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The Role of Support in Sexual Decision-Making for People with Intellectual and Developmental Disabilities

JASMINE E. HARRIS*

In response to Alexander Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201 (2015).

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I. INTRODUCTION

Alexander Boni-Saenz’s most recent article, *Sexuality and Incapacity*, challenges the normative foundations of legal incapacity doctrines in the context of sexual decision-making of older adults with cognitive disabilities.¹

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¹ See generally Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201 (2015). I use the term “older adults” in line with the movement away from “elderly” and other terms that signify the frailty of this population. See, e.g., *Times Have Changed; What Should We Call ‘Old People’?*, NPR (Feb. 6, 2016), <http://www.npr.org/templates/transcript/transcript.php?storyId=465819152> [<https://perma.cc/8FFX-P6TL>] (discussing the least disliked descriptor for a person over sixty-five years old and declaring “older adults” as the winner).

Sexuality and Incapacity reimagines the foundations of legal incapacity doctrine in the context of sexual assault. Boni-Saenz is guided by principles of Martha Nussbaum's "capabilities approach" to human development² and the nascent theory and practice of supported decision-making (SDM), which is "a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life."³ This normative shift more accurately reflects the consultative, relational manner in which almost all people (those with and without disabilities) make decisions—with support from trusted friends, advisors, and family members.

Boni-Saenz constructs a three-step functional test for legal capacity—what he calls "cognition-plus." The test has two relatively familiar components and a third novel addition: (1) a threshold question of volition (can the person express a preference free from coercion?); (2) a question of understanding (does the person possess the cognitive capabilities to understand the nature and consequences of a sexual decision?); and (3) a question of the existence of an "adequate" support network.⁴ A person who lacks the cognitive capabilities identified in (2) may still be found legally capable if an "adequate" network of trusted supporters exists who can facilitate sexual decision-making.⁵ Cognition-plus offers administrable elements to address concerns about expansive judicial discretion under a test previously advanced by Deborah Denno, known as the "contextual approach."⁶

²Martha C. Nussbaum, *Capabilities and Human Rights*, 66 *FORDHAM L. REV.* 273, 279–85 (1997); see also Margaret Chon, *Intellectual Property and the Development Divide*, 27 *CARDOZO L. REV.* 2821, 2877–78 (2006) (applying Nussbaum's capabilities approach to intellectual property globalization); William W. Fisher & Talha Syed, *Global Justice in Healthcare: Developing Drugs for the Developing World*, 40 *U.C. DAVIS L. REV.* 581, 639–44 (2007) (citing Nussbaum's capabilities approach in support of recognizing a human right to health); Robin West, *Rights, Capabilities, and the Good Society*, 69 *FORDHAM L. REV.* 1901, 1922–26 (2001) (applying Nussbaum's capabilities approach to argue for state protection against private violence and a right to provide care to dependents).

³Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making*, 19 *HUM. RTS. BRIEF* 8, 10 (2012). Such contractual options allow a person to indicate will and preferences in advance of a time of diminished capacity and perhaps prevent the need for a future, formal court determination of incapacity.

⁴Boni-Saenz, *supra* note 1, at 1234–36.

⁵*Id.* at 1236.

⁶Compare Deborah W. Denno, *Sexuality, Rape, and Mental Retardation*, 1997 *U. ILL. L. REV.* 315, 355–57 (1997) (outlining her "contextual approach" for legal capacity that "focusses on the situational context and particular circumstances of each case" along with current research), with Boni-Saenz, *supra* note 1, at 1221 (noting that Denno's "open-ended flight to context" may create more uncertainty as it "widens the factual inquiry by the court"), and Peter Margulies, *Identity on Trial: Subordination, Social Science Evidence, and Criminal Defense*, 51 *RUTGERS L. REV.* 45, 60–61 (1998) (arguing for a

The addition of SDM as an alternative means of demonstrating legal capacity expands the possibilities for greater sexual access for people with cognitive disabilities. The use of SDM challenges existing sociopolitical beliefs in autonomous decision-making as the ideal.⁷ It shifts the analysis of legal incapacity from a focus on individual cognitive deficiencies to an examination of the sufficiency of external supports and resources available to the individual.⁸ In cases of cognitive impairment, the lack of external support itself generates legal incapacity. Boni-Saenz's discussion of "sexual capability" rebrands sex as a positive good;⁹ as a result, inclusion requires that people with cognitive disabilities be considered part of a broader sexual minority.¹⁰

This Response analyzes three aspects of Boni-Saenz's cognition-plus test. First, I position his normative and prescriptive proposals within an existing, robust conversation regarding legal capacity, SDM, and the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Scholars of international human rights law offer valuable insights on challenges of redefining legal capacity and implementing SDM. Advocates continue to

narrower test because expanding the contextual frame of criminal law often "perpetuates stereotypes that subordinate entire groups"). Denno focuses on cases where persons with intellectual or developmental disabilities were victims of sexual assault. Denno, *supra*, at 315.

⁷ Jonathan Herring, *Entering the Fog: On the Borderlines of Mental Capacity*, 83 IND. L.J. 1619, 1620 (2008) ("For those who possess legal capacity, the cardinal principle is the right of self-determination or autonomy."); *see also* Nancy J. Knauer, *Defining Capacity: Balancing the Competing Interests of Autonomy and Need*, 12 TEMP. POL. & C.R. L. REV. 321, 325 (2003) (arguing that the American legal system implicitly endorses "abstract principles of autonomy"). The fact that diverse areas of the law assign liability for activities undertaken without the requisite consent also suggests a broad normative judgment in favor of individual autonomy. *See id.* at 322–23 & nn.2–14 (noting a capacity requirement in a variety of contexts, ranging from medical treatment to marriage and divorce to jury duty).

⁸ *See* Boni-Saenz, *supra* note 1, at 1230–32.

⁹ *See id.* at 1224–25.

¹⁰ *See* Herring, *supra* note 7, at 1625 (noting that "while notions of competence purport to be neutral, these notions in fact reflect majority interests and values" such that "[w]omen and ethnic minorities remain particularly vulnerable to assessments that they lack mental capacity"); Shelia Jennings, *Reflections on Personhood: Girls with Severe Disabilities and the Law*, 2 CANADIAN J. DISABILITY STUD. 55, 58 (2013) ("[P]atriarchy and racism have denied legal personhood to certain individuals and groups."); *see also* KIM E. NIELSEN, A DISABILITY HISTORY OF THE UNITED STATES, at xii (2012) ("African Americans, immigrants, gays and lesbians, poor people, and women have been defined categorically as defective citizens incapable of full civic participation."). For further discussion of *A Disability History of the United States*, *see* Alison M. Parker, *Intersecting Histories of Gender, Race, and Disability*, 27 J. WOMEN'S HIST. 178, 178–79 (2015) (reviewing NIELSEN, *supra*, and agreeing that "what people perceive to be 'disabilities' changes over time and is socially constructed").

debate and contest SDM as a practical, administrable, and measurable alternative.¹¹

Second, I identify potential normative implications of incorporating SDM into domestic law, specifically for procedural and evidentiary law. Third, Boni-Saenz applies his test to the case of older adults with dementia in *State v. Rayhons*.¹² I question a comparable application of cognition-plus to people with more severe intellectual and developmental disabilities (ID/DD) who are currently precluded from exercising sexual agency but may have the mental capability to do so.¹³ Boni-Saenz's taxonomy of cognitive disabilities uses the onset of incapacity to distinguish "persistent acquired incapacity" from "persistent lifelong incapacity."¹⁴ In his article, the former group is older adults while the latter have experienced intellectual and developmental disabilities since birth or early childhood, with no prior period of unimpaired cognitive functioning.¹⁵ This distinction matters with respect to assessing sexual decisions. I offer a number of factors unique to persons with ID/DD for Boni-Saenz to consider as he further develops cognition-plus.

