

# **“Legal Capacity” Under the UN Convention on the Rights of Persons with Disabilities: In Support of Supported Decision-Making**

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## **Abstract**

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in 2008, has been ratified or acceded to by 183 countries. The author examines the elusive juridical notion of “legal capacity” set out in Article 12 of the Convention and the concomitant concept of “supported decision-making” (SDM). States Parties to the CRPD reaffirm that persons with disabilities have the right to “recognition everywhere as persons before the law” and “enjoy legal capacity on an equal basis with others” in all aspects of life. Parties also agree to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” and to ensure that these measures “provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.” Some signatories registered Declarations or Reservations regarding Article 12, on the distinction between rights and performance or capacity to act. This includes nations where Islamic influence is strong. SDM is cherished in the disability community as the antidote to guardianship and other antiquated frameworks for governing the lives of people with mental health, psycho-social and intellectual disabilities. References to disability (and cognitive disability in particular) are found in the Qur’an and other Islamic texts and in contemporary commentary and legislation in Muslim majority nations. Closely intertwined with the concept of legal agency is the last core Article 12 element: implementation of decision-making with support. The analysis in this article relies on CRPD Committee commentary as well as cultural, religious and secular interpretations, and on reflections based on the author’s personal experience.

**Keywords:** Convention on Rights of Persons with Disabilities, Guardianship, Islamic Law, Legal Capacity, Supported Decision-Making.

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## Introduction

Much ink has been spilled—or, rather, keyboard text manipulated—over this controversial provision of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).<sup>1</sup> In this article, I examine the elusive juridical notion of “legal capacity” in light of CRPD Article 12 and the concomitant concept of “supported decision-making” (SDM).<sup>2</sup> This examination relies on secular, cultural and religious interpretations, as well as reflections on personal experience.

The text of a treaty never tells the whole story. CRPD Article 12 reads as follows:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.<sup>3</sup>

## A. Islamic Law & Disability

The Qur’an and collected traditions of the Prophet Mohammed in the Hadith do not identify one particular term encompassing impairments associated with the general notion of disability. Instead, these classical sources of Islamic law use specific terms for

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<sup>1</sup>. See, United Nations Treaty Series, CRPD (Declarations and Reservations), [https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&clang=en#EndDec](https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=en#EndDec) (hereinafter “CRPD (Decl. & Reserv.”). The controversy is manifested by the high number of treaty reservations, understandings and declarations that have been lodged by states-parties. Brenton Kinker, *An Evaluation of the Prospects for Successful Implementation of the Convention on the Rights of Persons with Disabilities in the Islamic World*, 35 MICH. J. INT’L L. 443, 479-80 (2014).

<sup>2</sup>. I am indebted to Melbourne Law School Professor Anna Arstein-Kerslake for much of my thinking and commentary on this topic. See, ANNA ARSTEIN-KERSLAKE, RESTORING VOICE TO PEOPLE WITH COGNITIVE DISABILITIES: REALIZING THE RIGHT TO EQUAL RECOGNITION BEFORE THE LAW (Cambridge University Press, 2017) [hereinafter RESTORING VOICE].

<sup>3</sup>. 2515 U.N.T.S. 3. The Convention, which was enacted on 13 December 2006 and entered into force on 3 May 2008, has been ratified or acceded to by 183 countries and one regional organization. See, UN Enable website, <https://www.un.org/development/desa/disabilities/>. An additional subsection of Article 12 requires that state parties ensure equality in disabled persons’ ownership, inheritance and disposition of property, control of their financial affairs and access to credit. *Id.*, subsec. 12(5).

describing various disabilities, including *majnūn* (insane)<sup>1</sup> or *junūn* (madness or insanity).<sup>2</sup> Furthermore, while the generic term “disability” was not mentioned in the Qur’an, “disadvantaged people” may be used to refer to those with special needs.<sup>3</sup>

In contemporary (Arabic) law and literature in the Muslim world, broader terms are used, albeit derived from roots for words like defect, weakness, difficulty, limitation or inability: *as-ha`b ul-`ahat*, *dhawul `ahat*, *mu`awwaqūn*, or *`a`jizūn*. For example, *mu`awwaqūn* refers to individuals limited in their physical or mental ability—very similar to the English phrase “mentally or physically challenged”—and is commonly used in legal treatises on the subject.<sup>4</sup>

From an examination of terminology in the legal sources of Islam, one may conclude that the words used are descriptive and there is no stigma or evil associated with terms referring to disabled individuals. Furthermore, the classical sources recognize disability in the context of both individual condition and social disadvantage. This frames the discussion as one of individual rights and obligations of societal responsibility and service. It may then follow that “the lack of a term comparable with disability in the classical Islamic sources affirms the moral neutrality and normalcy of disability as a fact of life.”<sup>5</sup>

