

423. The LCO is a well-funded law reform and legal policy organization which, although located in Ontario and directed toward Ontario's laws, has an outsized influence throughout Canada. LAW COMM'N OF ONT., <https://www.lco-cdo.org/en/> [<https://perma.cc/PC5S-JQX6>] (last visited Feb. 20, 2018).

424. There was a simultaneous project on laws relating to older persons. *See infra* note 435 and accompanying text.

425. E-mail from Lana Kerzner, co-author of A NEW PARADIGM, *supra* note 42, to author (on file with author).

426. *See Legal Capacity, Decision-making and Guardianship*, LAW COMM'N OF ONT., <https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/> [<https://perma.cc/3QQZ-U4V5>]. (last visited Feb. 20, 2018).

427. That model has proved influential in other countries where there have been efforts to bring laws into compliance with Article 12 as, for example, Bulgaria, where Bach and Kerzner have been involved with BCNL. *See infra* Section II.A.2.

428. CANADIAN ASS'N FOR CMTY. LIVING, A STATUTORY FRAMEWORK FOR THE RIGHT TO LEGAL CAPACITY AND SUPPORTED DECISION MAKING: FOR APPLICATION IN PROVINCIAL/TERRITORIAL JURISDICTIONS IN CANADA 2 (2014). The framework identified “starting points—key assumptions that need to be addressed in law reform,” and essential elements “to promote . . . legal capacity and access to needed supports.” The sample statutory text was intended as an example of how those elements could be drafted into a statute. *Id.*

429. For example, given the risk of neglect and abuse, the framework calls for the appointment of independent monitors “to ensure the decision-making process with and around the adult [with I/DD] maintains integrity in accordance with the purpose and principles of the legislation.” *Id.* at 10. It also calls for the relevant provincial government to establish a “fixed point” to deal with the multiple issues necessary to enable legal capacity, including provision of supports, and

promoted by CACL and its chapters in a number of provinces,⁴³⁰ the sample legislation has floundered, primarily over dispute as to whether some people are simply so impaired that they cannot be understood as having legal capacity.⁴³¹

This is the "hard case" scenario previously discussed.⁴³² In Canada, it has played out in particular as a question of whether a person whose "decision" is based solely on a supporter's interpretation of "will and preference" can be held legally responsible for a decision that person may not have understood.⁴³³

The same issue arose in the LCO's multi-year project. At the end of the process, despite extensive efforts by the Coalition on Alternatives to Guardianship,⁴³⁴ LCO rejected the position of the General Comment.⁴³⁵ In its Final Report, the LCO took a "moderate" position,⁴³⁶ retaining capacity assessments and permitting the continuation of substitute decision-making (guardianship) for a "limited" class of persons with severe impairments⁴³⁷ because, "[there must be] some assessment of decisional abilities . . . to determine issues of accountability and enforceability."⁴³⁸ Bach has criticized the LCO's

requires Adult Protective Services to interact with that focal point in responding to possible abuse and exploitation. *Id.* at 12–13.

430. See, e.g., Hoffman et al., *Canada Case Study*, *supra* note 165, at 9 (noting efforts in Newfoundland and Labrador, and Prince Edward Island).

431. See, e.g., Press Release, Canadian Ass'n for Cmty. Living, Nova Scotia Heading to Reject Charter Rights of People with Disabilities (Oct. 17, 2017), <http://www.cacl.ca/news-stories/blog/press-release-nova-scotia-heading-reject-charter-rights-people-disabilities> [<https://perma.cc/8Q4Y-XH99>] (last visited Apr. 2, 2018) (discussing the defeat of proposed legal capacity legislation proposed, in part, by CACL and its Nova Scotia affiliate).

432. See *supra* Section I.A.1.

433. E-mail from Lana Kerzner, co-author of A NEW PARADIGM, *supra* note 42, to author (on file with author).

434. The Coalition was made up of People First Ontario, People First Canada, Community Living Ontario and CACL. It submitted a lengthy brief, and offered expert testimony on the requirements of the CRPD from recognized international human rights experts, which was ultimately rejected by the LCO. *Id.*

435. LAW COMM'N OF ONT., LEGAL CAPACITY, DECISION-MAKING AND GUARDIANSHIP: FINAL REPORT 84–87 (March 2017), <http://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/final-report/> [<https://perma.cc/6S6Z-M7B7>] [hereinafter LCO, FINAL REPORT].

436. *Id.*

437. "The LCO . . . believes that there are circumstances where it is appropriate to find that an individual does not have the decision-making ability to make a particular decision or type of decision independently." *Id.* at 84.

438. *Id.*

Final Report, stating, “the very idea that cognitive ability should no longer be the defining feature of what it means to be a full citizen appears to strike too close to the heart of the dominant account of human agency, at least for some of its most powerful defenders.”⁴³⁹

The LCO’s Final Report appears already to have had an impact well beyond Ontario. Advocates had been optimistic about the possibility of a CRPD-compliant statute in Nova Scotia,⁴⁴⁰ especially after that province’s existing guardianship law, the Incompetent Persons Act,⁴⁴¹ was held to violate the Canadian Charter of Rights and Freedom (the Charter) by the Supreme Court of Nova Scotia.⁴⁴² After the LCO Report, the Law Amendments Committee of the Nova Scotia Legislature rolled out its draft “Adult Capacity and Decision Making Act.” Although it contained several progressive provisions,⁴⁴³ the new Act retained substitute decision-making by a court-appointed “representative” for those deemed to lack “capacity,” as determined, in part, by a “capacity assessment.”⁴⁴⁴ Despite last minute efforts by

439. Bach, *Inclusive Citizenship*, *supra* note 59, at 14.

440. E-mail from Michael Bach to author (Nov. 13, 2017). Bach is one of the preeminent theorists of legal capacity. In 2014, the Nova Scotia Government had made commitments that were widely supported by the community. *Protecting Autonomy and the Rights to Security and Liberty of the Person for All: Submission on Bill 16 – Adult Capacity and Decision Making Act 1 to the Law Amendments Committee* (2017) (submission of Nova Scotia Ass’n for Cmty. Living, Canadian Ass’n for Cmty. Living, and IRIS) (copy on file with author) [hereinafter *Protecting Autonomy*].