II. SUPPORTED DECISION-MAKING IN CONTEXT

SDM represents a significant departure from existing proxy decision-making practices.¹⁶ Although Boni-Saenz relies on SDM in his proposed doctrinal model, his discussion of SDM's evolution in international human rights law is underemphasized, particularly in light of the expanding literature in this area. This Part situates Boni-Saenz's analysis within existing conversations regarding universal legal capacity pursuant to the CRPD.

A. The U.N. Convention on the Rights of Persons with Disabilities: From Substitute Decisions to Decisional Support

Human rights scholar, Amita Dhanda, describes three dominant constructions of legal capacity: a status attribution test, a functional test, and an outcome test.¹⁷ Status attribution equates the presence of disability

¹¹ See, e.g., Peter Bartlett, *The United Nations Convention on the Rights of Persons with Disabilities and the Future of Mental Health Law*, 8 *PSYCHIATRY* 496, 497–98 (2009) (presenting a more skeptical view of the future of SDM in the United Kingdom).

¹² Boni-Saenz, *supra* note 1, at 1249–53.

¹³ See generally Jasmine E. Harris, *The Dignity of Sexual Agency: Regulating Risk and Mental Disability* (Sept. 12, 2016) (unpublished manuscript) (on file with the author).

¹⁴ Boni-Saenz, *supra* note 1, at 1212–13.

¹⁵ *Id.* at 1212.

¹⁶ Dinerstein, *supra* note 3, at 8 (“[T]his use of the word ‘support,’ and the related concept of supported decision making, represents nothing less than a ‘paradigm shift’ away from well-established but increasingly discredited notions of substituted decision making.” (footnote omitted)).

¹⁷ Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?*, 34 *SYRACUSE J. INT’L L. & COM.* 429, 431–32 (2007);

(physical, mental, intellectual, or psychosocial) with a presumption of legal incapacity.¹⁸ Under a functional test, the presence of disability does not necessarily result in a finding of legal incapacity; rather, the person is deemed incapable if, because of her disability, she cannot perform a specific task or make a specific decision.¹⁹ The outcome test uses a socially disfavored outcome or decision as evidence that the person with a disability is incapable of rational decision-making.²⁰ Dhanda argues that all three operate “in principle or in practice” as status attribution tests, and rely primarily on forensic psychologists to evaluate individuals’ (in)ability to reason using standardized assessments such as IQ scores.²¹

The assessments Dhanda lays out favor risk aversion over decisional agency and, as a result, restrict people with cognitive disabilities in a way that constrains their human rights.²² Reform efforts have focused on increasing due process protections and the reliability of assessment tools in adjudicating legal capacity but generally do not challenge the normative baseline and assumptions, at least not in the United States.²³ The functional test has become the modern standard and first emerged during the late twentieth century.²⁴

In practice, the functional test conflates *legal* capacity with *mental* capacity. Legal personhood (defined in the CRPD as “legal capacity”) recognizes an individual’s right to utilize courts and adjudicatory institutions as a means of protecting or exercising rights and responsibilities.²⁵ In this sense, legal personhood resembles legal standing. Alternatively, mental capacity is narrower, functional, and asks the question whether the person has

see also Comm. on the Rights of Perss. with Disabilities, General Comment No. 1 (2014), Article 12: Equal Recognition Before the Law, para. 15, at 4, U.N. Doc. CRPD/C/GC/1 (Apr. 2014) [hereinafter General Comment No. 1] (discussing the three types of legal tests for capacity).

¹⁸ Dhanda, *supra* note 17, at 431.

¹⁹ *Id.*

²⁰ *Id.* at 431–32.

²¹ *Id.* at 433.

²² *See id.*

²³ *Id.* at 433–35; *see also* István Hoffman & György Könczei, *Legal Regulations Relating to the Passive and Active Legal Capacity of Persons with Intellectual and Psychosocial Disabilities in Light of the Convention on the Rights of Persons with Disabilities and the Impending Reform of the Hungarian Civil Code*, 33 LOY. L.A. INT’L & COMP. L. REV. 143, 158 (2010) (noting that in the United States and other Western nations, legal systems emphasized bans on discrimination and focused on ensuring equal opportunities versus challenging baseline constructions of capacity); *cf.* E. Lea Johnston, *Representational Competence: Defining the Limits of the Right to Self-Representation at Trial*, 86 NOTRE DAME L. REV. 523, 527 n.26, 531 n.55, 583 n.341 (2011) (discussing case law in the context of self-representation and noting that courts rely on the Due Process Clause for representation determination decisions).

²⁴ Eilíonóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT’L L. 124, 127 (2014).

²⁵ *See* G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, art. 12 (Dec. 13, 2006) [hereinafter CRPD].

the cognitive ability to understand and appreciate a decision—e.g., marital, sexual, financial, medical.²⁶ Legal capacity, then, should vary according to the nature of the decision and the gravity of the potential consequences.²⁷

The CRPD reflects a significant paradigm shift away from the functional test to a full recognition of universal legal capacity.²⁸ A central debate among international human rights scholars concerns the meaning and scope of Article 12 and SDM, specifically, whether legal capacity includes both the capacity for rights (passive possession of the right) as well as the capacity to act (active, meaningful exercise of the right).²⁹ During the treaty deliberation process, this distinction inspired much debate and contestation among state parties.³⁰ Generally, state actors agreed that people with disabilities should have rights to legal personhood, but diverged with respect to whether the law would and should recognize an individual's capacity to act when and if he or she could not do so independently without support. Permitting a person who lacks the mental capacity to make a decision and act upon it to retain that right instead of designating a substituted decision-maker challenged deeply rooted conceptions of choice and agency. As Amita Dhanda explained, there are two models:

One recognizes that all persons have legal capacity and the other contends that legal capacity is not a human attribute. . . . [T]he first choice *does not mean* that it is also being contended that all human beings in fact possess similar capacities. Even as all human beings are being accorded similar value, the differences between them [are] not being ignored or devalued. The second, on the other hand, recognizes the fact that there are some human beings who do not possess legal capacity and hence can be declared incompetent. One system is

²⁶ See Boni-Saenz, *supra* note 1, at 1209–10.

²⁷ See generally CHRISTOPHER SLOBOGIN, MINDING JUSTICE: LAWS THAT DEPRIVE PEOPLE WITH MENTAL DISABILITY OF LIFE AND LIBERTY 186–88 (2006) (discussing the Supreme Court's decision in *Godinez v. Moran*, 509 U.S. 389 (1993), and noting that competency varies according to the special decision and the stakes; for example, a criminal defendant's competence to plead guilty varies from that required to participate in his representation and trial); Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEW ENG. J. MED., 1834, 1836 (2007) (describing the "sliding scale" concept of legal capacity as reflective of its functional nature).

²⁸ CRPD, *supra* note 25, art. 12 ("State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.").

²⁹ See, e.g., Dhanda, *supra* note 17, at 452–56; Dinerstein, *supra* note 3, at 8–9 (noting that the footnote in Article 12 of the CRPD differentiating between the two was ultimately excluded from the final text but that the deliberation and drafting process was nonetheless significant).

³⁰ See Dhanda, *supra* note 17, at 438–56 (discussing the sequence of drafts that emerged as reflective of conflicting views regarding how to define legal capacity and what responsibility state parties would have for providing individual decision-making support).

premised on the universal presence of competence; the other on the selective presence of competence.

....

With the recognition of universal capacity, there is . . . a claim of equality of opportunity but difference of treatment . . .³¹

The latter “exclusionary model” of legal capacity segregates those with significant mental disabilities, for whom the current standard of legal capacity is unattainable.³²

Dhanda’s clarification that a shift to universal legal capacity does not mean that everyone has the same set of capabilities (and, consequently, the level of support for decisional agency will vary according to the capabilities an individual does possess and the decision at hand) represents a crucial distinction. Legal capacity is better understood as a continuum of capabilities and a cross-sectional axis of different types of decisions or conduct. The provision of decision-making supports or accommodations depends on the intersection of the two axes.