Both the Qur’an and the body of traditional Islamic social and legal custom and community practice in the Sunnah support the concept of social responsibility toward persons with disabilities and other “disadvantaged” individuals. Disadvantaged situations (lack of a physical, economic or social characteristic) are believed to be a result of

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<sup>1</sup> Isra Bhatti, Asad Ali Moten, Mobin Tawakkul & Mona Amer, *Disability in Islam: Insights into Theology, Law, History, and Practice* in 1 DISABILITY IN ISLAM: INSIGHTS INTO THEOLOGY, LAW, HISTORY, AND PRACTICE 159-60 (Catherine A. Marshall, Elizabeth Kendall, Martha E. Banks & Mariah S. Gover, eds., 2009).

<sup>2</sup> Muḥammad Fawzy Ḥasan ‘Abdel-Hay, *Mental Disability in Islamic Jurisprudence from a Moral Perspective* J. FACULTY OF LANGUAGES & TRANSLATION 380, 384 (citation omitted) (Issue No. 15, July 2018). *Junūn* is further classified by jurists into “congenital” and “accidental” insanity. The former is defined as incurable and the latter, resulting from psychological disorders, is deemed curable. *Id.* at 384-85 (citation omitted). The rationale and medico-legal bases for these distinctions remain unclear to me.

<sup>3</sup> See, Maysaa S. Bazna & Tarek A. Hatab, *Disability in the Qur'an: The Islamic Alternative to Defining, Viewing, and Relating to Disability*, 9 J. RELIGION, DISABILITY & HEALTH 5, 24-25 (2005) & Hiam Al-Aoufi, Nawaf Al-Zyoud & Norbayah Shahminan, *Islam and the Cultural Conceptualisation of Disability*, 17 INT’L J. ADOLESCENCE & YOUTH 205, 205 (Dec. 2012). Al-Aoufi *et al.* write that “an in-depth look into the notion of disability in Islam will help in understanding the development of special needs services within the context of Islamic culture.” *Id.*

<sup>4</sup> Bhatti *et al.*, *supra* note 5 at 160 (citing (VARDIT RISPLER-CHAIM, DISABILITY IN ISLAMIC LAW (2007))). One Al-Azhar scholar has expounded further on the origin of *mu`awwaqu`n* or “those who hinder or discourage.” See, ‘Abdel-Hay, *supra* note 6 at 384 (citation omitted). According to the holy book of Islam, “Allah knows well those holding others back” (Qur’an 33:18). “Evidently, the verse refers to those who create kinds of spiritual disability in souls of the believers, holding them back from taking active part in struggle against the aggressive enemies.” *Id.* at 384 & n. 9. For a more nuanced discussion of disability and Islamic law, see generally, Bazna & Hatab, *supra* note 7 and Kinker, *supra* note 2 at 553-60.

<sup>5</sup> Bhatti *et al.*, *supra* note 5 at 160. See also, Bazna & Hatab, *supra* note 7 at 23-24. There is, however, a counter narrative of the normalcy of disability or lack of stigma. Jurist Ibn Al-Jawzi of the Hanbali school wrote that God’s creation of disabled—i.e. “imperfect”—human beings was intended to “lead[] a person to realize the essence and loftiness of perfection, so a human being would appreciate the divinely-granted blessings as should be.” ‘Abdel-Hay, *supra* note 6 at 381-82 (citations omitted).

barriers produced by society and society is responsible for taking care of these individuals and for improving their conditions.<sup>1</sup>

## B. Capacity for Rights or to Act

In its final form, Article 12 “challenges paternalistic policies relating to people who lack ‘capacity.’”<sup>2</sup> As noted above, the Convention declares that “persons with disabilities have the right to recognition everywhere as persons before the law... [and] enjoy legal capacity on an equal basis with others in all aspects of life.” This became a point of contention in the latter stages of drafting the treaty text. A penultimate version of Article 12 contained a footnote that read: “In Arabic, Chinese and Russian, the expression ‘legal capacity refers to legal capacity for rights’ and not the ‘capacity to act.’”<sup>3</sup> This position was underscored in a letter to the *Ad Hoc* Committee from the Chair of the Group of Arab States, declaring that legal capacity should be limited to the capacity for *rights* “in accordance with the national laws of these countries.”<sup>4</sup> The Committee eventually deleted the footnote before the Convention was adopted, and decided that for translation purposes, the language on legal capacity should be adapted from the UN treaty aimed at combatting sex- and gender-based discrimination.<sup>5</sup>

Nevertheless, some state party signatories did register Declarations or Reservations regarding Article 12, on the distinction between rights and performance or capacity to act. This included nations where Islamic influence is strong. For example, although it signed the Convention, Egypt made an Interpretative Declaration that echoed the deleted footnote.<sup>6</sup> Syria issued an Understanding that adopted the interpretation of capacity stated in the letter to the drafting committee from the Chair of the Arab Group; Kuwait

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<sup>1</sup> See, Al-Aoufi, *et al.*, *supra* note 7 at 207.