441. Incompetent Persons Act, R.N.S. 1989 c. 218 (Can.), as amended. The Court described the Act as “an all or nothing approach [that] allows for no nuance.” *Webb v. Webb*, 2016 NSSC 180, 6.

442. As the Court noted, “the Attorney General of Nova Scotia has agreed that sections of the *Incompetent Persons Act* are unconstitutional . . . [and] maintains that it will take a year for new legislation to be prepared and made into law . . . [so that] a declaration of invalidity . . . would be issued, but will be suspended for one year.” *Id.* at 182.

443. For example, the proposed bill provided that a person might meet the test of capacity “with or without support.” Adult Capacity and Decision-making Act, Sec. 3(d), 63rd Gen. Assemb., Reg. Sess. (as introduced N.S. 2017), and that one outcome of a capacity assessment would be to indicate “what forms of support or assistance, if any, would help the adult to manage the adult’s needs successfully . . . without the need for a representative for the adult being appointed,” Adult Capacity and Decision-making Act, Sec. 18 (c), 63rd Gen. Assemb., Reg. Sess. (as introduced N.S. 2017).

444. Such assessment is prohibited by the General Comment’s interpretation of Article 12. General Comment No. 1, *supra* note 9, ¶ 13.

advocates,⁴⁴⁵ the bill was finalized and received Royal Assent on October 26, 2017.⁴⁴⁶

Also, shortly after issuance of LCO's Final Report, the CRPD Committee issued its Concluding Observations on the initial report submitted by Canada.⁴⁴⁷ As it wrote in its "Principal areas of concern and recommendations,"

[t]he Committee recommends that the State party withdraw its declaration and reservation to Article 12(4) of the Convention and carry out a process to bring into line with the Convention federal, provincial and territorial legislation that allows for the deprivation of legal capacity of persons with disabilities. The Committee encourages the State party, in doing so, to consider the criteria set out in the Committee's general comment No. 1 (2014) on equal recognition before the law.⁴⁴⁸

Given its Declaration and Reservation, it is, at best, an open question whether the Canadian federal government will take any action in response to the Concluding Observations.⁴⁴⁹ Nor is it likely that the CRPD Committee's action will change the result of the LCO

445. See *Protecting Autonomy*, *supra* note 440. Representatives of People First also testified movingly before the Committee. E-mail from Michael Bach to author (Nov. 13, 2017) (on file with author).

446. Adult Capacity and Decision-making Act, S.N.S. 2017, c. 4 (Can.). The bill took effect on December 28, 2017.

447. Comm. on the Rights of Pers. with Disabilities, Concluding Observations on the Initial Report of Canada, U.N. Doc. CRPD/C/CAN/CO/1 (May 8, 2017).

448. *Id.* ¶ 8. In its section on "Specific Rights," the Committee recommended, as to Article 12, that Canada, "in consultation with organizations of persons with disabilities and other service providers, take leadership in collaborating with provinces and territories to create a consistent framework for recognizing legal capacity and to enable access to the support needed to exercise legal capacity." *Id.* ¶ 28.

449. One possibly promising development was attention to the issue at the Eighth Annual Policy Forum on Inclusion: Realization of the Right to Legal Capacity for Persons with Intellectual Disabilities in Canada, co-sponsored by the Office for Disability Issues, Employment and Social Development Canada (a federal agency). See *Eighth Annual Federal Policy Forum on Inclusion: Realization of the Right to Legal Capacity for Persons with Intellectual Disabilities in Canada*, CANADIAN ASS'N FOR CMTY. LIVING (Nov. 20, 2017), <http://www.cacl.ca/news-stories/blog/8th-annual-federal-policy-forum-inclusion-realization-right-legal-capacity-persons> [<https://perma.cc/DE2B-UWGA>].

report.⁴⁵⁰ Advocates will, however, continue their work to abolish substitute decision-making.⁴⁵¹ Michael Bach has recently written that, regardless of these setbacks, “advocates’ responses to [LCO’s] rejection of a more inclusive framework for the right to legal capacity suggest the contest is far from over.”⁴⁵² Further, as other commentators have observed, “the success of civil society organizations in raising the political prioritization of [CRPD] rights in Canada has promising implications for developments in the future.”⁴⁵³

2. Bulgaria

Although Bulgaria signed the CRPD in September 2007,⁴⁵⁴ there was little inclination to ratify until an imaginative campaign by a lawyer-led NGO,⁴⁵⁵ the Bulgarian Center for Not for Profit Law (BCNL).⁴⁵⁶ The Convention was finally ratified in 2012,⁴⁵⁷ shortly after

450. In its Final Report, the LCO states pointedly that “[n]either the *General Comment* nor the *Declaration and Reservation* determines the LCO’s potential recommendations Given the non-binding nature of a *General Comment* . . . neither the government of Canada nor Ontario is clearly bound to carry out the program of reform set out [there].” LCO, FINAL REPORT, *supra* note 435, at 68.