The CRPD model accounts for even the most severely disabled person who may require full support from a third party; however, two things distinguish it from the current functional approach using substituted decision-making systems such as guardianship. First, the principle of universal legal capacity recognizes a person with severe disabilities as a legal person with rights, responsibilities, and recourse.³³ Second, it preserves the person’s central role in the decision-making process, calling on the third party to make her best approximation of the will and preferences of the person with a cognitive disability based on actual knowledge about the person, prior interactions, and the existence of an ongoing relationship.³⁴

³¹ *Id.* at 457–58 (emphasis added).

³² *See id.* at 460.

³³ CRPD, *supra* note 25, art. 12.

³⁴ General Comment No. 1, *supra* note 17, para. 21, at 5 (“Where, 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, in accordance with article 12, paragraph 4. The ‘best interests’ principle is not a safeguard which complies with article 12 in relation to adults. The ‘will and preferences’ paradigm must replace the ‘best interests’ paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.”); *see also* Canadian Ass’n for Cmty. Living, Response to Draft General Comment No. 1 on Article 12, U.N. Committee on the Rights of Persons with Disabilities, at 5 (Feb. 26, 2014), http://www.ohchr.org/Documents/HRBodies/CRPD/GC/CanadianAssociationCommunityLiving_Ar12.doc [https://perma.cc/ZN5R-ZLE3] (“In recognizing the reality of such situations, we recommend that GC advance the notion of ‘best interpretation of will and preference’ to replace the best interest test for application in these situations. Such a test would recognize

The terms of the CRPD do not formally apply to the United States at this time, owing to the fact that the U.S. Senate has twice failed to ratify the treaty, although the country is a signatory to it.³⁵ Boni-Saenz—like international legal scholar Amita Dhanda³⁶—recommends a normative shift to a notion of sexual capabilities, rooted in Martha Nussbaum and Amartya Sen’s theory of “human capabilities.”³⁷ While this proposal reflects a shift in theory in line with international human rights norms, Boni-Saenz’s approach does not recognize universal legal capacity. Reliance on a model of exclusion means that some cadre will still be stripped of legal personhood if, for example, they cannot pass the threshold requirement of expressing volition verbally or through conduct. Boni-Saenz’s approach reflects an interim compromise, adding depth to the functional test and drawing attention to the benefits of SDM without going as far as the CRPD.

The “stickiness”³⁸ of norms of substitute decision-making should not be underestimated and are intimately connected with the historical invisibility of

that will and preference cannot always be interpreted with certainty, but that there are always better interpretations than others.”).

³⁵ Strong opposition to the CRPD’s ratification has come from conservative groups, such as the Heritage Foundation and the Family Research Council, who argue that the CRPD challenges U.S. sovereignty, as well as strips parents of children with disabilities of their decisional authority and gives it to state authorities. Josh Rogin, *Senate GOP Rejects U.N. Disabilities Treaty*, FOREIGN POL’Y (Dec. 4, 2012), <http://foreignpolicy.com/2012/12/04/senate-gop-rejects-u-n-disabilities-treaty> [<https://perma.cc/8NW9-GNXG>]; see also *Convention on the Rights of Persons with Disabilities Before the S. Foreign Relations Comm.*, 113th Cong. (2013) (statement of Sen. Robert J. Dole), http://www.foreign.senate.gov/imo/media/doc/Senator_Dole_Testimony.pdf [<https://perma.cc/4KJS-V5SA>] (noting that the treaty fell just five votes short of passage the previous year because “treaty opponents expressed concern that the CRPD would diminish American sovereignty”); *id.* (statement of the Hon. Tom Ridge, Chairman, National Organization on Disability), http://www.foreign.senate.gov/imo/media/doc/Ridge_Testimony.pdf [<https://perma.cc/9YBE-LT5N>] (voicing disappointment “following last year’s failure to ratify the treaty” and pleasure at revisiting the issue).

³⁶ Dhanda, *supra* note 17, at 435–38 (describing a “capabilities” approach and the utility of this normative approach to legal incapacity).

³⁷ Boni-Saenz, *supra* note 1, at 1223–33; accord Nussbaum, *supra* note 2, at 275–77 (describing the development of the “capabilities approach” and distinguishing it from Amartya Sen’s approach).

³⁸ Dan M. Kahan, *Gentle Nudges vs. Hard Shoves: Solving the Sticky Norms Problem*, 67 U. CHI. L. REV. 607, 609 (2000) (explaining the failure of overly harsh legal sanctions, or “hard shoves,” as means to shift social norms in contrast to “gentle nudges” designed to delicately prod social norms in the direction of change); see also Richard H. McAdams, *Relative Preferences*, 102 YALE L.J. 1, 10 (1992) (distinguishing individual absolute preferences from individual relative preferences, i.e., those preferences influenced by the preferences of “others,” in the context of market consumption); Cass R. Sunstein, *Choosing Not to Choose*, 64 DUKE L.J. 1, 10–11 (2014) (discussing the difficulties inherent in active choice models versus substituted decision-making and other default rules); Cass R. Sunstein, *Social Norms and Social Roles*, 96 COLUM. L. REV. 903, 929 (1996) (noting that “social norms can make people act and talk publicly in ways that are different from

people with intellectual and developmental disabilities.³⁹ Scholars have called for the use of SDM networks (both formal and informal) as viable alternatives to legal determinations of incapacity and appointment of surrogate decision-makers through vehicles such as guardianship and conservatorship.⁴⁰ Article 12 of the CRPD makes the shift to universal legal capacity in four steps: (1) a formal declaration of the right of people with disabilities to universal legal capacity; (2) a legal mandate that state parties “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life;” (3) a second requirement that states take affirmative, “appropriate measures to provide access . . . to the support [needed to] exercis[e] . . . legal capacity;” and (4) due process safeguards to protect against abuse.⁴¹ State disagreement regarding the proper scope of Article 12 reflected significant confusion over the meaning of legal capacity and its deserved recipients. To make this paradigm shift, a state must explicitly recognize the right to and exercise of legal capacity irrespective of the degree of support one might need to do so. The CRPD, therefore, is “not just a legal document, but also a political document, and as such, its message on the legal capacity of an excluded community should be unequivocal and forward looking.”⁴²

The principle law reform efforts and experiences with SDM occur in other countries, such as Canada, Ireland, Sweden, India, and others.⁴³ A total of five provinces in Canada now use SDM systems, such as legally enforceable “representation agreements,” as effective contractual alternatives to

how they actually think” and that “[p]eople often act in accordance with norms that they wish were otherwise or even despise”).

³⁹ See Jasmine E. Harris, *Processing Disability*, 64 AM. U. L. REV. 457, 468–72 (2015) (discussing the historical roots of current normative presumptions of incapacity associated with people with mental disabilities).

⁴⁰ See generally 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, 157 (2010) (“[I]t would be preferable to support decision making rather than supplant it through guardianship”).

⁴¹ CRPD, *supra* note 25, art. 12.

⁴² Dhanda, *supra* note 17, at 447–48. Much of the international debate today turns on the timing of the implementation of the CRPD’s move to universal legal capacity. Some states contend that the move to universality must occur over time and requires normative shifts to take shape, and guardianship as an institution will continue to operate, albeit on a limited basis; other advocates call for the prompt deconstruction of guardianship entirely as a form of substituted decision-making. See, e.g., Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 146–47 (2012) (discussing British Columbia’s move towards SDM by use of “representation agreements”).

