

# CHANGING PARADIGMS: MENTAL CAPACITY, LEGAL CAPACITY, GUARDIANSHIP, AND BEYOND

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## I. INTRODUCTION

### A. Capacity and Incapacity

Guardianship is the legal process by which the state deprives a person of the power to make and act on some or all decisions, and grants that power to another individual or entity, upon a finding that the person lacks capacity.<sup>1</sup> Inherent in this process are several very

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1. A person may lack capacity for a number of reasons or as the result of a number of different medical and psychiatric conditions. She may have suffered brain damage in an accident, or lost cognitive function because of a stroke. She may have a mental illness (now denominated a psycho-social disability) like schizophrenia; her cognitive abilities may be impaired by virtue of medications she is taking or illegal drug use. In all these situations we are dealing with adults who have previously possessed, but have now temporarily or permanently lost, cognitive ability and, hence, "mental" capacity. These are the persons covered by current "adult guardianship" status. There are also persons—millions of them—who are born with cognitively disabling conditions like Down syndrome, cerebral palsy, and autism, which have been denominated "mental retardation" and "developmental disabilities" and which are now more generally referred to as "intellectual disabilities." Most guardianship statutes cover both groups: the newly "incapacitated" and people with intellectual disabilities. *But see* notes 86

different notions of capacity<sup>2</sup> and incapacity, which have changed dramatically over time.

The earliest, binary<sup>3</sup> model was one premised on status: incapacity as a defect that deprived an individual of the ability—and consequently the legal right—to make choices. Thus, under early English law, guardianships were imposed on persons declared to be “idiots” or “lunatics.” With advances in medicine and the rise of psychiatry and psychology, the conditions that led to guardianship became “medicalized,” and the determination of incapacity moved to one that was primarily diagnosis-driven.

By the second half of the twentieth century, this model morphed into a more nuanced and functional approach. It saw capacity as inherently cognitive, and understood *incapacity* as the inability both to understand information relevant to making a decision and to understand the potential consequences of making—or not making—that decision.

Under a functional approach, capacity is also seen as varying over time and with regard to specific decisions to be made. This model, which may impose plenary or limited guardianship on “wards” or “incapacitated persons,”<sup>4</sup> is the one generally in use in the United States today.<sup>5</sup>

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and 127 (listing statutes separately imposing guardianship on the latter). While recognizing the enormous differences between these various groups and among the individuals within them, the term “persons with intellectual disabilities” will be used for all, unless the specific incapacitating disability has particular relevance (as, for example, in the involuntary commitment of persons with mental illness). See *Heller v. Doe*, 509 U.S. 312 (1993) (finding a rational basis for applying different standards of proof to commitment of “mentally ill” and “mentally retarded” persons).

2. The term “capacity” here is used to denominate “mental” capacity or “the cognitive requisites necessary for individuals to be recognized as able to exercise legal capacity.” I take this distinction and terminology from an extraordinarily thoughtful paper, Michael Bach & Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* 15 (Oct. 2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

3. That is, a person either had, or did not have capacity. If the latter, he was “incapacitated” and subject to the full power of the state.

4. Nomenclature is important. Understanding and naming a person solely based on her disability—“idiot, incapacitated person”—reduces the person to her disability and makes her an *object* of the law. In the equality model of human rights, the person is central and universal; and temporary or permanent disabilities are only characteristics she possesses. Thus, underscoring her position as a legal *subject*, the move is to “*person with* (intellectual or other) disability.” See Arlene S. Kanter, *The Law: What’s Disabilities Studies Got to Do With It* or

The opposite of these models of incapacity, the “unstated norm,”<sup>6</sup> has sometimes been referred to as legal capacity characterized by the lack of any mentally disabling condition and/or by possession of “normal” cognitive functioning. Two leading commentators on guardianship law have called legal capacity and incapacity a legal fiction, necessary “to tell us when a state legitimately may intrude into an individual’s affairs and take action to limit an individual’s rights to make decisions about his or her own person or property.”<sup>7</sup>

Legal incapacity, so conceived, is important precisely because a [legal] fiction is determined by prevailing values, knowledge, and even the economic and political spirit of the time. . . . [T]he criteria or elements needed to establish legal incapacity are the products of society’s prevailing beliefs concerning individual autonomy and social order, tempered by the restraint of legal precedent. Just as societal values and needs have evolved over time, so will the legal criteria for capacity and incapacity.<sup>8</sup>

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*an Introduction to Disability Legal Studies*, 42 Colum. Hum. Rts. L. Rev. 403, 434 (2011). For a thorough discussion of the “evolutionary” development of terminology applied to disability (i.e., feeble-minded to mentally deficient to mentally retarded), see Robert L. Burgdorf, Jr., *The Legal Rights of Handicapped Persons: Cases, Materials and Text* 46–47 (1980).

5. To a greater or lesser extent, the current model, as those before it, may also encompass an “outcomes” test of capacity. That is, a person’s ability to make decisions may be judged by whether those decisions are “bad” or “unwise” or potentially dangerous. See, e.g., Peter Margulies, *Access, Correction and Voice: A Contextual Approach to Representing Senior Citizens of Questionable Capacity*, 62 Fordham L. Rev. 1073, 1082 (1994). The medical profession historically has adopted a paternalistic view of capacity based on the substance of decisions. If the decisions appear “right,” the individual possesses capacity. If the decisions are “wrong,” the individual lacks capacity. *Id.* at 1075. To state this position, however, is not to agree with it. Personal autonomy includes what has sometimes been called the “dignity of bad choices.”