451. For example, under the “Our Work” section of its website, IRIS stated that, as of February 17, 2018, it is working on a new initiative for 2017–18 “to design and support a consultation to identify key issues and options for supported decision making in Newfoundland and Labrador.” *Our Work*, INSTS. RES. & DEVELOPMENTAL INCLUSION & SOC’Y, <http://irisinstitute.ca/our-work/> [<https://perma.cc/7XEM-Y5R8>].

452. Bach, *Inclusive Citizenship*, *supra* note 59, at 14.

453. Hoffman et al., *Canada Case Study*, *supra* note 165, at 12.

454. Convention on the Rights of Persons with Disabilities, List of Parties, Dec. 13, 2006, 2515 U.N.T.S. 3.

455. The campaign involved the creation of postcards that were widely distributed throughout the country, and which were then mailed to the Government, prompting it finally to act. Kristin Booth Glen, *Kris and Marieta re Bulgarian pilot June 14, 2017*, SUPPORTED DECISION-MAKING N.Y. (June 14, 2017) [hereinafter Dimitrova Interview], <https://vimeo.com/232540225> [<https://perma.cc/5EH5-UG58>].

456. BCNL began in 2001 and is an affiliate of the International Center for Not-for-Profit Law. It has dealt with a number of issues, including enhancing the development of civil society and civic participation. *About Us*, BULG. CTR. FOR NOT-FOR-PROFIT LAW, <http://bcnl.org/en/about-us.html> [<https://perma.cc/64JA-QM7P>] (last visited Feb. 17, 2018).

457. On January 26, 2012, the Bulgarian General Assembly adopted a law (prom. SG issue 37/2012), ratifying the Convention. Virginia Micheva-Ruseva, *Untitled Introduction by the Deputy Minister of Justice*, in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 8–9 (2015).

the European Court of Human Rights (ECHR) decided the case of *Stanev v. Bulgaria*.⁴⁵⁸ *Stanev* involved a man who was placed under guardianship and involuntarily committed to an institution where he remained, in degrading and inhumane conditions, for seven years, before his case was litigated by another NGO, Validity (formerly known as Mental Disability Advocacy Centre).⁴⁵⁹ Although the decision in *Stanev* did not refer to the right of legal capacity,⁴⁶⁰ it brought considerable public attention to the situation of persons with IDD and the guardianship regime in Bulgaria.⁴⁶¹

BCNL had been working with a number of disability-based groups on social protection issues, and, in the course of promoting CRPD ratification, decided to launch a major initiative to bring the right of legal capacity into Bulgarian law.⁴⁶² As a formal matter, they had the advantage of a provision in the Bulgarian Constitution that

458. Grand Chamber, European Court of Human Rights Jan. 17, 2012; 2012 ECHR 46 (Application no. 36706/06). The decision is reprinted in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 52–58.

459. See *A Tribute to Rusi Stanev*, VALIDITY (Mar. 9, 2017), <http://validity.ngo/a-tribute-to-rusi-stanev/> [https://perma.cc/39U4-J3WQ] [hereinafter *A Tribute to Rusi Stanev*]. Validity is an NGO working to advance the rights of persons with intellectual disabilities and mental health issues through strategic litigation, advocacy, research and monitoring, and capacity building. *Who We Are*, VALIDITY, <http://validity.ngo/who-we-are/> [https://perma.cc/H9AZ-CAB8] (last visited Feb. 17, 2018).

460. The Court found that, in violation of international human rights principles, the conditions of Stanev's confinement amounted to "degrading treatment" and that he suffered unlawful detention. See generally Oliver Lewis, *Stanev v. Bulgaria: On the Pathway to Freedom*, 19 HUM. RTS. BRIEF 2 (2012) (recounting the details of Stanev's case and detailing the court's decision).

461. See *A Tribute to Rusi Stanev*, *supra* note 459; see also ACCESS TO JUST. FOR PERSONS WITH DISABILITIES, GUIDE OF PROMISING PRACTICES ON LEGAL CAPACITY AND ACCESS TO JUSTICE: REFLECTIONS FOR THE IMPLEMENTATION OF THE ARTICLES 12 AND 13 OF THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES 30, ajupid.eu/en/promising-practices/guide-of-promising-practices [https://perma.cc/X9FM-UPR4] [hereinafter AJUPID, GUIDE OF PROMISING PRACTICES] ("Shortly after the [Stanev] ruling, Bulgaria ratified the UNCRPD. The context was therefore suitable for the preparation of a change in legislation."); (Article 9-2) *Protection of Morals*, HUMAN RIGHTS, <http://humanrights.bg/Contents/Item/Display/1335> [https://perma.cc/6EW2-6GVB] (translated from Bulgarian).

462. BULGARIAN CTR. NOT-FOR-PROFIT LAW, SUPPORTED DECISION-MAKING OR HOW PEOPLE WITH INTELLECTUAL DISABILITIES OR MENTAL HEALTH PROBLEMS CAN LIVE INDEPENDENT LIVES 2 (2014) [hereinafter BCNL, SUPPORTED DECISION-MAKING]. The initiative was named "Article 12—next Step" and was originally expected to last from 2012–14, but was extended to 2014–16 and continues to this day. *Id.*

provides for the incorporation of international treaties,⁴⁶³ although it was unlikely that the existing guardianship law would be abolished without legislative action.