⁴³ See, e.g., Flynn & Arstein-Kerslake, *supra* note 24, at 133–37 (discussing reforms of legal capacity statutes and doctrine in Ireland, Canada, and India); see also Robert D. Dinerstein et al., *Emerging International Trends and Practices in Guardianship Law for People with Disabilities*, 22 ILSA J. INT’L & COMP. L. 435, 436 (2016) (exploring “the recent history of guardianship in international law”).

guardianship.⁴⁴ On March 16, 2016, the Israeli Knesset passed an amendment to the existing Legal Capacity and Guardianship Law adding a provision for SDM as the least restrictive means to decisional agency.⁴⁵ Furthermore, the Bulgarian National Assembly soon will decide the fate of the Natural Persons and Support Measures Bill, designed to abolish guardianship and bring Bulgaria in line with the CRPD.⁴⁶ Domestically, Texas is the first state to statutorily recognize SDM agreements as legitimate alternatives to guardianship.⁴⁷

Although the United States has yet to see a domestic judicial decision based solely on the principles of Article 12 of the CRPD or SDM,⁴⁸ at least

⁴⁴ KRISTA JAMES & LAUREN WATTS, LAW COMM'N OF ONT., UNDERSTANDING THE LIVED EXPERIENCES OF SUPPORTED DECISION-MAKING IN CANADA 4 (Mar. 2014), <http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ccel.pdf> [<https://perma.cc/DN22-JTCS>] (listing British Columbia, Yukon, Alberta, Manitoba and Saskatchewan as provinces with experience using SDM); *see also* MICHAEL BACH & LANA KERZNER, LAW COMM'N OF ONT., A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 53 (Oct. 2010), <http://www.lco-cdo.org/disabilities-commissioned-paper-bach-kerzner.pdf> [<https://perma.cc/NQG2-LPCB>] (“British Columbia’s Representation Agreement Act has been hailed by the disability community as highly successful legislative recognition of supported decision-making.” (emphasis omitted)); LANA KERZNER, PAVING THE WAY TO FULL REALIZATION OF THE CRPD’S RIGHTS TO LEGAL CAPACITY AND SUPPORTED DECISION-MAKING: A CANADIAN PERSPECTIVE 37 (Apr. 2011), http://supporteddecisionmaking.org/sites/default/files/paving_the_way_for_crpdcanada.pdf [<https://perma.cc/3BLY-LCWA>] (describing the purposes of the Representation Agreement Act).

⁴⁵ Capacity and Guardianship (Amendment No. 18) Law, 5776-2016, § 67B (Mar. 16, 2016), *translated in* <http://bizchut.org.il/en/wp-content/uploads/2016/04/new-Israeli-law-on-supported-decision-making.docx> [<https://perma.cc/X7DP-F6NE>] (adding section 67B defining a decision-making supporter, limiting her role and duties, and establishing the “express interest” standard as the guiding principle of SDM).

⁴⁶ Oliver Lewis, *Why Should Bulgaria Change Its Guardianship System?*, OLIVER TALKS (Mar. 14, 2016), <http://www.mdac.info/en/olivertalks/2016/03/14/why-should-bulgaria-change-its-guardianship-system> [<https://perma.cc/34QG-G6UR>]. Latvia, Lithuania, and Czech Republic are also in the process of adopting SDM. *See MDAC’s Recent Legal Capacity Advocacy Activities in Lithuania, Bulgaria and in Hungary*, MENTAL DISABILITY ADVOC. CTR. (Oct. 15, 2012), http://www.mdac.info/en/16/10/2012/MDAC_s_recent_legal_capacity_advocacy_activities_in_Lithuania_Bulgaria_and_in_Hungary [<https://perma.cc/N9X4-5FFT>].

⁴⁷ Supported Decision-Making Agreement Act, TEX. EST. CODE ANN. § 1357 (West 2015). Legislators passed House Bill 39 and Senate Bill 1881 during the 84th Texas Legislative Session in 2015. *Id.*

⁴⁸ Flynn & Arstein-Kerslake, *supra* note 24, at 138 (“We have not yet seen the full application of Article 12 in a judicial decision.”); *see also* *Medellin v. Texas*, 552 U.S. 491, 504 (2008) (stating that international law commitments do not function as binding federal law); *Sanchez-Llamas v. Oregon*, 548 U.S. 331, 353–54, 353 n.4 (2006) (holding that legal interpretations by international courts deserve “respectful consideration” but are not binding and do not necessarily have effect as federal law). *But cf.* *Roper v. Simmons*, 543 U.S. 551, 575–76 (2005) (acknowledging the relevance of the views of the international community and that “the Court has referred to the laws of other countries and to

one state court judge has discussed SDM's conceptual and practical import as an alternative to guardianship.⁴⁹ In the case of *In re Guardianship of Dameris L.*, Judge Kristin Booth Glen connected federal and state constitutional principles of substantive due process with international human rights—specifically, the CRPD—in support of her decision to revoke guardianship of a twenty-nine-year old woman, Dameris, with an intellectual disability.⁵⁰ Judge Glen reasoned that “where a person with an intellectual disability has the ‘other resource’ of decision making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian.”⁵¹

In Dameris's case, Judge Glen concluded that the evidence demonstrated that she had the mental and adaptive abilities to “exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network.”⁵² Thus, the judge determined that “[t]erminating the letters of guardianship previously granted to [Dameris's husband and mother] recognizes them, instead, as persons assisting and supporting her autonomy, not superseding it.”⁵³

Legal scholars have argued that the use of SDM models is not aspirational or benevolent; rather, current reliance on substituted decision-making vehicles (such as the very institution of legal guardianship) violates Title II of the Americans with Disabilities Act's integration mandate.⁵⁴

international authorities as instructive”); *Lawrence v. Texas*, 539 U.S. 558, 573 (2003) (citing the European Convention on Human Rights and decisions by the British Parliament and the European Court of Human Rights as indicative of prevailing norms).

⁴⁹ See, e.g., *In re Guardianship of D.D.*, 19 N.Y.S.3d 867, 871 (N.Y. Sur. Ct. 2015) (citing *In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848, 856 (N.Y. Sur. Ct. 2012)) (stating that “supported decision making must be explored and exhausted before guardianship can be imposed”); see also Court Order, *Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 2, 2013); Theresa Vargas, *Woman with Down Syndrome Prevails Over Parents in Guardianship Case*, WASH. POST (Aug. 2, 2013), https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html [<https://perma.cc/J8B5-NFQQ>] (describing a case in which a judge rejected a guardianship request from the parents of a woman with Down syndrome).

⁵⁰ *In re Guardianship of Dameris L.*, 956 N.Y.S.2d at 855–56.

⁵¹ *Id.* at 856.

⁵² *Id.*

⁵³ *Id.* Courts in other countries have used a similar rationale. See *Stanev v. Bulgaria*, 2012-I Eur. Ct. H.R. 81, 147 (citing the CRPD and noting “the growing importance which international instruments for the protection of people with mental disorders are now attaching to granting them as much legal autonomy as possible”); *Shtukurov v. Russia*, 2008-II Eur. Ct. H.R. 353, 356–58 (finding that the legal incapacitation of petitioner, Shtukurov, violated Article 6, the right to a fair trial, Article 8, the right to privacy, and, for the subsequent involuntary hospitalization, the right to liberty and to petition the court for relief).

⁵⁴ Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 279, 314 (2011); Salzman,

B. Normative Implications of Supportive Decision-Making in U.S. Law

SDM reflects a significant normative shift in the structure of Anglo-American conceptions of legal rights and responsibilities, yet, in the spirit of legal realism, better reflects the everyday decision-making of people with and without disabilities. Although SDM more accurately reflects decisional agency, the current normative framework of legally recognized decisions is built around an individual decision-maker and the rights and responsibilities that attach to a particular decision. Thus, a shift in the normative framework requires a conversation about the implications of such a shift more broadly.