<sup>2</sup> 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. 528, 559 (2007).

<sup>3</sup> See Rep. of the Ad Hoc Comm. on a Compr. & Integral Int’l Convention on the Prot. & Promotion of the Rights & Dignity of Pers. with Disabilities (Annex II), art. 9(2), 5th Sess., Jan 24-Feb. 4, 2005, U.N. Doc. A/AC.265/2005/2 (Feb. 23, 2005).

<sup>4</sup> See, Tina Minkowitz, *The United Nations Convention of the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions*, 34 SYRACUSE J. INT’L L. & COM. 405, 411, n. 26 (2007) (Letter of 5 Dec. 2006 from Iraq’s Permanent Representative to the United Nations, in his capacity as Chair of the Group of Arab States (emphasis added)). While the Arab Group’s statement did not explicitly address Islamic law or tradition, it presumably resonated for many member nations with Muslim majorities. See text *infra*, accompanying notes 16-18. The difficulty in defining permissible levels of support under Article 12 is evidenced in part by the *Ad Hoc* Committee’s recognition that disabled individuals “should be free from ‘forced interventions or forced institutionalization aimed at correcting, improving or alleviating any actual or perceived impairment,’” but its inability to define the terms “institutionalization” and “perceived.” Kinker, *supra* note 2 at 480 (citations omitted).

<sup>5</sup> Under the Convention on the Elimination of All Forms of Discrimination against Women, “States Parties shall accord to women, in civil matters, a legal capacity identical to that of men” and any private instruments “directed at restricting the legal capacity of women shall be deemed null and void.” *Id.*, art. 15 (2)-(3)(1979)United Nations, Treaty Series, vol. 1249, p. 13.

<sup>6</sup> Egypt’s interpretation of Article 12, ¶ 2 is that “persons with disabilities enjoy the capacity to acquire rights and assume legal responsibility (*ahliyyat al-wujub*) but not the capacity to perform (*ahliyyat al-ada*), under Egyptian law.” CRPD (Decl. & Reserv.), *supra* note 2. See also, Kinker, *supra* note 2 at 481-82 (explaining the distinction in these terms under Islamic jurisprudence and further categorization of “receptive” and “active” legal capacity).

appended a vague interpretive declaration, citing national law.<sup>1</sup> Other states-parties indicated more general reservations to the treaty or declarations based on possible conflicts between the Convention and Shari'a or conflicts with national statutes or constitutional law.<sup>2</sup> One commentator concludes, however, that "insofar as these Islamic states are more broadly restrictive than Western liberal democracies, these restrictions do not necessarily signal incompatibility with the CRPD."<sup>3</sup>

### C. Abandonment of Medical Model of Disability

The social model of disability has supplanted the outdated medical model. The former "does not disavow medical treatment or interaction with medical professionals,"<sup>4</sup> which is a position on professional judgment that many disability rights advocates might not share.<sup>5</sup> Unlike its antecedent, the social model views disability as caused by society and an environment which creates disabling barriers, rather than by a physical or mental impairment that needs to be treated, cured or rehabilitated. Its focus is on society rather than the individual.<sup>6</sup> This emphasis on the handicapping environment and social responsibility is consistent with the Islamic perspective discussed above. The debate over whether a human rights model<sup>7</sup> is now the favored framework for addressing disability could be the subject of a treatise all its own.<sup>1</sup>

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<sup>1</sup>. *Id.* Kuwait interpreted paragraph 2 to mean the "enjoyment of legal capacity shall be subject to conditions applicable under Kuwaiti law." *Id.* In its signature, Muslim majority Uzbekistan was joined by nations such as Canada, Estonia, Ireland and Poland with more restrictive or cautionary declaratory language on supported and substitute decision-making. CRPD (Decl. & Reserv.), *supra* note 2.

<sup>2</sup>. *See, e.g.,* Brunei (reservation regarding provisions that may be contrary to Brunei's Constitution and "the beliefs and principles of Islam"); Libya (health-care services to be provided to disabled persons without discrimination "in a manner that does not contravene the Islamic sharia and national legislation") and Iran ("not...bound by any provisions of the Convention, which may be incompatible with its applicable rules"). *Id.* Objections to such broad declarations were lodged by a number of treaty signatories. *Id.* In addition to alleging incompatibility with the Vienna Convention on the Law of Treaties, these objections mirrored the eleventh hour *Ad Hoc* Committee debate over the contentious footnote and the subjugation of universal human rights principles to national laws. Kinker, *supra* note 2 at 483.