Given the long history of stigma and prejudice against persons with intellectual and psychosocial disabilities in Bulgaria,⁴⁶⁴ the lawyers at BCNL decided that it was critical to demonstrate that supported decision-making could be effective in enabling legal capacity and permitting persons with I/DD and psychosocial disabilities to live inclusive lives in their communities.⁴⁶⁵ To do so, they created pilot projects utilizing SDM for those two different populations. On the I/DD side, they joined forces with the Bulgarian Association for People with Intellectual Disabilities (BAPID)⁴⁶⁶ and the Autism Association (a parent-based organization).⁴⁶⁷ For the pilot involving people with psychosocial disabilities, they joined with the Global Initiative in

463. CONSTITUTION OF THE REPUBLIC OF BULGARIA, art. 5, § 4 (“International treaties which have been ratified in accordance with the constitutional procedure, promulgated and having come into force with respect to the Republic of Bulgaria, shall be part of the legislation of the State. They shall have primacy over any conflicting provision of the domestic legislation.”).

464. AJUPID, GUIDE OF PROMISING PRACTICES, *supra* note 461, at 30 (“Persons with intellectual disabilities have been ‘invisible’ in Bulgarian society for many years . . . hidden away in social care institutions.”).

465. BCNL, SUPPORTED DECISION-MAKING, *supra* note 462, at 2. BCNL was to “coordinate the activities of the partners [in the pilots] as well to support the preparation of . . . legal mechanisms and regulations, that can guarantee capacity of persons with intellectual disabilities and with mental health problems to enjoy their rights.” *Id.*

466. BAPID is a national representative organization of people with intellectual disabilities in Bulgaria, whose members are people with intellectual disabilities, their friends and families. It is a member of Inclusion International and Inclusion Europe. BCNL, SUPPORTED DECISION-MAKING, *supra* note 462. BAPID’s website, www.bapid.com [<https://perma.cc/U3L2-RXV5>] is, unfortunately, only in Bulgarian.

467. BULGARIAN CTR. NOT-FOR-PROFIT LAW, THE NEXT STEP PROGRAM: FIGHT FOR IRREVERSIBILITY (Nov. 3, 2017) <http://bcnl.org/en/projects/the-next-step-program-fight-for-irreversibility.html> [<https://perma.cc/P45P-S23G>]. Dimitrova Interview, *supra* note 455. I personally visited the Autism Association and interviewed some of the facilitators.

Psychiatry-Sofia⁴⁶⁸ and the National Organization of Mental Health Service Users.⁴⁶⁹

The pilots began in 2012 in the cities of Sofia, Vidin, and Blagoevgrad, with at least forty participants, and containing a mix of those who were on the autism spectrum, had intellectual disabilities, or had psychosocial disabilities.⁴⁷⁰ Although no participants came *directly* from what are euphemistically called “care institutions,” a number had been previously institutionalized and lacked family or community relationships.⁴⁷¹ For those participants, the first year of support was essentially “environmental,” in that it was directed to creating relationships from which the participants could ultimately choose supporters.⁴⁷² For others, facilitating a process that chose trusted supporters and entered participants into supported decision-making agreements moved more quickly.⁴⁷³

Meanwhile, following the direction of the court in *Stanev*, the Ministry of Justice established a working group to change Bulgaria’s guardianship legislation and to address the right of legal capacity in the recently ratified CRPD.⁴⁷⁴ In autumn 2012, after an advocacy action by BCNL and BAPID, the government adopted a strategic document: “Implementing Article 12 UNCRPD: Standards in the National Legal Framework.”⁴⁷⁵ According to the Director of BCNL, this

468. Global Initiative in Psychiatry-Sofia (GIP-SOFIA) is a constituent organization of Global Initiatives in Psychiatry. Its mission is “promoting human[e], ethic[al] and effective mental health care throughout the world.” BCNL, SUPPORTED DECISION-MAKING, *supra* note 462, at 13 (inside back cover).

469. The National Organization of Mental Health Service Users (NOMHSU) “is an association of people with mental health problems . . . [and] is a member of the World Network of Users and Survivors of Psychiatry (WNUSP).” *Id.* at 14 (back cover).

470. *Id.* at 2; *see also* Dimitrova Interview, *supra* note 455, at 10:25:00 (noting that pilots started mainly with people living in the community).

471. Dimitrova Interview, *supra* note 455.

472. The individual stories of the participants in the pilots, some of whom I was honored to meet, deserve an article of their own. One woman with I/DD who spent 26 years in a “care institution” related that in all that time, she had never been asked to, or was able to make, a single decision—not what to eat, what to wear, or how to spend her time. After a year of support, she was now living a self-determined, inclusive life in the community. Dimitrova Interview, *supra* note 455, at 12:00:00.

473. *Id.*

474. AJuPID, GUIDE OF PROMISING PRACTICES, *supra* note 461, at 30.

475. Enacting the standards laid down in Article 12 of the UN Convention on the Rights of Persons with Disabilities will require the adoption of legislative

document opened the door for more comprehensive reform related to legal capacity in civil law.⁴⁷⁶

By 2013, BCNL was ready to publicly unveil the pilot projects and their results to date,⁴⁷⁷ simultaneously with a two-day international workshop on legal capacity and law reform.⁴⁷⁸ Although such reform would ultimately require action by the Bulgarian Parliament, the government was in a state of deadlock and crisis, so the conference was instead aimed at judges, lawyers, and legal educators.⁴⁷⁹ Speakers included international experts on legal capacity and the CRPD, including Michael Bach and Lana Kerzner.⁴⁸⁰ BCNL presented a lengthy paper on legal capacity and the principles necessary for legislation that would be in accord with Article 12.⁴⁸¹

Among those in attendance was a judge of the District Court, Verginia Micheva-Ruseva, who, several months later, entertained a petition for guardianship brought by the parents of a young man with

measures aimed at support for persons with disabilities and the independent exercise of their rights, respect for their individual characteristics, and protection of their interests. Adopted by the Council of Ministers on 14 November, 2012, by Protocol 43/14. 11.2012 of the Council of Ministers, cited in Velina Todorova, *The Bulgarian Discussion on Guardianship Between the Judgment of the Constitutional Court and the Draft Law on Natural Persons and Support Measures*, in BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 64 (2015) [hereinafter Todorova, *The Bulgarian Discussion*].