I have explored the implications of SDM in court procedures and rules such as rules for discovery—e.g., interrogatories, admissions, and declarations. How should the law recognize responses produced with the assistance of another person? Furthermore, SDM would require evidentiary reforms to account for the decision-making model—e.g., evidentiary rules including burdens of proof and related presumptions, hearsay, character evidence, and conceptions of “unavailability.” The very presence of a supporter would challenge the four core testimonial qualities that define evidence law—memory, perception, sincerity, and narration.⁵⁵

Beyond procedural and evidentiary rules, consider the “meeting of the minds” required for the valid formation of a contract. Contract law principles reflect a meeting of the minds of two *individuals*.⁵⁶ How would the law account for the third party supporter in terms of the formation, execution, and enforceability of the contractual terms and obligations? Could the existence of a support network suffice for contract formation?⁵⁷ A key question concerns

supra note 40, at 160; see *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 589 (1999) (citing 42 U.S.C. § 12101(b)(1)) (“The statute as a whole is intended ‘to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities’”).

⁵⁵ See FED. R. EVID. 601 advisory committee’s note (noting admissibility of materials “bearing upon the perception, memory, and narration of witnesses”).

⁵⁶ See RESTATEMENT (SECOND) OF CONTRACTS § 3 (AM. LAW INST. 1981) (“An agreement is a manifestation of mutual assent on the part of *two* or more persons.” (emphasis added)). Note that corporations are legal persons under the law and can enter into enforceable contracts. MODEL BUS. CORP. ACT § 3.02 (AM. BAR ASS’N 2005) (“[E]very corporation has . . . the same powers as an individual to do all things necessary or convenient to carry out its business and affairs, including without limitation power . . . to make contracts . . .”).

⁵⁷ See Terry Carney & Fleur Beaupert, *Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making*, 36 UNSW L.J. 175, 187–88 (2013) (discussing the potential contractual and fiduciary obligations that might arise in the context of a SDM agreement); Glen, *supra* note 42, at 146–47 (exploring “representation agreements” and their use and enforceability by disabled and aging persons to manage routine affairs, including financial transactions, health care decisions, legal services, “and other areas of personal care”); Michael Wald & Eli D. Pierce, *Elder Ethics: How Supported Decision-Making Could Protect Incapacitated*

the existence of a non-cognitive-based account for will and preferences.⁵⁸ What would this look like and would it be acceptable? How would SDM work in the context of informed consent in health law or for participation in research studies?⁵⁹ The answers are beyond the scope of this Response but worthy of exploration if we are committed to using SDM systems.

III. APPLICABILITY OF COGNITION-PLUS TO PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Boni-Saenz applies his cognition-plus test to older adults with dementia and uses the case of former Iowa state representative, Henry Rayhons, to illustrate the mechanics of his test.⁶⁰ He makes the claim that his test applies to people with persistent cognitive disabilities more broadly, which includes people with intellectual and developmental disabilities.⁶¹ There are certainly similarities and overlap between the effects of cognitive impairments on older adults and persons with intellectual disabilities.⁶² This Part, however, discusses the differences between individuals who currently lack cognitive abilities and those who have never had them, and how these differences challenge the broader applicability of cognition-plus. I do not suggest that cognition-plus is inapplicable to people with intellectual disabilities, but rather that Boni-Saenz may wish to account for these differences in either design or application of his proposed doctrinal test.

Seniors, 79 TEX. B.J. 104, 105 (2016) (discussing the use of SDM to aid seniors who are not considered incapacitated in making financial and other life decisions).

⁵⁸ See Telephone Interview with Robert D. Dinerstein, Professor of Law and Dean for Experiential Learning, Am. Univ. Wash. Coll. of Law (Apr. 15, 2016).

⁵⁹ See Sandra Berkowitz, *Informed Consent, Research, and the Elderly*, 18 GERONTOLOGIST 237, 242 (1978) (noting the risks inherent in allowing third party decision-making in the gerontology context); Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 JAMA 2067, 2069 (1992) (discussing the “family rights” argument wherein “the family deserves recognition as an important social unit that ought to be treated . . . as a responsible decisionmaker in matters that ultimately affect its members”); Alan Meisel, *Managed Care, Autonomy, and Decisionmaking at the End of Life*, 35 HOUS. L. REV. 1393, 1422 (1999) (noting that family members are often involved in the medical decision-making process “under the aegis of the substituted judgment standard”).

⁶⁰ Boni-Saenz, *supra* note 1, at 1247–53.

⁶¹ *Id.* at 1243–44 (distinguishing cognition-plus from existing sexual incapacity doctrines and emphasizing its benefits particularly with respect to individuals with persistent cognitive impairments).

⁶² People with intellectual disabilities are more susceptible to dementia later in life. *Learning Disabilities and Dementia*, ALZHEIMER’S SOC’Y 1, https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 [<https://perma.cc/74U7-RK2K>] (last updated Mar. 2015) (“People with learning disabilities, particularly those with Down’s syndrome, are at increased risk of developing dementia.”).

A. Volition

Boni-Saenz establishes a threshold test of volition that focuses on whether the person with “persistent cognitive impairments still has the capacity to express volition.”⁶³ The goal of this step is to establish whether the person *can express* will and preferences,⁶⁴ not a factual determination of whether volition actually existed in the case before the court. He accounts for both verbal and non-verbal means of expressing volition, such as facial expressions, and the comorbid presentation of communication impairments and cognitive disabilities.⁶⁵ If the individual is unable to express will and preferences, according to Boni-Saenz, he lacks the capacity to consent to sex, and liability would attach to his sexual partner.⁶⁶

People with intellectual or developmental disabilities may have a particularly difficult time getting past the threshold test when they communicate through non-normative methods. Consider a recent Ninth Circuit decision, *United States v. James*, in which the court reversed the trial judge’s decision to acquit after the jury returned a guilty verdict on federal charges of sexual abuse of a “severely disabled” woman.⁶⁷ The statute prohibits sexual intercourse with a person the defendant knows is “*physically incapable* of declining participation in, *or communicating unwillingness to engage in*, that sexual act.”⁶⁸

Judge Tallman, writing for the majority, discusses the sufficiency of evidence supporting T.C.’s, the victim’s, inability to communicate volition under the statute: (1) “witnesses—even those who knew her well—could not always understand T.C.,” (2) “the evidence demonstrated [T.C. and the defendant] never spent any appreciable time together before [the defendant] sexually assaulted her. Nothing indicates he knew her well enough to understand her or could otherwise understand her attempts at communication;” (3) although she communicated through head nodding, biting, or other non-verbal indicators, “the evidence demonstrated that [T.C.] had difficulty communicating even with her longtime caregivers, close family members, the emergency room nurse, and investigators;”⁶⁹ (4) the defendant’s statement that T.C. “just lay there” during the alleged assault; and (5) that T.C. was unable to

⁶³ Boni-Saenz, *supra* note 1, at 1234.

⁶⁴ *Id.* at 1235.

⁶⁵ *Id.*

⁶⁶ *Id.*

⁶⁷ *United States v. James*, 810 F.3d 674, 676, 683 (9th Cir. 2016). This case involved an alleged rape on the Fort Apache Indian Reservation. *Id.* at 677. The federal government, and not the state of Arizona, had jurisdiction to indict and try the defendant pursuant to 18 U.S.C. § 2242(2)(B). *Id.*

⁶⁸ 18 U.S.C. § 2242(2)(B) (2006) (emphasis added).

⁶⁹ For example, T.C. did not communicate with the treating nurse in the emergency room after the alleged attack. *James*, 810 F.3d at 682.

care for herself, “groom,” or walk independently.⁷⁰ Judge Tallman concludes his opinion with an editorial statement somewhat removed from the legal question in this case yet apropos of his decision: “The law in its majesty protects from assault those who are too weak and feeble to protect themselves. No society worthy of being called civilized may do any less.”⁷¹ Judge Tallman saw T.C.’s disability, and its physical and behavioral manifestations, as evidence of her helplessness and vulnerability sufficient for a jury to convict the defendant.