6. Martha Minow notes that “we generally adopt an unstated point of reference when assessing disabled persons and that the point of reference typically expresses perspectives of the majority of power-holders within society.” Kanter, *supra* note 4, at 421 n.57 (citing Martha Minow, *Making All the Difference: Inclusion, Exclusion, and American Law* 51 (1990)).

7. Charles P. Sabatino & Erica Wood, *The Conceptualization of Capacity of Older Persons in Western Law*, in *Beyond Elder Law: New Directions in Law and Aging* 35, 36 (Israel Doron & Ann Snoden eds., 2012).

8. *Id.*

Or, as another observer notes, “capacity is a shifting network of values and circumstances.”<sup>9</sup>

Legal capacity has another meaning in international human rights law and international conventions<sup>10</sup> and within the discourse of the disability rights movement.<sup>11</sup> Legal capacity here refers both to people’s capacity to *have* rights on an equal basis with others<sup>12</sup> and to have the capacity to *act* and have their actions recognized by the law.<sup>13</sup>

In 1962, Thomas Kuhn published a remarkable book that coined the expression “paradigm shift.”<sup>14</sup> Although he was writing

9. Margulies, *supra* note 5, at 1083.

10. Legal capacity is first mentioned in the Convention on the Elimination of All Forms of Discrimination Against Women, *opened for signature* Dec. 18, 1979, art. 15, 1249 U.N.T.S. 13, 20 (entered into force Sept. 3, 1981).

11. One leading disability advocate puts it this way:

Let me suggest that legal capacity is the epiphenomenon. It provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe—a web of mutual rights and obligations voluntarily entered into with others. . . . Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions.

Gerard Quinn, *Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD*, Paper Presented at Harvard Law School, Feb. 20, 2010, *reprinted* in NIU Galway Ctr. for Disability Law & Policy, *Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality* app. 6, at 73, *available at* [http://www.nuigalway.ie/cdlp/documents/cdlp\\_submission\\_on\\_legal\\_capacity\\_the\\_oireachtas\\_committee\\_on\\_justice\\_defence\\_and\\_equality\\_.pdf](http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf).

12. This is sometimes referred to as passive legal capacity or “legal capacity for rights.” See, e.g., 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 (2010); Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Strangehold of the Past or Lodestar for the Future?*, 34 Syracuse J. Int’l L. & Com. 429 (2007). Thus, for example, children have rights—to be free of abuse and neglect, to financial support, to education—but they lack legal status to act on them. That is, they may not enter into legally binding contracts, vote, etc. For a nuanced discussion of children’s “rights” and legal disabilities, see Martha Minow, *Making All the Difference: Inclusion, Exclusion, and American Law* 51 (1990).

13. Unlike children, adults can engage in transactions which the law will recognize and enforce (contracts), vote, marry, make binding health care decisions, etc. For discussion of the distinction between the capacity to *have* rights and the capacity to act legally in the context of the Convention on the Rights of Persons with Disabilities, see *infra* Section IV(C)(2).

14. Thomas S. Kuhn, *The Structure of Scientific Revolutions* (1962).

specifically in the context of the history of science, Kuhn's notion of paradigm shift has been exported to describe seismic changes in almost every conceivable realm, from politics to economic theory, fashion to sports, literary criticism to musicology—and frequently to law. While the notion of paradigm shift has become a cliché,<sup>15</sup> it is a useful and often compelling way of succinctly portraying a real (here social, legal, and political) phenomenon.

Kuhn described paradigms as “universally recognized scientific achievements that for the time provide model problems and solutions to a community of practitioners.”<sup>16</sup> He urged us to look at “the role of . . . external social, economic, and intellectual conditions”<sup>17</sup> which create a “change in the perception and evaluation of familiar data” that “[reorient]” our vision and understanding, creating a paradigm shift that “alters the historical perspective of the community that experiences it.”<sup>18</sup>

Kuhn's formulation of re-orientation and re-evolution explains both the ways in which the law changes, discussed at some length here, and the more ephemeral way in which changes *in* law—here the enactment of the United Nations Convention on the Rights of Persons with Disabilities (“CRPD” or “the Convention”)<sup>19</sup>—affect the way in which we see the world. As two leading commentators have noted,

[H]uman rights norms have power to work change  
through non-legal mechanisms. . . . [They] trigger

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15. The characterization of legal changes or shifts in the law as paradigm shifts arises seemingly endlessly in any conversation about disability rights. As one leading figure in the field has said, “I know what you are thinking! If I hear one more person sprouting platitudes about the ‘paradigm shift’ I might be inclined to random acts of violence!” Gerard Quinn, *Rethinking Personhood: New Directions in Legal Capacity Law & Policy or How to Put the ‘Shift’ Back into ‘Paradigm Shift’*, Paper Presented at the University of British Columbia, Apr. 29, 2011, reprinted in NIU Galway Ctr. for Disability Law & Policy, *Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality* app. 5, at 44, available at [http://www.nuigalway.ie/cdlp/documents/cdlp\\_submission\\_on\\_legal\\_capacity\\_the\\_oireachtas\\_committee\\_on\\_justice\\_defence\\_and\\_equality\\_.pdf](http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf).

16. Thomas S. Kuhn, *The Structure of Scientific Revolutions* x (3d ed. 1996).

17. *Id.* at xii.

18. *Id.* at x–xi.