<sup>3</sup>. *Id.* at 283.

<sup>4</sup>. RESTORING VOICE, *supra* note 3 at 71. This model asks that professionals not provide treatment or care "through the lens of a diagnosis or disability" but based on what individuals want for themselves, in order to overcome "a potentially unbending social or physical environment." *Id.*

<sup>5</sup>. A prominent disability civil rights attorney and former colleague reminded me a few years ago that "the Independent Living Movement was fueled in large part by a rejection of professional control over disabled lives." Stephen A. Rosenbaum, *Une Procédure en Difficulté: A Blueprint for Resolving "Special" Education Disputes through a Quasi-Inquisitorial Process*, 32 (2) WINDSOR Y.B ACCESS TO JUSTICE/RECUEIL ANNUEL DE WINDSOR D'ACCÈS À LA JUSTICE 115,130, n. 72 (2015). *See also, id.* at 130 (noting "radical critique that professional judgment is *per se* objectionable, given the authority and oversight historically exercised by medical personnel, therapists, social workers, educators and all manner of administrators") and Susan Stefan, *Leaving Civil Rights to the "Experts:" From Deference to Abdication under the Professional Judgment Standard* 102 YALE L.J. 639, 680, 691(1992) (disabled person's "voice is so completely silenced" vis-à-vis the professional's).

<sup>6</sup>. *See, Theresia Degener, A Human Rights Model of Disability* 3-5 (Dec. 2014) <https://www.researchgate.net/publication/283713863>.

<sup>7</sup>. For an introduction to the human rights model of disability, *see, Gerard Quinn and Theresia Degener, A Survey of International, Comparative and Regional Disability Law Reform, in DISABILITY RIGHTS LAW AND POLICY (MARY LOU BRESLIN AND SILVIA YEE, EDs.)* 13 (2002). In distinguishing between the human rights and social models of disability, renowned jurist and academic Theresia Degener writes that the latter's "sociological explanation of disability may lay the foundation for a social theory of disability," but does not provide

Article 12 rejects the liberal political theory notion of the individual as a “rational man, walking alone through the world” in favor of a rights holder legal scheme in which the individual “exercises her liberty through her social connections.” This change in thinking may be attributed to feminist scholars who have “pointed out the fallacy of the isolated autonomous man...instead highlight[ing] the interdependence of every individual...” Notably, “[s]ome individuals use social support more than others, but no one is free from the web of familial and social structures that make up our communities.”<sup>2</sup>

Recognition of interpersonal relationships and mutual dependencies should not detract from the notion of individual autonomy, but is part of the assistance in decision-making and taking autonomous actions utilized by many people with cognitive disability.

Nevertheless, while striving for the optimal balance between a person’s empowerment and inclusion on the one hand, and less forced dependency on the other, there is “[t]he reality that some people with cognitive disability may always be dependent on others” for decision-making and exercising legal capacity.<sup>3</sup> This acknowledgment is what underscored implicitly, if not explicitly, a number of states parties’ Declarations and Reservations related to Article 12 and/or to supported decision-making in particular.

#### **D. Advent of Supported Decision-Making**

SDM is cherished in the disability community as the antidote to guardianship and other antiquated frameworks for governing the lives of people with mental health, psycho-social and intellectual disabilities.<sup>4</sup> Closely intertwined with the concept of legal

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foundational moral principles or values, such as the human rights and fundamental freedoms which are articulated in the disability rights convention. Degener, *supra* note 21.

<sup>1</sup>. Professor Degener, a former chair of the CRPD Committee, notes that one of the social model’s founding fathers, Michael Oliver, has called for a halt to the strong criticism of this model by disability studies scholars “unless someone can come up with an alternative.” She asserts that the human rights model as embodied in the disability convention is just such an alternative. *Id.* at 3 (citation omitted). “[W]hereas the social model merely explains disability, the human rights model encompasses the values for disability policy that acknowledge[] the human dignity of disabled persons. Only the human rights model can explain why human rights do not require absence of impairment.” *Id.* at 6. Arstein-Kerslake, on the other hand, says “[t]he social model is embedded within the CRPD.” *RESTORING VOICE*, *supra* note 3 at 72. And so, the debate continues.

<sup>2</sup>. *Id.* at 62-63.