Judge Kozinski, the sole dissenter, draws attention to the statutory language that established the prosecutorial burden to prove beyond a reasonable doubt that T.C. was *physically incapable of communicating* her unwillingness to engage in sex.⁷² Judge Kozinski dismisses the majority’s evidence as irrelevant, nothing more than “a number of facts that are pretty much beside the point and . . . cannot overcome the solid wall of evidence that T.C. was capable of communicating her lack of consent when she was so inclined.”⁷³ Furthermore, he notes that T.C.’s need for assistance with personal care was also irrelevant to the statutory inquiry.⁷⁴ Judge Kozinski foretells of potentially disastrous effects of the majority’s holding to people with disabilities and atypical communication methods:

The majority claims that its holding “does not preclude someone suffering from a physical disability from ever having consensual sexual intercourse.” I’m not so sure. James will go to prison, likely for many years, because he had sex with someone whose physical handicap impaired her ability to communicate, even though those who knew her testified that she could physically convey the idea of “no” when she wanted to. Today’s opinion will make others more reticent about engaging in sex with people who are physically impaired. Their already difficult task of seeking out a partner for sexual gratification will become even more daunting.

. . . T.C. herself, for example, will never have sex again; who’d be foolish enough to risk it?⁷⁵

The *James* case supports skepticism that those with communication impairments will be able to overcome even the most basic threshold test for volition. Sadly, I suspect *People v. Miranda*, cited in Boni-Saenz’s article,⁷⁶ is

⁷⁰ *Id.*

⁷¹ *Id.* at 683.

⁷² *Id.* at 684 (Kozinski, J., dissenting).

⁷³ *Id.* at 686.

⁷⁴ *Id.* at 687.

⁷⁵ *James*, 810 F.3d at 687 (Kozinski, J., dissenting) (citation omitted).

⁷⁶ Boni-Saenz, *supra* note 1, at 1235 n.166.

more likely the exception, and *United States v. James* is more reflective of courts' analyses of volition.

B. Knowledge and Consequences

A majority of courts employ some version of the “knowledge and consequences” test that asks whether the person has the cognitive capacity to reason about a specific sexual decision.⁷⁷ Boni-Saenz advances a more nuanced vision of this test that accounts for the dangers of requiring knowledge of moral or social consequences of a sexual decision.⁷⁸ He calls for a minimal understanding of the individual’s right to choose whether to consent or not.⁷⁹ Surpassing this doctrinal hurdle requires an assessment of what people with intellectual disabilities know.⁸⁰ This is a function of asking well-formulated questions as well as deciding, as a baseline, what is important for them to know with respect to a particular decision.⁸¹

People with intellectual and developmental disabilities present at least three unique challenges in meeting this test.⁸² First, as an evidentiary matter, this prong of the functional test often turns on an expert assessment of intelligence as a proxy for reasoning and knowledge. Most rape and sexual assault cases today, where the alleged victim is a person with an intellectual disability, rely on the testimony of a court-appointed or party-appointed forensic psychologist.⁸³ The expert administers one of several IQ tests based on one or two interviews with the person with ID/DD to ultimately produce a composite, numerical reflection of intelligence.⁸⁴ While IQ tests have an

⁷⁷ *Id.* at 1216–22.

⁷⁸ *Id.* at 1234–53.

⁷⁹ *Id.* at 1230–33.

⁸⁰ *See id.*

⁸¹ *See id.*

⁸² I recognize the internal diversity within the population of people with intellectual and developmental disabilities, and use the aggregate terms to facilitate a discussion about persons with intellectual and developmental disabilities, such as autism or cerebral palsy, who may share some degree of mental impairment related to their disabilities.

⁸³ Dhanda, *supra* note 17, at 432 (“[J]udges arrive at decisions of incompetence relying upon medical experts opining as to the presence or absence of disability.”); *see, e.g., Ely v. State*, 384 S.E.2d 268, 268 (Ga. Ct. App. 1989) (holding that court-ordered psychological evaluation by expert, which included IQ testing, was relevant in determining victim’s ability to consent); *People v. Whitten*, 647 N.E.2d 1062, 1065 (Ill. App. Ct. 1995) (citing victim’s IQ score and mental health expert’s testimony in finding of victim’s inability to consent); *People v. McMullen*, 414 N.E.2d 214, 215 (Ill. App. Ct. 1980) (considering testimony of psychologist that victim had IQ scores below the average range for finding of victim’s ability to consent); *People v. Cratsley*, 653 N.E.2d 1162, 1164 (N.Y. 1995) (using an IQ test to establish female victim’s moderate retardation in sexual assault case); *People v. Easley*, 364 N.E.2d 1328, 1330–31 (N.Y. 1977) (considering school psychologist’s testimony and victim’s IQ scores to determine victim’s capacity to consent).

⁸⁴ In 1905, French psychologist Alfred Binet and medical student Theodore Simon published the first Binet-Simon scale, a test meant to identify children with intellectual,

adaptive measure built in, they are focused primarily on measuring cognitive and adaptive deficits rather than strengths in those areas.⁸⁵ The danger in moving to the functional test has been an overreliance on expert testimony and medical diagnostic evidence without assessing evidence of adaptive capabilities rather than deficits. Without more, the functional test becomes a status attribution model of legal capacity.

Second, a history of exclusion from meaningful, inclusive public education and involuntary institutionalization has contributed to significant structural deficiencies in sex education. Even those public schools that require

mental, or psychosocial disabilities. Trisha Imhoff, *Alfred Binet*, MUSKINGUM C. (May 2000), <http://www.muskingum.edu/~psych/psycweb/history/binet.htm> [https://perma.cc/WXA3-LU93]. The scale's purpose was to determine a child's most appropriate educational setting. Jenifer P. Marom, *Stanford-Binet Intelligence Scale*, ENCYCLOPEDIA MENTAL DISORDERS, <http://www.minddisorders.com/Py-Z/Stanford-Binet-Intelligence-Scale.html> [https://perma.cc/5MDA-5ZZQ]. The Binet-Simon test produced an identifiable numerical score and a conclusion regarding the mental age of the individual in comparison to her chronological age. Alfred Binet & TH. Simon, *New Methods for the Diagnosis of the Intellectual Level of Subnormals*, 12 L'ANNÉE PSYCHOLOGIQUE 191, 191–244 (1905), reprinted in THE DEVELOPMENT OF INTELLIGENCE IN CHILDREN 37–90 (Elizabeth S. Kite trans., 1916). Today, IQ assessments include more than the Binet-Simon test—the Stanford-Binet Intelligence Scale is the Binet-Simon test's modern equivalent and is in its fifth iteration. Gale H. Roid, *Stanford-Binet Intelligence Scales*, HOUGHTON MIFFLIN HARCOURT (2003), <http://www.hmhco.com/hmh-assessments/other-clinical-assessments/stanford-binnet> [https://perma.cc/E63C-EVYD]. Today, there are a multitude of different intelligence tests—e.g., the Woodcock Johnson III test, Differential Ability Scales (DAS-II), the Universal Nonverbal Intelligence test, the Wechsler Intelligence Scale for Children (WISC-V), etc. See Erica Patino, *Types of Intelligence and Achievement Tests*, UNDERSTOOD.ORG (June 5, 2014), <https://www.understood.org/en/school-learning/evaluations/types-of-tests/types-of-intelligence-and-achievement-tests> [https://perma.cc/7F7F-7PW4].