19. International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, G.A. Res. 61/106, Annex I, U.N. Doc. A/RES/61/106 (Dec. 13, 2006), available at <http://www.un.org/esa/socdev/enable/documents/tccconve.pdf> [hereinafter CRPD].

belief changes by providing information to societies about the human rights ideas with the attendant effect of serving as educational tools for altering social mores.<sup>20</sup>

In the past half-century we have observed just such a paradigm shift. The idea of incapacity as an illness or defect that renders the person suffering it to an object of charity and protection, subject to plenary guardianship based on best interests which constrains her personal life and the control of her property has been re-examined and largely rejected. This is the “old” paradigm.

With changes in medical practice, psychology, and a burgeoning legal framework of civil rights and procedural due process, we have moved to a functional, cognitive understanding of incapacity. This current paradigm leads to “tailored” or limited guardianships, which represent the least restrictive means of protection, the promotion of greater autonomy for the incapacitated person, and robust procedural protections in the determination of incapacity and appointment of a guardian. New York’s adult guardianship statute, Article 81 of the Mental Hygiene Law (“MHL Art. 81”), exemplifies these changes and the current paradigm.

Now, less than two decades later, in an increasingly globalized world, a new paradigm is emerging, premised on international human rights.<sup>21</sup> This paradigm sees incapacity as socially constructed, insists on the full legal capacity of every person with intellectual disabilities, and does away with substituted decision-making in favor of society’s obligation to provide appropriate supports to permit everyone to make his or her own decisions. Like every emerging paradigm, this challenges our perceptions and our understanding of when, how, and even *if* the state may intervene in a person’s life, and it has the potential to be deeply unsettling. And, unsurprisingly, it takes time.

The framework of paradigm shift is therefore helpful in moving us from what has become a comfort zone to a new way of thinking about people with intellectual disabilities and their capacities. This new conceptualization based on international human rights may initially appear hopelessly utopian, or dangerously naive.

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20. Janet E. Lord & Michael Ashley Stein, *The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities*, 83 Wash. L. Rev. 449, 474–75 (2008).

21. See Arlene S. Kanter, *The Globalization of Disability Rights Law*, 30 Syracuse J. Int’l L. & Com. 241 (2003).

Locating the shift in a history of society's—and the law's—radically changing views of the very same people may facilitate the reorientation Kuhn so brilliantly described and named.

As he wrote, a new paradigm “is seldom or never just an increment to what is already known. Its assimilation requires the reconstruction of prior theory and the re-evolution of prior fact, an extrinsically revolutionary process that is [never] completed . . . overnight.”<sup>22</sup>

This Article maps the paradigm shifts in society's view of incapacity and the law's responses through guardianship, and now, potentially, its abolition. For each paradigm shift, it briefly describes some of the social and political changes that contributed to the shift. And, as a framing device, I employ some personal stories of my own experiences as a judge and advocate—“vignettes”—to humanize Kuhn's more abstract explanations of how radical change happens.

In Part II, I briefly describe the centuries-long history of notions of incapacity from “status,” or inherent defect, to a more medicalized model which views incapacity as the result of a disability that is susceptible to treatment, if not always a cure. I introduce Part I with a vignette that demonstrates the Kuhn-ian moment in which the received wisdom about incapacity and the law's treatment of incapacity no longer seems to make sense in light of changed conditions.

Part III explains how social and legal/constitutional changes led to a new, more functional model of incapacity, to significantly increased procedural protections in guardianship law, and to a preference for limited guardianship intended to maximize an “incapacitated person's autonomy and dignity.” These were the changes responsible for “alter[ing] the . . . perspective of the community that [has] experience[d]” the paradigm shift.<sup>23</sup> New York's adult guardianship statute is illustrative and is described in some detail. A central issue in the current paradigm, also examined in some detail, is the standard to be employed by a guardian in making decisions for the person under guardianship: substituted decision-making or best interests. Part III includes one vignette (No. 2) about the resistance that inevitably accompanies paradigm shift and closes with another (No. 3), which illustrates the disbelief and resistance that occur as a new paradigm begins to emerge.

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22. Kuhn, *supra* note 16, at 7.

23. Kuhn, *supra* note 16, at xi.

Part IV briefly traces the development of the disability rights movement, the transformation to a social model of disability, ideas of normalization and inclusion, the development of “person-centered planning” and legislative progress toward a non-discriminatory vision of equal participation for people with disabilities,<sup>24</sup> which culminated domestically in 1990 with the passage of the Americans with Disabilities Act (ADA).<sup>25</sup> Part IV also briefly traces the roughly contemporaneous growth of an international human rights discourse and the use of United Nations machinery by disability advocates and persons with disabilities to enact the CRPD.

The CRPD, described in some detail, sets forth a radically new principle of equality for persons with intellectual and psychosocial disabilities in which, as a matter of international human rights law, all such persons are entitled to full “legal capacity” and to make all personal and financial decisions for themselves. Legal guardianship, substituted and best interests decision-making, and legal *incapacity* are potentially abolished in favor of a model of supported decision-making. Vignette No. 4 provides an example of how that model can begin to “[alter] the historical perspective of the community that experiences it.”<sup>26</sup>

Part V describes the various legal and practical efforts to create and honor supported decision-making for such persons currently in effect, surveying supported decision-making laws in Europe and North America. Part VI describes the CRPD’s mandate for change, the structural innovations it incorporates to accomplish that end, and the “next steps” on the abolition of guardianship being taken by countries that have—and have not yet—ratified the CRPD. I conclude with a vignette (No. 5) about how the emerging paradigm can begin to transform our vision and what may lie ahead if and when the United States ratifies the CRPD, noting that, in Kuhn’s words, this is “an extrinsically revolutionary process that is [never] completed . . . overnight.”<sup>27</sup>

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24. This history is, in fact, incredibly complex and no condensed description can do it justice. For an excellent and deeply nuanced account, see Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America* (2009).