<sup>3</sup>. *Id.* at 63, 181. Our son was surely a candidate for long-term dependence. We vigilantly oversaw best practices applied in his 17 years of inclusive education and the developmental disabilities system’s life-time menu of supports and services. Still, it would be a stretch to describe David’s decision-making on matters that pertained to his legal capacity as “supported”—rather than discernment of his best interest. *See*, Stephen A. Rosenbaum, *Representing David: When Best Practices Aren’t and Natural Supports Really Are*, 11 UC DAVIS J. JUV. L. & POL’Y 161 (2007).

<sup>4</sup>. Professor Arlene Kanter sets out a clear and comprehensive overview of guardianship laws, their (unintended) consequences for people with disabilities and other vulnerable individuals, and the impact of Article 12. *See* Kanter, *supra* note 11 at 562-64. Professor Robert Dinerstein offers a pithy definition of SDM: “[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.” Robert 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).

agency is the last core Article 12 element: implementation of decision-making with support.

Compliance with the Convention means more than *pro forma* creation of a support system. One of the primary concerns with Article 12 is determining what decisions constitute “legal agency,” as this is central to the definition of legal capacity. The list of decision-making points is a familiar one: residential options, political participation and association, informed consent to medical treatment, commercial transactions and criminal justice system defense.

Not every act or decision rises to the level of an Article 12 exercise of legal agency. Moreover, the right to equal recognition is particularly interconnected with other rights, and individual decision-making may also embrace such rights as privacy, free expression, living independently and being included in the community. These are rights that may be protected under the CRPD, as well as a myriad of other human rights treaties that have been adopted in the last half century affecting women, children, racial minorities, migrant workers and members of the body politic and society at large.

All human beings have the potential to exercise legal agency, irrespective of the significance or complexity of their disability.<sup>1</sup> Agency should require an element of intention, which may be broadly and presumptively manifested by any indication of purpose and deliberation behind an action, decision or omission. This meaning comports with the universal law of contract.<sup>2</sup> However, rather than ascribe intentionality to an act that could legally bind a party who lacks an understanding of what they have signed, isn’t it better to maximize their autonomy as informed by robust decision-making support?

While debate remains amongst CRPD signatories about their interpretation of Article 12, there is general consensus on these core elements:

- Recognition of legal capacity for everyone on an equal basis
- Primacy of an individual’s will and preferences
- Establishment of adequate safeguards
- Replacement of *substitute* decision-making systems with *supported* decision-making.<sup>3</sup>

To view the right to support as narrow and only applicable to situations in which an individual is acting as a legal agent underestimates the difficulty in its operationalization and overestimates realization of the right to equal recognition and exercise of legal

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<sup>1</sup>. See, Eilionóir Flynn and Anna Arstein-Kerslake, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, 10 INT’L J. L. IN CONTEXT 81 (2014). Dr. Flynn holds an established chair in law at National University of Ireland (NUI) Galway and directs its Centre for Disability Law and Policy.

<sup>2</sup>. Professor Jasmine Harris squarely raises the question: “How would the law [of contract] 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?” Jasmine E. Harris, *The Role of Support in Sexual Decision-making for People with Intellectual and Developmental Disabilities*, 77 OHIO STATE L.J. FURTHERMORE 83, 94 (2016). Some commentators have tried to analyze this thorny question. See, *id.* at n. 57.

<sup>3</sup>. RESTORING VOICE, *supra* note 3 at 73.

capacity, without guaranteeing all levels of support.<sup>1</sup> “Support” includes both informal and formal arrangements and varies from one individual to another in its type and intensity.<sup>2</sup>

In promoting SDM over guardianship, conservatorship and other forms of proxy decision-making, Dr. Arstein-Kerslake reclaims a stigmatizing term so often associated with disability, when she calls out the human rights violations that one “suffers” when placed under guardianship and is thereby relegated to a “life without legal capacity.”<sup>3</sup> This stands in contrast to the traditional view in the Islamic world, as manifested at the time Article 12 was before the United Nations treaty drafting committee.

As noted above, social responsibility is viewed as a guiding principle in Islam, and the attention awarded to disabled members of the community is not laden with stigma. Arguably, the Qur’an and other Islamic texts lay down the idea of guardianship for so-called “disadvantaged” individuals—a generic term discussed above that could comprise groups such as persons with intellectual or developmental disabilities or individuals with mental health issues. Guardianship stems from “a sense of duty, fairness and kindness” and “ceases once the individual can be held accountable for their own decision-making ability.”<sup>4</sup> This charitable response to disability has been criticized as one that “may lead to a paternalistic view that devalues and discourages self-motivation amongst individuals with disabilities.”<sup>5</sup> Other commentators, however, point out that “in Islamic countries this view of disability is quite appropriate as it encourages and instils a sense of social responsibility.”<sup>6</sup>