⁸⁵ Definitions of ID/DD have evolved over time and, most recently, reflect the adaptive components of ID/DD that determine the extent of supports needed. This is the product of questions concerning the validity of IQ tests, particularly for those with atypical communication methods. See *IQ Testing in Individuals with Intellectual Disability*, U.C. DAVIS HEALTH SYS. (June 18, 2015), http://www.ucdmc.ucdavis.edu/welcome/features/2014-2015/06/20150618_IQ-testing-Hessl.html [https://perma.cc/66W9-24XN]. All standard IQ tests, for example, have a “floor,” or a level below which they are unable to measure cognitive functioning. Individuals with intellectual disabilities often “have a cumulative (or Full Scale) IQ that is below what the test can measure But a floored score doesn't tell you anything about their true abilities.” *Id.*; see also *Frequently Asked Questions on Intellectual Disability*, AM. ASS'N ON INTELL. & DEVELOPMENTAL DISABILITIES (2013), <https://aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability#.VxNGOkf3gco> [https://perma.cc/M4AY-QQ9M] (defining intellectual disability as a function of both cognitive and adaptive measures that account for both strengths and limitations and urging evaluators to consider such criteria as “community environment typical of the individual's peers and culture,” “linguistic diversity,” and “cultural differences in the way people communicate, move, and behav[e]”).

formal sex education⁸⁶ do not provide a curriculum substantively tailored to meet the needs of people with intellectual disabilities.⁸⁷ Furthermore, the dominant messages and policy concerns in sex education are based on managing the risks associated with sex and disability and preventing abuse rather than on portraying sex as a positive good.

Effectively, the current doctrine of sexual incapacity creates a familiar catch-22 for disenfranchised populations: the test requires knowledge and appreciation of the consequences of sexual activity, yet it denies them meaningful educational and experiential opportunities to meet this standard.⁸⁸ The lives of people with ID/DD are highly regulated in return for economic support and personal assistance, particularly if they live in institutional settings such as nursing or group homes. In these settings, there is an absence of formal and informal opportunities to amass knowledge about sex and its biological consequences or to exercise sexual decision-making. Although older adults may experience a similar lack of privacy and dearth of private spaces, they are more likely to have experienced sexual decision-making prior to acquiring cognitive impairments, as was true, for example, in the Donna Rayhons case.⁸⁹

Third, and relatedly, the method of assessing knowledge and eliciting information from people with intellectual and developmental disabilities may require attention to the types of questions asked (e.g., leading questions may not produce accurate information because of a tendency to please) and asking

⁸⁶ As of March 1, 2016, twenty-four states and the District of Columbia require their public schools to teach sex education. *State Policies on Sex Education in Schools*, NAT'L CONF. ST. LEGISLATURES (Feb. 16, 2016), <http://www.ncsl.org/research/health/state-policies-on-sex-education-in-schools.aspx> [<https://perma.cc/SL3V-54TM>].

⁸⁷ Alison Boehning, *Sex Education for Students with Disabilities*, 1 L. & DISORDER 59, 59, 65 (2006), <https://scholarworks.iu.edu/dspace/bitstream/handle/2022/203/Boehning%20sex%20education%20for%20students.pdf?sequence=1> [<https://perma.cc/3PAU-7UDF>] (noting that sex education is controversial in general, and becomes even more so when the students in question have disabilities, and concluding that “sex education for America’s disabled students is lacking”).

⁸⁸ Conceptually, this resembles the position of blacks during the Jim Crow era who were denied meaningful educational opportunities on the one hand and, on the other, were presented with literacy tests as threshold barriers to exercising the right to vote. I do not suggest that voting and sex are analogous, nor that the experience of people with ID/DD is the same as blacks during Reconstruction. Rather, I raise this comparison to highlight shared experiences of systematic denials of meaningful education constructing barriers to the exercise of rights. See Gabriel J. Chin & Randy Wagner, *The Tyranny of the Minority: Jim Crow and the Counter-Majoritarian Difficulty*, 43 HARV. C.R.-C.L. L. REV. 65, 92 (2008) (noting that because “literacy tests could be passed by educated citizens of any color,” there was an incentive not to educate African-Americans—to do so “would be to risk that they would vote”).

⁸⁹ Boni-Saenz, *supra* note 1, at 1202–03, 1247–53 (discussing the case of Donna Ray, a woman with Alzheimer’s disease, whose husband faced criminal charges for engaging in sexual relations with her while her mental capacity to consent was in question).

those questions in different ways over several sessions.⁹⁰ This affects both the process of the forensic assessment as well as any interviews, depositions, or trial testimony elicited.

C. Supported Decision-Making

The practice of SDM in the context of people with ID/DD presents challenges distinct from its operation in the context of older adults with acquired impairments. As Boni-Saez notes, intellectual disability is an umbrella term with internal variances based on capacity to communicate (through words or conduct), physical mobility, severity of cognitive impairment, and education level, to name a few elements.⁹¹ The use of SDM as an alternative to forms of substituted decision-making, such as guardianship, does not neglect the existence of impairments and the need for support.⁹² Instead, the practice draws upon existing trusted networks of family, friends, and professionals already in the lives of people with disabilities.⁹³

Boni-Saenz's novel third prong of the test for sexual incapacity assumes that a support network exists and that it is willing and capable of identifying, facilitating, and, if necessary, executing the decisional agency of the person with an intellectual disability.⁹⁴ For example, consider a single mother whose son has cerebral palsy and cognitive impairments. The nineteen-year-old son receives special education services at school and significant support from his mother at home. Effectively non-verbal, he communicates through sounds and behaviors known to his mother and some teachers at his school and is learning to use an assistive communication device. On his eighteenth birthday, when the educational decision-making rights transfer from mother to son, the school district sends his mother a letter directing her to petition for guardianship in order to continue to be involved in her son's education.⁹⁵ Her legal

⁹⁰STEPHEN ELLMANN ET AL., *LAWYERS AND CLIENTS: CRITICAL ISSUES IN INTERVIEWING AND COUNSELING* 109–39 (2009) (discussing the interview process of an “atypical” client with diminished mental capacity and how to adjust questions accordingly). See generally Robert D. Dinerstein, *Client-Centered Counseling: Reappraisal and Refinement*, 32 ARIZ. L. REV. 501 (1990); Robert Dinerstein et al., *Legal Interviewing and Counseling: An Introduction*, 10 CLINICAL L. REV. 281 (2003); Stanley S. Herr, *Capacity for and Consent to Legal Representation*, in A GUIDE TO CONSENT 77 (Robert Dinerstein et al. eds., 1999).

⁹¹See Boni-Saenz, *supra* note 1, at 1212–13; Michael L. Wehmeyer & Shea Obremski, *Intellectual Disabilities*, INT'L ENCYCLOPEDIA REHABILITATION (2010), <http://cirrie.buffalo.edu/encyclopedia/en/article/15/#content> [https://perma.cc/Y5SR-VZP2].

⁹²See *supra* Part II.A.

⁹³*Id.*

⁹⁴Boni-Saenz, *supra* note 1, at 1235.

⁹⁵See 20 U.S.C. § 1414(a)(1)(D) (2006) (vesting the educational decision-making rights of a child with a disability to parents or legal guardians); *id.* § 1415(m)(2) (same as

representative recommends that she consider SDM as a less restrictive alternative to guardianship. Does this young man have the legal capacity to consent to using SDM? Does he have a meaningful choice in identifying his supporter? Practically, his mother has been and will continue to be his supporter. How does she determine her son's will and preferences? Given the level of support her son requires and his atypical communication, it is likely that his mother will continue to make decisions on his behalf in his best interests but with fewer records to show her decision-making role than if she had a court order appointing her as her son's guardian. How might such a mother approach the issue of sexual decision-making and support on behalf of her son? Empirical studies indicate high risk aversion and conservatism about sexual expression shared by families and care workers of people with intellectual and developmental disabilities.⁹⁶

Take *The Strange Case of Anna Stubblefield*, as the *New York Times* headline read.⁹⁷ New Jersey tried and convicted Anna Stubblefield, a Rutgers University professor, to twelve years in prison for sexually assaulting a thirty-year-old man with severe physical and communication impairments, DJ, with whom she claims to have had a romantic relationship.⁹⁸ DJ lived with his co-guardians, his mother and brother.⁹⁹ His brother was a former student of

§ 1414(a)(1)(D), if the child does not “have the ability to provide informed consent”); 34 C.F.R. § 300.520 (2011) (same).