476. E-mail from Nadya Shabani to author (Sept. 21, 2017) (on file with author).

477. BCNL presented the pilots to the public after a well-organized publicity campaign, and with a well-attended kick-off event at the “Red House,” the unofficial headquarters of a number of NGOs in Sofia. The kickoff featured a photography exhibit of pilot participants. Several of them spoke movingly, and the event was broadly covered by print and broadcast media. *Id.*

478. BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, *A Few Words Instead of an Introduction to the [2016] Legal Workshop*, in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 5 (2015).

479. *See id.* (BCNL credits the Workshop as “play[ing] an important role in some events that had occurred afterwards and mak[ing] change happen[.]” including the subsequent court decision and Ombudsman challenges described *infra* pp. 86–87.).

480. NADYA SHABANI ET AL., BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, *THE NEW FORMULA FOR CAPACITY TO ACT- OPPORTUNITY FOR EVERYONE TO EXERCISE THEIR RIGHTS* 3, 12 (2014).

481. NADYA SHABANI ET AL., BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, *The New Paradigm of Legal Personality: Article 12 of the UN Convention on the Rights of Persons with Disabilities*, in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 97–106 (2015) [hereinafter NADYA SHABANI ET AL., *The New Paradigm of Legal Personality*].

psychosocial disabilities.⁴⁸² Relying on the incorporation of the CRPD into Bulgarian law, she dismissed the petition on the ground that guardianship violated the right of legal capacity in Article 12.⁴⁸³ She wrote:

Faced with conflicting domestic law [(the existing guardianship statute)] this panel finds that it should apply the rules of a higher rank, which have precedence, [under domestication provisions of the Bulgarian Constitution,] namely the UN Convention on the Rights of Persons with Disability and the principles of the ECHR. Article 5 of the Persons and Family Act [the guardianship law] is in conflict with these standards and should not be applied. Unfortunately there are no domestic legal mechanisms, adopted by the Bulgarian legislation, which will set out concrete measures for protection and support which the state, and in particular, the court should provide to the people with disabilities in Bulgaria.⁴⁸⁴

While Judge Micheva-Ruseva's decision caused a huge backlash from other judges and the organized bar, it also foregrounded the need for action to bring Bulgaria's domestic law into compliance with the CRPD. In a stunning twist of fate, the ruling government was replaced and Judge Micheva-Ruseva was appointed Deputy Minister

482. Sofia District Court, Civil Division Oct. 4, 2013, Civil Case # 16532 (Bulg.). The decision is available in NADYA SHABANI ET AL., *The New Paradigm of Legal Personality*, *supra* note 481, at 59–63 (2015).

483. *Id.* at 62 (citing the CRPD, Bulgaria's ratification and the ratification by the European Union, of which Bulgaria is a member).

484. *Id.* at 62. She later wrote:

As a judge . . . I was in the position to directly apply the principles of the UNCRPD and the European Convention on the Human Rights, for which there are no particular national measures for application. I was extremely worried of the fact that I as a judge cannot provide full protection of people with psychosocial and intellectual disabilities. However according to article 27 from the Vienna Convention on the Law of Treaties, . . . the lack of internal legal framework could not be used as an excuse by the state for failing to fulfill its obligations under the international conventions.

Id. at 9 (statement of Deputy Minister of Justice Vergenia Micheva-Ruseva).

of Justice.⁴⁸⁵ Under her leadership, a coalition including BCNL began to work with the Ministry to draft a new, CRPD-compliant law to be introduced in Parliament with the support of the government.⁴⁸⁶ In November 2014, the draft Natural Persons and Support Measures Act (NPSMA) was published for preliminary discussion.⁴⁸⁷

Article 1 of the draft law stated: “This law shall regulate the acquisition of legal status and the exercise of legal capacity by natural persons, and the terms and conditions for receiving support in decision-making in relation to performing specific legal actions.”⁴⁸⁸ Two footnotes to this provision define legal status as “capacity to acquire rights and hold obligations” and legal capacity as “capacity to exercise rights and obligations with personal actions.”⁴⁸⁹ Article 7(1) provided that “[a]ny person, irrespective of the type of their disability shall be entitled to appropriate support for the purpose of independently exercising his/her rights.”⁴⁹⁰

In 2014, in another action intended to bring Bulgarian law into compliance, the Bulgarian Ombudsman brought a challenge to the Constitutional Court, requesting a declaration that the existing national guardianship legislation was inadequate under the new Bulgarian Constitution, adopted in 1991, and the ratified CRPD.⁴⁹¹ The

485. Interview with Nadya Shabani, Director, Bulgarian Ctr. for Not-for-Profit Law (Sept. 21, 2017); *see also* SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 8–9.

486. As she said later, “[f]or me it was a great honor to participate in a unique process of creating a new modern framework of the status for people with disabilities that is in line with article 12 [of] the UNCRPD.” *Id.* at 9.

487. *Id.* at 20–39.

488. *Id.* at 20.

489. *Id.*

490. SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 21.

491. He later wrote,

[D]ue to the exhaustion of all possible instruments which can make the state fulfil its obligations under the[CRPD] I made my most emotional, even extravagant request to the Constitutional Court . . . knowing that the request will most likely be rejected. My goal was, however to shock the executive and the legislative powers and to force them . . . to harmonise the regulation of the legal capacity to act of people with intellectual disabilities in such a way as to stop the daily violation of rights of those Bulgarian citizens.