25. See *Equal Opportunity for Individuals with Disabilities*, 42 U.S.C. §§ 12101–12213 (2001).

26. Kuhn, *supra* note 16, at xi.

27. *Id.* at 7.



## II. THE OLD PARADIGM

## Vignette No. 1: January 1986

*I was a state judge assigned to the civil side of our trial court of general jurisdiction in Manhattan.<sup>28</sup> The court had just adopted an individual assignment system ("IAS") pursuant to which I was given an "inventory" of about 2,500 cases, ranging from personal injury to contract, matrimonial to toxic tort, and administrative review to real estate law. Among them, and already set for hearing my first week, was a case under then-Article 78 of the Mental Hygiene Law, New York's conservatorship and committee legislation.<sup>29</sup> I had never presided over such a case before and was entirely unfamiliar with the statute.*

*I entered the courtroom to find a phalanx of lawyers, several psychiatrists, and a number of representatives of the press. The hearing involved a petition to appoint a committee of the person and a conservator of the property of the elderly widow of a famous art critic, the latter having collected some very important and very valuable art. To my surprise, the widow herself was not present. I was puzzled. I asked the lawyers why. "Oh no," they said. "She's demented, and she wouldn't understand. It would only upset her. And," they added, "the law doesn't require it."<sup>30</sup>*

*Before becoming a judge I had been a civil rights lawyer, had litigated and won a due process case in the United State Supreme Court on the rights of mentally-ill criminal defendants, and had taught constitutional law. Where was the due process here? Could the state really remove all of a person's rights—her liberty and control over her property—in her absence, solely on the testimony of a*

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28. In New York, the trial court is called the Supreme Court because it predated the federal court system and the U.S. Supreme Court; the highest court is called the Court of Appeals.

29. N.Y. Mental Hyg. Law § 78 (McKinney 1988) (repealed 1993).

30. They were, unfortunately, correct. Under the law and practice then in effect, the committee statute, Article 78 of the New York Mental Hygiene Law, did not provide for the appearance or non-appearance of the person for whom a committee was sought although the conservator statute permitted a hearing in the absence of the proposed "conservatee" only if "he is unable to attend by reason of physical or other inability and such inability is established to the satisfaction of the court." N.Y. Mental Hyg. Law § 77.07 (McKinney 1998) (repealed 1993). Anecdotally, courts were generally satisfied to exclude the subjects of both conservatorship and committee proceedings.

psychiatrist that she suffered from "organic brain syndrome" and lacked capacity?

*Under the law as it then stood, the answer was yes.<sup>31</sup> However, unknowingly, everyone in that courtroom and everyone dealing with adult guardianship in the United States was on the cusp of a dramatic paradigm shift from a medical model of capacity and guardianship to one focused on the civil rights of what was soon to be called the "alleged incapacitated person" and the due process requirement of least restrictive alternatives.*

### A. Capacity, Guardianship, and the Oldest Paradigm

Guardianship originally derives from Roman law, where, as early as 450 B.C.E., the Roman XII Tables provided, "If a person is a fool, let this person and his goods be under the protection of his family or his paternal relatives, if he is not under the care of anyone."<sup>32</sup> Roman law evolved from the protective powers granted to families to the appointment of "tutors" for persons under various disabilities, with the tutor's powers determined in part by the nature of the disability.<sup>33</sup>

English guardianship law embodied the concept of *parens patriae* which persists to this day. This concept began in 1290 with the enactment of *de Praerogativa Regis*,<sup>34</sup> which provided:

A king . . . as the political father and guardian of his kingdom, has the protection of all his subjects, and their land and goods, and he is bound, in a more peculiar manner, to take care of those who, by reason

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31. Notwithstanding the existing law, I insisted on adjourning the hearing to permit the widow to be brought to court and to be given an opportunity to obtain counsel of her own. Ultimately the case was settled with her consent—which she was clearly competent to give—to have some oversight and assistance in her financial dealings.

32. See *The Mentally Disabled and the Law* 1 (Samuel J. Brakel & Ronald S. Rock eds., 1971).

33. Lunacy, for example, was regarded as curable, so a lunatic's property would not be transferred under the title and ownership of the tutor. See A. Frank Johns, *Ten Years After: Where is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?*, 7 Elder L.J. 33, 46 (1999) (citing W.W. Buckland, *A Text Book of Roman Law from Augustus to Justinian* V 141–46 (2d ed. 1932)).

34. See *Mentally Disabled*, *supra* note 32, at 2.

of their imbecility or want of understanding, are incapable of taking care of themselves.<sup>35</sup>

Persons with intellectual/mental disabilities were divided into two classes: the idiot, who had never had capacity, and the lunatic, “a person who hath had understanding but . . . has lost the use of his reason.”<sup>36</sup> Both determinations were made by juries but had different consequences. The guardian of an idiot (akin to what the law today might call a person with intellectual disabilities) was required to provide the idiot with “necessaries” but could otherwise retain the profits from his land during his lifetime. Guardianship of lunatics was far less lucrative as their land was held by the king and all profits generated had to be applied to their maintenance and the maintenance of their households.<sup>37</sup>

As A. Frank Johns notes, from the thirteenth century, “the Crown’s exercise of its royal prerogative relating to subjects unable to protect themselves was not so benevolent. The more attractive revenue-raising dimension diluted the protective welfare intent.”<sup>38</sup> Over time too, kings’ personal prerogative was modified by delegating royal powers to agencies or private citizens appointed as guardians or curators, a practice continued to this day as committees of the person or the estate.<sup>39</sup>

Adoption of guardianship legislation was slow in coming both to the colonies and to the post-Revolutionary Republic, although, as Drogin states:

In 1637, “the first guardianship petition in the New World was decided under English law”<sup>40</sup> . . . with the unfortunate result that the disabled [person’s] revenues “were to be used almost entirely for purposes other than his upkeep. . . . [N]o guardian accounted for his stewardship and surplus profits were not preserved for any heirs.”<sup>41</sup>

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35. Barbara A. Cohen et al., *Tailoring Guardianship to the Needs of the Mentally Handicapped Citizens*, 6 Md. L.F. 91, 92 (1976).