Under SDM, it is imperative that a trustee or supporter “give primacy to a person’s will and preferences...and not over-regulate the lives of persons with disabilities.”<sup>7</sup> The objective is to empower the individual to make and communicate their own decisions and not “undu[ly] influence” those decisions.<sup>8</sup> The disabled person must be free of the

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<sup>1</sup>. Support for the quotidian decisions that do not rise to the level of legally protected status are nonetheless “intricately tied to our personhood and the construction of our individual personalities.” *Id.* at 148

<sup>2</sup>. Committee on the Rights of Persons with Disabilities, General Comment, No. 1, ¶¶ 17-18 (Eleventh Session)(CRPD/C/GC/1, 19 May 2014)(hereinafter “General Comment”). Human rights monitoring bodies, such as the CRPD Committee, adopt General Comments when there is concern about States Parties misinterpreting, or giving insufficient attention to, certain areas of human rights law. The comments are not legally binding but are considered an authoritative interpretation. Arstein-Kerslake and Flynn lobbied the CRPD Committee and heavily influenced its adoption of a General Comment interpreting Article 12. *See*, Anna Arstein-Kerslake and Eilionóir Flynn, *The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law*, 20 INT’L J. HUM. RIGHTS .471 (2016).

<sup>3</sup>. RESTORING VOICE, *supra* note 3 at 64. On the re-appropriation of epithets or references like *suffers from*, *see*, Stephen A. Rosenbaum, *Hammerin’ Hank: The Right to Be Raunchy or FM Freak Show?* 23 DISABILITY STUDIES QTRLY., n. 54 (2003), on-line journal (<http://www.dsqsds.org/article/view/432/609>). Reclaimed terms are “personally and politically useful as a means to comment on oppression because they assert our right to name our own experience.” Rachel Adams, SIDESHOW U.S.A. 227 (2001).

<sup>4</sup>. Al-Aoufi *et al.*, *supra* note 7 at 208.

<sup>5</sup>. *Id.* at 209 (citing MICHAEL OLIVER & COLIN BARNES, DISABLED PEOPLE AND SOCIAL POLICY: FROM EXCLUSION TO INCLUSION (1998)).

<sup>6</sup>. *See*, e.g., *id.*, citing H. Hagrass, “Definitions of Disability Policy in Egypt,” in THE SOCIAL MODEL OF DISABILITY: EUROPE AND THE MAJORITY WORLD (COLIN. BARNES & GEOFF MERCER (eds.)(2005).

<sup>7</sup>. General Comment, *supra* note 31 at ¶ 29.

<sup>8</sup>. *See, id.*, ¶¶ 22 & 29(b), (d) & (g). Professors Anita Silvers and Leslie Pickering Francis posit a prosthesis model in which a prosthetic device may execute functions of a missing limb but does not *supplant* the limb.



trustee's personality and preferences to ensure that their conception of the "good" is not conflated with the trustee's own biases and preferences.<sup>1</sup>

Arstein-Kerslake lays out four principles for safeguarding supported decision-making:

- Both parties are respected as legal agents with full personhood.
- The power or dependency imbalance does not result in domination by the support person.
- The product of the relationship is an expression of the will and preferences of the person with cognitive disability.
- The SDM system does not overregulate the lives of persons with disability.<sup>2</sup>

There is a particularly fine line between *substituted* and *supported* decision-making for persons who are nonverbal, minimally communicative and/or those who have complex disability. Moreover, it may be difficult to bridge the factions on whether substituted decision-making should be eradicated in its entirety for persons with a cognitive disability. One camp opposes the CRPD Committee position<sup>3</sup> and asserts that there must always be a legal option for substituted decision-making, with a regulated standard, although unclear what that standard is. The "abolitionist" camp, on the other hand, argues just as adamantly that to permit any substituted decision-making is an Article 12 violation.<sup>4</sup>

## E. Family and Other Carers

Family members provide the most obvious form of "natural support" and where family is not an option, friends and the community can fulfill that role.<sup>5</sup> However, could family dependency be more harmful than healthy? Should the state intervene? These questions preoccupy social welfare agencies charged with protecting children, youth and

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Likewise, a trustee can execute, but not substitute, another's thinking process; each individual can reach her own conception of the "good" through the legal validation of her will and preferences. RESTORING VOICE, *supra* note 3 at 179-82 (citing Anita Silvers and Leslie Pickering Francis, *Thinking About the Good, Reconfiguring Liberal Metaphysics (or Not) for People with Cognitive Disabilities*, 40 METAPHILOSOPHY 475, 485 (2009)).