Statement of Konstantin Penchev, Ombudsman of the Republic of Bulgaria, in SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 7.

Court held that the remedy was to change the legislation, with only Parliament capable of filling the legal "gap."⁴⁹²

Later in 2015, BCNL convened another "Legal Workshop," this time in conjunction with the Ministry of Justice and the Institute for Legal Studies, Bulgarian Academy of Sciences.⁴⁹³ By this point, the pilot projects had successfully created fifty-three support networks for people with I/DD and had taken action toward revoking guardianship of four people with I/DD.⁴⁹⁴

In 2016, the proposed legislation was sent to the National Assembly, where it passed a first reading and appeared poised to be the first legal capacity law enacted in the European Union.⁴⁹⁵ Unfortunately, once again the government changed,⁴⁹⁶ and the Minister and Deputy Minister of Justice were replaced.⁴⁹⁷ It seemed that, despite all of the intellectual, policy, and advocacy work done for more than five years, and the ever-increasing number of persons

492. Todorova, *supra* note 475, at 65 n.7 (citing Request by the Ombudsman of the Republic of Bulgaria to establish, on the grounds of Article 150(3) of the Constitution, the unconstitutionality of Article 5(1), with respect to the words "and lose their legal capacity," and Article 5(3) of the Persons and Family Act whereby citizens' rights are violated; Judgment No. 12 of 17 July 2014 in Constitutional Case 10/2014). Todorova explains the jurisdictional basis for the Court's decision. *Id.* at 66.

493. SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS, *supra* note 91, at 17.

494. *Current Projects*, BULGARIAN ASS'N FOR PERSONS WITH INTELL. DISABILITIES (BAPID), rapid.com/bapid/?pagesid=108&lang=en [https://perma.cc/8QLM-UB6D] (last visited Feb. 25, 2018).

495. In response to ratification of the CRPD, other European countries had engaged in law reform, but all retained some form of substitute decision-making in violation of Article 12. MHE REPORT, *supra* note 166, at 4. *See also* Nils Muižnieks, *Steps Forward in Protecting Persons with Disabilities in Bulgaria*, COUNCIL OF EUROPE, COMMISSIONER FOR HUMAN RIGHTS (July 6, 2016), <https://www.coe.int/en/web/commissioner/-/steps-forward-in-protecting-persons-with-disabilities-in-bulgaria?inheritRedirect=true&redirect=%2Fen%2Fweb%2Fcommissioner%2Fopinon-articles> [https://perma.cc/3F7C-HPLD] (noting that, with passage of the proposed legislation "Bulgaria can become a model country in this field").

496. Boryana Dzhambazova, Kit Gillet & Rick Lyman, *Pro-Russia Candidate Appears Likely to Win Bulgarian Presidency*, N.Y. TIMES (Nov. 13, 2016) <https://www.nytimes.com/2016/11/14/world/europe/pro-russia-candidate-appears-likely-to-win-bulgarian-presidency.html> (on file with *Columbia Human Rights Law Review*).

497. *Bulgarian PM Appoints Two Deputy Justice Ministers*, NOVINTE.COM (Jan. 4, 2016), <http://www.novinite.com/articles/172491/Bulgarian+PM+Appoints+Two+Deputy+Justice+Ministers> [https://perma.cc/ZQA8-UUUK].

successfully served by the pilots,⁴⁹⁸ the possibility of enshrining the right of legal capacity in Bulgarian law was over. But then, in a surprise “snap” election, the recently ousted government returned to power.⁴⁹⁹ As of this writing, while the new, current government is not overtly hostile to the legislation, it also has not shown any great interest in moving forward, which has led BCNL to renew its efforts to mobilize popular support.⁵⁰⁰

From a “lessons learned” perspective, what is at least equally important is that, despite all the political turbulence, BCNL and other members of the national reform team remained focused on creating sustainable community actions advocating for legal capacity reform. These included the demonstration pilots, education and information dissemination, public debate, and capacity-building like training institutes for self-advocates, parents, professionals, and others, which served as a significant motivational tool.⁵⁰¹ BCNL credits this organizational work—creating the pilots, relating their results to the proposed legislation, and building a grassroots movement—as critical to their inspiring efforts to advance legal capacity in Bulgaria.⁵⁰²

B. Lessons Learned

Although advocates in both countries have consistently focused on legal capacity as set forth in the CRPD, the cases of Canada and Bulgaria differ in a number of ways. Efforts in Canada were propelled by self-advocates and continued by organizations that included them. Bulgaria’s efforts began with lawyers in an NGO who then entered into

498. By June 2017, more than 150 people had been successfully facilitated in SDM. Dimitrova Interview, *supra* note 455, at 41:30:00. See BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, IS THE NEW LEGAL PARADIGM POSSIBLE? (June 8, 2017) [hereinafter IS THE NEW LEGAL PARADIGM POSSIBLE?].

499. Boryana Dzhambova, *Bulgaria’s Ex-Premier Nears Return to Power in a Key Election for Europe*, N.Y. TIMES (Mar. 26, 2017), <https://www.nytimes.com/2017/03/26/world/europe/bulgaria-election-boiko-borisov.html> (on file with the *Columbia Human Rights Law Review*).

500. E-mail from Nadia Shabani, Dir., Bulgarian Ctr. for Not-for-Profit Law, to author (Dec. 8, 2017) (on file with author).

501. E-mail from Nadia Shabani, Dir., Bulgarian Ctr. for Not-for-Profit Law, to author (Sept. 21, 2017) (on file with author).