36. See Johns *supra* note 33, at 48–49 (quoting *Mentally Disabled*, *supra* note 32, at 10). This distinction was noted by the Supreme Court in *Heller v. Doe*, 509 U.S. 312, 326–327 (1993).

37. Johns, *supra* note 33, at 49; 1 William Blackstone, *Commentaries* \*302–304.

38. Johns, *supra* note 33, at 51.

39. See Eric Y. Drogin & Curtis L. Barrett, *Evaluation for Guardianship* 4–5 (2010).

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

41. *Id.* at 481 (internal citations omitted).

In the nineteenth and first half of the twentieth century, however, the primary social and legal policy for persons with intellectual and psycho-social disabilities was institutionalization. Beginning with well-intentioned "experimental schools,"<sup>42</sup> economic and other forces led quickly to "custodial asylums with reduced emphasis on educating residents and returning them to community life."<sup>43</sup> By the beginning of the twentieth century, poor farms or almshouses were also a significant aspect of state provision for people with intellectual disabilities.<sup>44</sup>

The segregation of this population was accompanied by, and in large part generated, a particularly virulent medical model<sup>45</sup> fueled by Social Darwinism. According to this model, persons with intellectual disabilities suffered from a hereditary, incurable disease that led to criminality, immorality or depraved behavior, and pauperism, all of which constituted an unacceptable drain on society. Hence this gave way to the rise of the eugenics movement, which led to prohibitions on marriage and procreation and the outright sterilization of tens of thousands of people with mental disabilities.<sup>46</sup> Sterilization laws were upheld, if not blessed, by the Supreme Court in Justice Holmes' famous decision in *Buck v. Bell*.<sup>47</sup>

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42. David L. Braddock & Susan L. Parish, *Social Policy Toward Intellectual Disabilities in the Nineteenth and Twentieth Centuries*, in *The Human Rights of Persons With Disabilities: Different but Equal* 88 (Stanley S. Herr et al. eds., 2003) [hereinafter Braddock & Parish].

43. *Id.* at 88.

44. Braddock & Parish, *supra* note 42, at 91.

45. Braddock and Parish note also "the medical model of defining and classifying disability became thoroughly accepted in [the late nineteenth] century." *Id.*

46. Thirty-two states passed compulsory sterilization laws in the twentieth century, with the last, West Virginia, adopted as late as 1975, while thirty nine states had, at least at one time, restrictive marriage laws. *Id.* at 90-93; *see also* Carey, *supra* note 24, at 3-6, 66-72.

47. *Buck v. Bell*, 274 U.S. 200 (1927). Embracing the medical model of intellectual disability, and the eugenics movement's expansion of that model to dangerous (but scientifically unsupported) consequences, Holmes famously wrote of "incompetents":

It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. . . . Three generations of imbeciles are enough.

*Id.* at 207.

In addition to institutionalization and legal restrictions<sup>48</sup> on what are now recognized as protected privacy rights of marriage<sup>49</sup> and procreation,<sup>50</sup> states also began to legislate in ways that limited or denied civil rights, including the right to contract,<sup>51</sup> to marry, to vote, and to serve on juries.<sup>52</sup> One legislative strategy was to create a legal process by which a person with intellectual disabilities could be adjudicated “incompetent.”<sup>53</sup> Such a determination assumed a medical status model of permanent, unchangeable defect. It resulted in denial of a broad array of rights, otherwise known as active legal capacity, as well as appointment of a surrogate decision maker—as guardian, committee or conservator—who exercised virtually total control over the person’s life.<sup>54</sup>

By the early 20th century, with *parens patriae* still providing the protective rationale, guardianship laws began to move toward a more nuanced, but still medical model of incapacity. That model was “ostensibly based on more objective, scientifically based medical and functional criteria” which were, however, “broadly and vaguely enumerated.”<sup>55</sup> Among the “disabling conditions” which could result in guardianship were “mental retardation,” “mental illness,”

48. Institutionalization, institutional segregation, and deprivation of reproductive rights fell especially heavily on women with intellectual disabilities “who could bear children and who, in the context of this worldview, would perpetuate [their] disability . . . [S]uch a woman was inherently morally defective and the birth of an illegitimate child proved her feeble-mindedness.” Frances Owen, Dorothy Griffiths, Donato Taralli & Jacqueline Murphy, *Historical and Theoretical Foundations of the Rights of Persons with Intellectual Disabilities: Setting the Stage*, in *Challenges to the Human Rights of People with Intellectual Disabilities* 27–28 (Frances Owen & Dorothy Griffiths eds., 2009).

49. See, e.g., *Loving v. Virginia*, 388 U.S. 1 (1967) (striking down anti-miscegenation laws on due process grounds).

50. See, e.g., *Poe v. Ullman*, 367 U.S. 497 (1961) (legalizing contraception); *Roe v. Wade*, 410 U.S. 113 (1973) (legalizing abortion).