<sup>1</sup>. Here again, I find myself struggling to reconcile the imagery with the pragmatic, i.e., the difference between "best interpretation" of a person's will and preferences (support) and ascertaining what is in their "best interest" (substitution).

<sup>2</sup>. RESTORING VOICE, *supra* note 3 at 190. See also, General Comment, *supra* note 31 at ¶¶ 21, 22, 24, 25 & 29.

<sup>3</sup>. In fact, the Committee's position may not be absolutist, given the guidance provided in the General Comment on replacing substituted decision-making "regimes" with SDM. See, RESTORING VOICE, *supra* note 3 at 75.

<sup>4</sup>. *Id.* at 74.

<sup>5</sup>. See, Rosenbaum, *supra* note 25 at 176-77. Family and natural support models vary from California's legislated "circles of support" to members of the family or extended family found in a variety of cultural and religious settings. See, e.g., Bazna & Hatab, *supra* note 7 at 23-24; Rooshey Hasnain, Laura Cohon Shaikh & Hasan Shanawani, *Disability & The Muslim Perspective: An Introduction for Health Care & Rehabilitation Providers* §IV(a)-(b)(discussing family duties and responsibilities and cultural collectivism)(Center for International Rehabilitation Research Information & Exchange, 2008), <http://cirrie-sphp.webapps.buffalo.edu/culture/monographs/muslim.php#s4> (last visited 4 Apr. 2022).

older adults against abuse and neglect. In the disability context, the concern is about adults with “high support needs” and the degree to which a parent, with whom the adult child resides, is paternalistic, controlling, exasperated or frustrated in their relationship.<sup>1</sup>

Philosopher and ethicist Eva Feder Kittay posits that “society must consider the needs of the ‘care worker’ or support person”<sup>2</sup> who may also need support, through information and training, in negotiating between family members on what constitutes influence or sharing.<sup>3</sup> While a parent would not likely be viewed as someone “with lived experience of disability,” they should nonetheless be considered a member of “the disability community.”<sup>4</sup>

As to the status of non-familial carers, support persons and service providers, we must acknowledge the universality of support: “None of us exercise legal capacity alone or in a vacuum. We take support from those around us—our friends, families, *experts*, and *professionals*.”<sup>5</sup> A neo-liberal approach would seek to remove state-supported assistance to individuals with disabilities. Notwithstanding legitimate concern about overregulation of disabled lives, professionalization is not in itself a bad trend.<sup>6</sup> A professional service provider need not replace an appropriate family member or friend or run counter to religious or cultural values that favor the relationship between disabled individuals and their families. If the international community’s goal is for the genuine exercise of legal capacity by persons with cognitive disability, respect for individual will and preferences, without domination and power imbalance, the mechanism could be professional as much as familial or communal.

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<sup>1</sup>. State intervention to “fix” disabled lifestyles carries its own risks. Disability rights colleagues and I engaged in a spirited debate several years ago about the plight of an intellectually disabled young man who appeared to enjoy maximum autonomy and minimum decision-making support. This included the right to make bad or uninformed choices, even when it leads to ridicule, stigmatization or abuse. See, Rosenbaum, *supra* note 32 at text accompanying notes 124-174.

<sup>2</sup>. Eva Feder Kittay, *LOVE’S LABOR: ESSAYS ON WOMEN, EQUALITY AND DEPENDENCY* (1999).

<sup>3</sup>. The stresses faced by parents, siblings or other family members who engage in care or support may indeed be substantial and are not simply alleviated by extra hours of “respite care.” Rosenbaum, *supra* note 25 at 169.

<sup>4</sup>. *RESTORING VOICE*, *supra* note 3 at 207, 218.

<sup>5</sup>. *Id.* at 181 (emphasis added).

<sup>6</sup>. I sometimes find myself in the minority in the disability community in my deference to professional judgment, even though, with respect to other key decision-making, we don’t tend to discount expert advice *per se*. On the contrary. See, Rosenbaum, *supra* note 20 at 128-30 & accompanying notes.

## Conclusion

At what point does supported decision-making become a contrived exercise? With this template-like guidance there is a risk of *pro forma* compliance, public backlash or confusion. It is not enough to recite a general recipe for legal agency, capacity, or appropriate decision-making mechanism, when what is required is nuance, contextualized adaptation and common sense. In other words, the paradigm does not always fit, even when guided by dignity<sup>1</sup> and normalization.<sup>2</sup>

For the genuine exercise of legal capacity, it is not enough for a jurisdiction to be Article 12 compliant.”<sup>3</sup> There remain the questions of cost and pragmatic implementation. Who pays for support mechanisms and oversight of those mechanisms—whether a petition to the British Columbia Public Guardian and Trustee, establishment of the South Australia Supported Decision-making Committee or funding a municipal *god man*<sup>4</sup> in Sweden?