⁹⁶ Beverley Clough, *Vulnerability and Capacity to Consent to Sex – Asking the Right Questions?*, 26 CHILD & FAM. L.Q. 371, 385–86 (2014) (noting that current approaches to sexual autonomy in the disability context over-emphasize sexual vulnerability, such that the focus “becomes risk management and protection”); Nina A. Kohn, *Matched Preferences and Values: A New Approach to Selecting Legal Surrogates*, 52 SAN DIEGO L. REV. 399, 408 (2015) (describing social science literature on incongruence in surrogate decision-making and “the extensive literature on surrogate decisionmaking in the health care context suggest[ing] that surrogate decisionmakers frequently make choices for patients that are inconsistent with what the patients would have done”). Risk aversion is a common theme in the disability context. For example, in the employment context, case law suggests that employers are entitled to engage in risk-averse behavior when it comes to hiring persons with disabilities. See Russell Powell, *Beyond Lane: Who Is Protected by the Americans with Disabilities Act, Who Should Be?*, 82 DENV. U. L. REV. 25, 35 (2004) (noting that the Supreme Court's interpretation of the ADA allows employers to fire or deny employment on the basis of paternalism). For example, in *Chevron v. Echazabal*, the Supreme Court unanimously held that employers may terminate or decline to hire a person whose disability poses a potential risk to the individual, even if no disability accommodations are requested. *Chevron v. Echazabal*, 536 U.S. 73, 86 (2002) (distinguishing between paternalism resulting in workplace discrimination and paternalism as an employer's mechanism of self-defense); Powell, *supra*, at 35.

⁹⁷ Daniel Engber, *The Strange Case of Anna Stubblefield*, N.Y. TIMES MAG. (Oct. 20, 2015), http://www.nytimes.com/2015/10/25/magazine/the-strange-case-of-anna-stubblefield.html?_r=0 [https://perma.cc/45Z8-PMNG].

⁹⁸ *Id.*; Daniel Engber, *What Anna Stubblefield Believed She Was Doing*, N.Y. TIMES MAG. (Feb. 3, 2016), <http://www.nytimes.com/2016/02/03/magazine/what-anna-stubblefield-believed-she-was-doing.html> [https://perma.cc/U5DV-NB3W].

⁹⁹ Engber, *supra* note 97.

Anna's who approached her and requested her assistance in using assistive communication methods with DJ.¹⁰⁰ Anna's academic scholarship touched on "facilitated communication," a method of physical support provided to the arm, hands, and fingers of a person with physical and communication impairments to assist them in the use of a type pad to express his or her thoughts.¹⁰¹ In the course of working with DJ, Anna claims that they fell in love and began a sexual relationship.¹⁰² After DJ and Anna approached his mother and brother to disclose their relationship, the family eventually accused Anna of rape and sexual assault, notified the police, and pursued prosecution.¹⁰³ The State advanced a theory of the case that Anna was a sexual predator who took advantage of DJ, in part to advance her own career in disability advocacy.¹⁰⁴ Its most persuasive evidence, according to the jury, was the presentation of DJ to the jury as demonstrative of his incapacity—the fact that his mother carried him into the courtroom (although prior photos of DJ suggest he uses a mechanical wheelchair), DJ's proclivity to drool, and his inability to verbally communicate.¹⁰⁵ In fact, because the judge determined that facilitated communication did not meet the rigorous evidentiary standards in *Daubert* for scientific evidence, the jury never had an opportunity to hear testimony or review documents about the use of facilitated communications between Anna and DJ.¹⁰⁶

In contrast, take the case of Henry and Donna Rayhons described by Boni-Saenz in his article.¹⁰⁷ Donna and Henry, a married couple, had a particular relationship with a past record of consent to sex, pleasurable interactions between them, knowledge of verbal and non-verbal communications, and no evidence of coercion or abuse.¹⁰⁸ Henry regularly visited Donna in her nursing home and, according to Henry, Donna would indicate her desire to engage in sexual conduct by saying, "[s]hall we play a bit?"¹⁰⁹ Boni-Saenz recognizes, "it is possible that [Donna] did not face a wide variety of relevant consequences because of her age, condition, and context, and she might thus satisfy" the knowledge and consequences prong of cognition-plus.¹¹⁰ Even if she did not meet the second prong of the test, Boni-Saenz contends that her

¹⁰⁰ *Id.*

¹⁰¹ *Id.*

¹⁰² *Id.*

¹⁰³ *Id.*

¹⁰⁴ *Id.*

¹⁰⁵ Engber, *supra* note 97.

¹⁰⁶ *Daubert v. Merrell Dow Pharms., Inc.*, 509 U.S. 579, 589–90 (1993); Engber, *supra* note 97.

¹⁰⁷ Boni-Saenz, *supra* note 1, at 1202.

¹⁰⁸ *Id.* at 1252–53.

¹⁰⁹ *Id.* at 1249; *see also* Bryan Gruley, *Rape Case Asks If Wife with Dementia Can Say Yes to Her Husband*, BLOOMBERG (Dec. 8, 2014), <http://www.bloomberg.com/news/articles/2014-12-09/rape-case-asks-if-wife-with-dementiacan-say-yes-to-her-husband> [<https://perma.cc/S7SZ-LPJ4>].

¹¹⁰ Boni-Saenz, *supra* note 1, at 1251.

sexual decision-making supporter, Henry, although in a position of potential conflict, presented enough evidence to overcome a rebuttable presumption of inadequacy given their relationship, history, and absence of evidence of force or coercion.¹¹¹ To the contrary, the evidence suggested that Donna did not want the nursing home staff to prevent her from sexual conduct with her husband.¹¹²

Unlike older adults who may have a more developed record of preferences and past decision-making, people with intellectual disabilities, by definition, have lifelong cognitive impairments that, for the reasons discussed in the Part above, have not generated the types of experiences to develop will and preferences. Furthermore, the people most likely to be their supporters are parents or family members who may have particular risk-averse views about sex and disability, or religious or cultural views about the appropriateness of sexual activity.

IV. CONCLUSION

Boni-Saenz's use of SDM as a way to decrease the number of people found sexually incapacitated is a novel and exciting application of SDM. Domestically, practitioners are currently experimenting with SDM models in health care, education, and in the exercise of financial and parental rights through advanced directives and other contractual models. SDM presents opportunities for legal scholars across specialty areas—here elder law, disability rights law, and international human rights—to push existing normative boundaries and redefine legal capacity in our domestic laws. The cognition-plus test for legal incapacity opens the door for greater recognition of the decisional-agency of persons with cognitive disabilities; however, Boni-Saenz continues to employ a functional approach to legal capacity that excludes some individuals from equal recognition before the law. There are also questions about how to define success and how to evaluate the implementation of SDM.¹¹³ This Response suggests a number of considerations for Boni-Saenz as he further develops his doctrinal test and seeks to apply it to people with intellectual and developmental disabilities.

¹¹¹ *Id.* at 1252–53.

¹¹² Gruley, *supra* note 109.

¹¹³ See, e.g., Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 995–1002 (2008) (questioning capacity of designated decision-makers to execute the principal's will and preferences); Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1129 (2013) (arguing the lack of empirical data on the success of SDM systems weighs against its ready adoption and prevents the development of empirically tested best practices).