51. Restrictions on the right to contract could be accomplished either by a prior judicial determination of incompetency or by laws making contracts void or voidable if entered into by persons who lacked understanding. Carey, *supra* note 24, at 38. See also *Dexter v. Hall*, 82 U.S. 9, 20 (1872) (“[A] lunatic, or a person non compos mentis, has nothing which the law recognizes as a mind, and it would seem, therefore, upon principle, that he cannot make a contract which may have any efficacy as such.”).

52. Carey, *supra* note 24, at 38.

53. For example, the New York Committee Statute evolved over time from a law first passed in 1874. N.Y. Mental Hyg. Law Hist. N. § 78.01 (McKinney 1976).

54. Carey, *supra* note 24, at 39.

55. Sabatino, *supra* note 7, at 37.

"developmental disability," "weakness of mind" and "advanced age" or "infirmities of aging."<sup>56</sup> In New York, for example, the law provided that

The [courts] have jurisdiction over the custody of a person and his property if he is incompetent to manage himself or his affairs *by reason of age, drunkenness, mental illness or other cause* or a patient . . . [defined as] a person who has been lawfully committed or admitted to any facility for the mentally ill or mentally retarded . . . .<sup>57</sup>

Procedural protections were few and oversight limited or non-existent. A determination of incompetency not only imposed a guardian on the incapacitated person, but often also resulted in the loss of rights, including the rights to contract, to marry, and to vote.

Courts thus had extraordinarily broad power, premised on vague definitions and categories, to declare a person "incompetent" with a corresponding loss of civil liberty and property rights.<sup>58</sup> It was this medicalized, diagnosis-driven, rights-depriving paradigm of guardianship, justified by the alleged protective benefits of *parens patriae*, that I confronted in my courtroom in January of 1986.

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56. See *id.* In 1990, 15 states included "advanced age" as a disabling condition justifying guardianship.

57. N.Y. Mental Hyg. Law § 78.01, repealed L. 1992, c. 698 § 2 eff. Apr. 1, 1993 (emphasis added). To be fair, the legislative scheme provided for a lesser intrusion, namely the appointment of a conservator rather than a committee under N.Y. Mental Hyg. Law § 77. The appointment of a conservator carried no finding of global incompetence. The committee statute specifically expressed a preference for the less restrictive imposition of a conservator. N.Y. Mental Hyg. Law § 78.02 (requiring a finding that there could be no finding of incompetency unless "the court first determines that it would not be in [the] person's best interest to [appoint a conservator]"). Notably, the conservator statute was only enacted in 1972, with the statutory preference for conservators added in 1974. Anecdotally, however, committees were often appointed without any significant inquiry into the viability of a less restrictive intervention.

58. In New York, a determination of incompetence resulted in "a complete loss of civil rights." Memorandum of the Law Review Commission Relating to Article 81 of the Mental Hygiene Law Appointment of a Guardian for Personal Needs and/or Property Management, Senate No. 4498, Assembly No. 7343, Leg. Doc. No.65 [C] (1992); Recommendation of the Law Revision Commission to the 1992 Legislature, Relating to Article 81 of the Mental Hygiene Law, Appointment of a Guardian for Personal Needs and or Property Management, at 6.

## II. THE CURRENT PARADIGM

### A. Changing Times: The 1940s to 1987

Even while eugenic sterilization was proceeding and hundreds of thousands of persons with intellectual disabilities were institutionalized or otherwise had their autonomy severely constrained, social and political forces were undermining the paradigm that supported and enforced such restrictions.<sup>59</sup> On the broadest scale, these included the heroic struggle for civil rights by black citizens of this country;<sup>60</sup> the enormous expansion of constitutionally protected rights, both in the criminal and civil arenas;<sup>61</sup> and the rise of a cohort of social justice lawyers, working strategically in organizations like the NAACP and the ACLU, as well as independently with communities and individuals oppressed by discriminatory and unjust laws.<sup>62</sup>

The sixties and seventies were decades of intense civil rights litigation that mandated equal treatment under the law for groups like women and racial minorities which had faced long histories of discrimination;<sup>63</sup> established new rights under the rubric of substantive due process;<sup>64</sup> and required the State to provide

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59. The transition from social control and social protection was also profoundly influenced by the horrors of the Holocaust, in which an estimated 90,000 people with disabilities were murdered by the state in the name of eugenics and social protection. Owen et al., *supra* note 49, at 28.

60. See, e.g., Taylor Branch, *Parting the Waters: America in the King Years 1954–1963* (1988); Taylor Branch, *Pillar of Fire: America in the King Years 1963–65* (1998); Taylor Branch, *At Canaan's Edge: America in the King Years 1965–68* (2006). The civil rights struggle resulted both in legislation like the Civil Rights Act of 1964, Pub. L. 88-352, 78 Stat. 241 (1964), and the Voting Rights Act of 1965, Pub. L. 89-10, 79 Stat. 437 (1965); and in court decisions striking down discriminatory laws and practices, most famously *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954).

61. In the area of criminal procedure these included *Miranda v. Arizona*, 384 U.S. 436 (1966) (imposing exclusion of evidence as a remedy for Fourth Amendment violations). In the area of civil procedure, these included *Goldberg v. Kelly*, 397 U.S. 254 (1970) (requiring due process in termination of government welfare benefits).

62. See Carey, *supra* note 24, at 139–40.

63. See, e.g., *Frontiero v. Richardson*, 411 U.S. 677 (1973) (applying equal protection analysis to strike down gender discriminatory laws); *Reed v. Reed*, 404 U.S. 71 (1971) (same proposition).