502. IS THE NEW LEGAL PARADIGM POSSIBLE?, *supra* note 498, at 15 (“From professional and organizational level—we are sure that the organizations that are involved—it is an irreversible process for them. From legal perspective—the conservative theory of legal capacity is questioned (in an irreversible way), hope soon we will move from the question ‘why’ to the statement ‘how.’”).

partnerships with DPO's and parent organizations, but who continued in a leadership role. Canada ratified the CRPD with a Declaration and Reservation that permitted at least limited continuation of substitute decision-making while Bulgaria ratified with no reservations. Canadian efforts have been largely legislatively-oriented,⁵⁰³ while Bulgarian efforts included litigation, the involvement of various state actors, and favorable judicial decisions.

Perhaps the most important distinction was the incorporation into Bulgarian efforts of a robust and expansive set of pilots that demonstrated the feasibility of SDM in successfully including persons with I/DD and psychosocial disabilities in their communities.

The Canadian effort was, from the beginning, almost purely one of law reform. Finally, the Bulgarian pilot projects were, from the outset, the object of carefully designed research which played an important role in convincing those who might otherwise be skeptical about advancing the rights of previously stigmatized and protected vulnerable populations.

What is truly encouraging, however, is how the connections among advocates in different countries can and do result in new strategies derived directly from "lessons learned." Drawing at least in part on the Bulgarian experience, advocates in Canada, where work on enhancing legal capacity and supported decision-making has been practiced informally for years, are now planning to create several "intentional" pilot projects. Some of these will include persons with particularly challenging social situations or more severe impairments, with the goal of persuading stakeholders who, at the very least, have previously been skeptical about claims of the right of legal capacity for all.⁵⁰⁴ Further, mirroring the leadership of self-advocates in the Canadian context, in its current public mobilization, BCNL is actively involving and training self-advocates to be the "true ambassadors" of the need for statutory recognition of legal capacity and supported decision-making.⁵⁰⁵

503. E-mail from Lana Kerzner to author (Nov. 28, 2017) (on file with author) (noting that Canadian efforts included some strategic litigation, but the choice to work on the legislative front was a necessary response to government commitments and LCO projects that required proposing legislative solutions, and that these projects had legislation at the heart of their dialogues).

504. Personal communication from Michael Bach to author (Nov. 13, 2017) (on file with author).

505. In January, 2017, in the city of Varshez, BCNL conducted a two-day meeting/training for self-advocates in furtherance of its position that, "[i]n practice,

III. THE AMERICAN EXPERIENCE

A. The Current Situation

Most of the ongoing activity in the United States has already been described in Section II.⁵⁰⁶ Disability rights activists in the United States lack the ability to argue on the basis of ratification,⁵⁰⁷ and, even if ratification were to occur, it would undoubtedly be with the usual limiting RUDs.⁵⁰⁸ Thus far, whatever movement exists has been directed more toward providing an alternative to guardianship than toward establishing and incorporating a right of legal capacity.⁵⁰⁹

Importantly, even efforts around the more limited goal of legal recognition for SDM have been led by public interest lawyers, with little participation by persons with I/DD or psychosocial disabilities.⁵¹⁰

persons with disabilities are the true ambassadors of the necessity of introducing a system of supported decision making Therefore BCNL and BAPID's efforts are now focused for [sic] the inclusion of persons with intellectual disabilities in various advocacy initiatives for the [proposed legislation]." *The Right to Decide Independently and How to Advocate for It*, BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW (Jan. 30, 2017), bcnl.org/en/news/the-right-to-decide-independently-and-how-to-advocate-for-it.html [<https://perma.cc/4B2T-F7EW>].

506. See *supra* Section I.B.

507. In addition to whatever direct or indirect legal effects ratification may cause, it has other, sometimes even more important consequences. The Canadian experience provides support for this observation. See Hoffman et al., *Canada Case Study*, *supra* note 165, at 2 ("[W]hile the CRPD remains conspicuously absent from Canadian legislation, public policy and jurisprudence, the country's ratification of the Convention has facilitated an important shift in the social and cultural paradigms surrounding psychosocial disability in Canada.").

508. See discussion on U.S. Exceptionalism, *supra* Section I.F. On a more optimistic note, see Bryan Y. Lee, *The U.N. Convention on the Rights of Persons with Disabilities and its Impact on Involuntary Civil Commitment of Individuals with Developmental Disabilities*, 44 COLUM. J.L. & SOC. PROBS. 393, 414 (2011) (stating that "[e]ven without ratification, the U.N. Convention marks global changes in societal changes towards individuals with disabilities; these shifting attitudes have the potential to dramatically influence U.S. jurisprudence regarding disability rights").

509. This is not insignificant; as more people with I/DD utilize SDM, and fewer are placed under guardianship, the right to legal capacity will surely be advanced, for them and the many others for whom guardianship might also have been sought.