More empirical research into the exercise of legal capacity is needed, as well as the potential for law reform in the areas of discrimination, medical consent and laws on crime and contract. This should be accomplished through “rights-based research” in which the voice of disabled people is incorporated at all levels.<sup>5</sup> No one can quibble with prescriptions for research design and co-production, but I have yet to see an inclusiveness that rises above *pro forma* participation by persons with significant intellectual disabilities in a stakeholder meeting or employment productivity that is meaningful. To ensure that “nothing about us without us” is more than a mantra, advocates and policy makers need to conscientiously design and execute an appropriately tailored research or self-advocacy vehicle for persons with cognitive disabilities.

Civil society organizations must contend with judges, mental health professionals, service providers, law enforcement, family members and others, as “[a]lienating these groups from the [Article 12] discussion can create additional barriers to rights

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<sup>1</sup>. See, e.g., Degener, *supra* note 21 at 15 (noting respect for inherent dignity of persons with disabilities is purpose and one of eight principles of CRPD, and a cornerstone of international human rights and domestic constitutional law) and Jonathan S. Simon and Stephen A. Rosenbaum, *Dignifying Madness: Rethinking Commitment Law in an Age of Mass Incarceration*, 70 U. MIAMI L. REV. 1, 21-25 (2015)(reviewing ancient and post-Holocaust emergence of pragmatic doctrine of dignity, based on five core meanings and informed by human rights practice). I would like to think that David ultimately lived what Dr. Arstein-Kerslake would describe as a life of “well-being” or “human flourishing.” RESTORING VOICE, *supra* note 3 at 49-50.

<sup>2</sup>. The paradigm did not fit for David as a teenager and later an adult. I chafed at such fictionalized decisions as David “signing over” his educational rights to my spouse and me at age 18 or seriously considering an invitation letter to apply for admission to University of California, Berkeley based on the 3.9 GPA he earned in his integrated high school program, where part of the day was spent in an “inclusion room.” See, Rosenbaum, *supra* note 25 at 171 (best practices “do[ ] not always jibe with one's own reality”). Likewise, I protest the infantilization by which family members and healthcare providers strip individuals like Ashley X of their autonomous right to bodily integrity and sexuality, the loss of which leaves them less valuable as human. Julia Epstein and Stephen A. Rosenbaum, *Revisiting Ashley X: An Essay on Disabled Bodily Integrity, Sexuality, Dignity, and Family Caregiving*, 35 TOURO L. REV. 101, 108-15 (2019).

<sup>3</sup>. See, General Comment, *supra* note 31 at ¶¶ 24, 28 &30.

<sup>4</sup>. Readers may be tempted to misinterpret what is a Swedish term for an appointed support person. Not a supernatural being, the *god man* “is akin to a mentor and does not alter the civil rights of the individual....[but] is meant to be a supportive and helping aid rather than a coercive authority...” RESTORING VOICE, *supra* note 3 at 210.

<sup>5</sup>. See, General Comment, *supra* note 31 at ¶ 50(c).

realization.”<sup>1</sup> Whether the barrier is active resistance to change or principled difference on the nature of decision-making support, continuous education and dialogue should be the byword.

Article 12 is so contentious because “it requires real changes to existing legal systems and challenges the popular notion that people with disabilities lack decision-making skills.”<sup>2</sup>

Even if the challenge is not due to popular misconception, but to a deeply held professional standard or a religious viewpoint, change is still hard. It may require a transformation more in culture and best practices than in legal interpretation.<sup>3</sup> “[A] preference for autonomy above all other rights and needs of the individual” is not the solution to attaining recognition of legal capacity, but must be reconciled with a panoply of other human rights.<sup>4</sup> In the end, the recognition of legal capacity and equal treatment for all people with cognitive disabilities, with the requisite decision-making support, may be more about human dignity than anything else.

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<sup>1</sup>. RESTORING VOICE, *supra* note 3 at 222.

<sup>2</sup>. *Id.* at 73.

<sup>3</sup>. NUI Galway Professor Emeritus and International Disability Expert Gerard Quinn invokes Roscoe Pound in observing that “[t]he pillars to [legal] doctrine shift...but...[i]t’s hard to change the underlying base completely and quickly.” *Id.* at xi-xii.

<sup>4</sup>. *Id.* at 181. *See also*, Simon and Rosenbaum, *supra* note 49 at 38 (discussing how individual autonomy and respect for inherent dignity are as essential to people with mental disabilities as enjoyment of internationally recognized human rights).

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