64. See, e.g., *Roe v. Wade*, 410 U.S. 113 (1973) (locating the “right to privacy” in substantive due process).

procedural safeguards when issues of the loss of liberty or property were at stake.<sup>65</sup> Armed with these new tools, particularly substantive due process and equal protection,<sup>66</sup> advocates for people with mental illness and intellectual disabilities challenged the institutional model with some success<sup>67</sup> and sought to establish a right to treatment with a less salutary result.<sup>68</sup> The Supreme Court was, however, unwilling to upset the medical model of intellectual disability<sup>69</sup> and was never asked to review the procedures by which individuals were deprived of autonomy and property through guardianship.<sup>70</sup>

## B. Guardianship Reform: Round One

The impetus for a dramatic change in the procedures utilized in guardianship<sup>71</sup> came less from litigators<sup>72</sup> than from the press, and

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65. See, e.g., *Goldberg v. Kelly*, 397 U.S. 254 (1970) (requiring due process in termination of government welfare benefits).

66. But see *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 442–46 (1985) (refusing to recognize persons with intellectual disabilities, referred to as the “mentally retarded,” as a suspect class under equal protection analysis).

67. See *O'Connor v. Donaldson*, 422 U.S. 563, 575 (1975) (holding that the mere existence of mental illness is an inadequate basis for involuntary commitment, but refusing to require states use the “least restrictive means” standard). See also Michael L. Perlin, “*Their Promises of Paradise*”: *Will Olmstead v. L.C. Resuscitate the Constitutional Least Restrictive Alternative Principle in Mental Disability Law?*, 37 *Hous. L. Rev.* 999, 1017 (2000) (“[S]tate legislatures began to apply [“the least restrictive alternative”] to state mental health laws. . . . By 1985, thirty nine states required courts to consider alternatives to hospitalization at the time of involuntary civil commitment.”).

68. See David Rothman & Sheila Rothman, *The Willowbrook Wars* (2d. ed. 2005) (discussing the efforts to establish a right to treatment and deinstitutionalization of persons confined at the infamous Willowbrook “School” in New York).

69. See *Cleburne*, 473 U.S. at 448 (finding that the City of Cleburne violated equal protection by discriminating unfairly based on fears related to mental retardation, but neither questioning a state’s power to require a special permit for a “hospital” for the “feeble-minded” nor the historically suspect and medically questionable use of the designation “feeble-minded”).

70. Surprisingly, the Supreme Court has never decided, or even heard, a single case dealing with guardianship.

71. The reform efforts in the 1970s led by drafters of the Uniform Probate Code, Article V on Guardianship and Conservatorship, and academics like the late Professor John Regan, resulted in “a modification of the doctrine of *parens patriae* with elements of procedural due process protections” and reforms in a number of state guardianship statutes including California, Maryland, New Hampshire and Minnesota. Johns, *supra* note 33, at 70–74.

72. There were, however, efforts to apply due process protections to civil commitment, as opposed to guardianship proceedings, presumably because of the



then also from the work of the American Bar Association Commission on Legal Problems of the Elderly and the Commission on Mental and Physical Disability.<sup>73</sup> In 1987 the Associated Press ran an exposé of adult guardianship<sup>74</sup> that caused a national furor, and prompted Congressional hearings.<sup>75</sup> The two Commissions organized an interdisciplinary conference of national experts in law, psychiatry, and psychology; advocates, court administrators, and judges met at the Wingspread Conference Center in Wisconsin. The conference generated the now eponymous “Wingspread Recommendations,” which were subsequently adopted by the ABA House of Delegates.<sup>76</sup> And in 1982, Article V of the Uniform Probate Code was revised as an initial attempt to temper the doctrine of *parens patriae* with constitutionally mandated due process protections.<sup>77</sup>

Those and other efforts in the 1980s resulted in a flurry of guardianship reform activity,<sup>78</sup> including greater procedural protections<sup>79</sup> and reconsideration of incapacity from a purely medical to a more functional model. Reform efforts continued for a decade, and included adoption of the more progressive Uniform Guardianship and Protective Proceedings Act of 1997

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greater deprivation of liberty thought to be imposed by the former. *See, e.g.*, *Jackson v. Indiana*, 406 U.S. 715 (1972) (holding indefinite commitment of criminal defendants solely because of a defendant’s incompetence to stand trial violated equal protection and due process); *see also* *Lessard v. Schmidt*, 349 F. Supp. 1078 (E.D. Wis. 1972) (holding that due process required procedural protection under a state statute’s civil commitment proceedings).

73. Today, these are called the ABA Commission on Law and Aging and the ABA Commission on Disability Rights.

74. Fred Bayles, *Declared “Legally Dead” by a Troubled System, in Guardians of the Elderly: An Ailing System*, Associated Press, Sept. 23, 1987.

75. The Chairman of Subcomm. on Health and Long-Term Care, 100th Cong., Report on Abuses in Guardianship of the Elderly and Infirm: A National Disgrace, H.R. Doc. No. 100-640 (1987). *See also* Pamela B. Teaster, Erica Wood, Winsor C. Schmidt, Jr. & Susan Lawrence, *Public Guardianship After 25 Years: In the Best Interest of Incapacitated People?*, Nat’l Study of Public Guardianship Phase II Report, 2008 Univ. of Ky. and A.B.A., at 14.

76. Recommendations of the Nat’l Guardianship Symposium and Policy of the A.B.A., *Guardianship: An Agenda for Reform*, Comm’n on the Mentally Disabled, Comm’n on Leg. Problems of the Elderly & A.B.A., 23–27 (1989).