510. There is often token representation on advisory boards or committees, but the movement is not being directed by "experts by experience" despite our best intentions. It is important to recognize, however, that the lives of most people with intellectual disabilities are difficult, and the constant struggle to obtain the benefits necessary to survive can be overwhelming, so that what may seem like more

Older persons with dementia and other forms of cognitive decline, although clearly covered by Article 12, have been entirely absent from the conversation, as have been people with psychosocial disabilities, with the exception of Tina Minkowitz's brilliant advocacy.⁵¹¹ To the extent that legislation recognizing SDM has been enacted, there has been little or no evidentiary base. The pilot projects that exist in the United States are primarily cast as alternatives to guardianship rather than demonstrations of a more expansive right of legal capacity.⁵¹²

B. Bringing Legal Capacity Home

There are many lessons to be learned, and much yet to do. In no particular order:

Because we suffer from a woeful lack of knowledge about human rights in the United States, work must be done to educate everyone, from young children to influential legislators and judges on the highest courts.⁵¹³

To the extent that we look to courts, state and federal, to adopt a human rights lens and to embrace particular human rights, including the right of legal capacity, international human rights should be included in all law school curricula, with a special emphasis on training those new graduates who will be clerking for judges to bring a human rights perspective to that work.⁵¹⁴

abstract issues such as legal capacity are hardly the most pressing concerns for self-advocates. We should also be cognizant, and respectful, of what Carrie Basas has called "advocacy fatigue," meaning "the increased strain on emotional, physical, material, social and wellness resources that come from continued exposure to system inequities and inequalities." Carrie Griffin Basas, *Advocacy Fatigue: Self-Care, Protest, and Educational Equity*, 32 WINDSOR Y.B. ACCESS JUST. 37, 39 (2015).

511. See discussion *supra* Section I.C.1.

512. See discussion *supra* Section I.B.

513. At the very first Roundtable on Legal Capacity and SDM, BEYOND GUARDIANSHIP, *supra* note 32, participants went around the table to say what single thing they thought would most make change for people with intellectual disabilities. I was fortunate enough to witness one prominent educator, activist, and parent presciently say: "Start teaching international human rights to first-graders and don't stop there."

514. See Penny Venetis, *Enforcing Human Rights in the United States: Which Tribunals are Best Suited to Adjudicate Treaty-based Human Rights Claims?*, 23 S. CAL. REV. L. & SOC. JUST. 121, 190–91 (2014) (noting the importance of educating law students on human rights issues who can then become tools in ushering in human rights as judicial clerks).

Pilot projects with thoughtful evaluation and anecdotes from more informal settings are critical in changing hearts and minds about what people with intellectual disabilities can do with supports and how much better their lives will be if afforded legal personhood and legal agency. Law reform, no matter how brilliantly conceived, is not by itself enough.

Meaningful law reform *will not* occur without demonstrations of the real-life experiences of persons with I/DD living good and healthy lives with supports, and *should not* occur without the robust participation of people with I/DD themselves—“experts by experience.” Although we often think of law as the driver of change, we are mistaken if we forget the incredible power of narrative and what happens on the ground and in the weeds.

It is critical to show that affording legal capacity to persons with intellectual, developmental, and cognitive disabilities is no less safe—it is almost certainly more so—than taking away their rights in the name of “protection.” We should not deny or trivialize the fears and concerns of parents and other concerned persons about the possibility of abuse or exploitation, but rather should insist on appropriate and effective measures of protection for *all* people—for universal design—rather than singling out people with and because of their disabilities.

While we may never achieve “pure” legal capacity for everyone, regardless of disability, the effort to embed the right of legal capacity in our understanding and practice⁵¹⁵ has the potential to dramatically and positively change the way we see, relate to, and value people with the widest range of intellectual and cognitive disabilities.

Paradigm shifts do not “just happen.” They are the result of enormous amounts of effort, strategy, and hard, sustained work. If they are as radical as a right of legal capacity for all human beings, they are improbable, but not impossible. Remember that less than thirty years ago homosexuality was considered a disease and a crime, and today we

515. The transformation from being seen, and so treated, as an “object” without legal capacity—as, for example, an African American person under slavery—to recognition as a legal “subject” with the capacity to have and exercise legal rights—as an African American after the abolition of slavery—has and must continue to have enormous practical and social consequences.

celebrate marriage equality.⁵¹⁶ Maybe we should rebrand as “decision equality”

Our work toward incorporation of the right of legal capacity here in the United States requires us to discard our own notions of exceptionalism and better appreciate the contributions of people with I/DD, and their supporters and advocacy organizations around the world—sometimes in the most unlikely places. Whenever I am questioned as to whether this is actually possible, I am proud (and relieved) to be able to answer, “so let me tell you what they have done in Bulgaria, or Kenya, or the Czech Republic, or Israel, or Australia, etc., etc.”

There is strength, energy, and purpose in the connections we forge with others, both here and abroad, in doing legal capacity work. Here is one last story, re-told to me by Robert Fleischner, one of the founders and movers of the CPR/Nonotuck project:

At the end of the first year of their pilot, CPR and Nonotuck decided to have a celebration and organized a dinner for all the participants, their families, and supporters. The date of the event also coincided with the first court order restoring rights to and terminating the guardianship of a project participant, so it was doubly special. Bob gave a speech in which, as an aside, he mentioned that the project was part of an international movement to secure the right of legal capacity. Everyone, especially the “decision-makers” in the project, was excited; they saw that while they were pioneers, they were not alone. They felt part of something much larger, connected to many others they didn’t even know. They experienced what Bob described as the “wonder” of it. They experienced, as we can as well, the inspiring, energizing, powerful force of *solidarity*.⁵¹⁷

What, after all, are human rights but the solidarity that binds all of us together, as members of what the Universal Declaration of Human Rights has named “the human family”?⁵¹⁸

516. See, e.g., LILLIAN FADERMAN, *THE GAY REVOLUTION: THE STORY OF THE STRUGGLE* (2015) (surveying the history of societal treatment of same-sex relationships, from medicalization and criminalization to marriage equality); *Obergefell v. Hodges*, 135 S. Ct. 2584 (2015) (establishing the constitutional right to marriage equality).

517. Personal Communication from Robert Fleischner, Assistant Dir., Ctr. for Pub. Representation, to author (Sept. 22, 2017) (on file with author).

518. UDHR, *supra* note 4, pmbl (“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world”).