77. Johns, *supra* note 33, at 70.

78. For example, in 1988, twenty-eight states introduced as many as 100 guardianship bills, with eighteen states passing twenty-three, four states creating guardianship study committees, and three states enacting comprehensive guardianship reform. Johns, *supra* note 33, at 78–79.

79. *See infra* Part II(C) (discussing Article 81 of N.Y. Mental Hyg. Law § 81 (McKinney 2012)).

(UGPPA)<sup>80</sup> and comprehensive revisions of guardianship statutes in seventeen states.<sup>81</sup>

These reforms did not happen without substantial opposition. For example, many judges were convinced that the prior statutory schemes better protected people who lacked capacity; that increased procedural protections would dramatically increase the cost of, and time necessary for, protective proceedings; that those protections would cause undue hardship to families seeking only to “do right” by their incapacitated relatives; and that the virtually unlimited power previously given to judges was appropriate because of their experience and belief that they “knew best.”

#### Vignette #2: 1990

*Like many other states, New York undertook to revise its outdated statutory scheme in light of the national reform movement. After the experience recounted in Vignette #1, I became involved with the New York Law Revision Commission,<sup>82</sup> which was charged with the effort. There was a series of official public hearings around the state, and many scheduled debates at local bar associations and similar venues. One of the hotly contested issues was whether the presence of what was now called “the alleged incapacitated person” (“AIP”) at the guardianship hearing should be mandated; I was a vocal proponent for such a rule. A much older (and, as he was quick to point out, more experienced) judge took the other side, and we repeated our public debate again and again. I was naive, he said. I hadn’t seen the enormous number of “incompetents” for whom he had appointed conservators and committees. I didn’t realize how serious their deficits*

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80. See Unif. Guardianship and Protective Proceedings Act (2010); see also Rebecca Morgan, *The Uniform Guardianship and Protective Proceedings Act of 1997—Ten Years of Developments*, 37 Stetson L. Rev. 1, 2 (2007).

81. These were: Oklahoma, Indiana and Michigan (1988); Florida, New Mexico, North Dakota, and Ohio (1989); Washington (1990); New York (1991); Pennsylvania, Rhode Island, and Tennessee (1992); Texas and South Dakota (1993); West Virginia (1994); Oregon (1995); Washington (1996); and Virginia (1997). Johns, *supra* note 33, at n.398 (citing the continuing compilations made by Erica Wood at the ABA Committee on Law and Aging).

82. The Law Revision Commission is an apparently unique institution created by legislature in 1934 to provide independent, scholarly, policy, and drafting aid. See Carolyn Gentile, *Speech Given at the Fordham University School of Law on the Occasion of the Celebration of the Law Revision Commission’s 50<sup>th</sup> Anniversary December 14, 1984*, 14 Fordham Urb. L.J. 103, 103 (1985). The Law Revision Commission’s explanatory notes to the various sections of Article 81 of the New York Mental Hygiene Law contain a wealth of information about, and support for, the changes made by its enactment.

*were, and why it most certainly would not be in their best interest to be forced into a courtroom for a hearing they would not understand and in which they were entirely unable to participate. In fact, bringing them to court would actually be cruel—as well as meaningless.*<sup>83</sup>

*How out of touch, I thought, with the arrogance of the converted. How stuck in an old, and discredited, way of thinking.*

### C. New York: A Near “Model” Statute

So—we (mostly) won.

New York’s adult guardianship statute, MHL Art. 81, was enacted in 1992 and took effect on April 1, 1993; with small changes, it remains the basis for appointing surrogate decision makers for “persons who have suffered a loss of capacity.”<sup>84</sup> It exemplifies the dramatic reforms of the current paradigm in guardianship, at the same time embodying fundamental assumptions challenged by the emerging human rights paradigm. As such, it is useful to consider its provisions in some detail.

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83. As originally drafted, Article 81 required the AIP’s presence at the hearing except in cases of persistent vegetative state. Literally at the eleventh hour, however, when proponents’ guard was down, opponents of the provision changed the language to permit non-appearance where it is “clearly establish[ed] that (i) the person alleged to be incapacitated is completely unable to participate in the hearing or (ii) *no meaningful participation will result from the person’s presence at the hearing*,” thus creating, depending on the judge, the proverbial “door big enough for a truck to drive through.” N.Y. Mental Hyg. Law § 81.11 (McKinney 2012) (emphasis added). Time has, unfortunately, demonstrated that judges appoint guardians of both person and property without ever seeing the person whose decision-making power and legal capacity they have just removed in far too many cases. See generally Law Revision Commission Comments, McKinney’s Consol. Laws of N.Y., Book 34, Mental Hyg. Law §81.11 (arguing that “[t]he exceptions to the requirement of holding the hearing at the person’s residence when he or she cannot come or [be] brought to the courthouse should be invoked only in the limited situations identified by the statute”).

84. New York has a separate statutory scheme for guardianship of persons with mental retardation and developmental disabilities. N.Y. Sur. Ct. Procedure Act § 1750-a (McKinney 2011). See *infra* note 128. In 1990, the legislature mandated a review of that statute in light of both changing views of, and more sophisticated knowledge about, that population, and changes in the law and constitutional requirements over the more than two decades since it had been enacted. 1990 N.Y. Laws 3208-09. No report was ever released, no recommendations made, and, with the exception of the addition of end-of-life decision-making power, no changes were made to the statute. See N.Y. Sur. Ct. Procedure Act § 1750-b (McKinney 2011).

The statute begins with a statement of legislative purpose, explicitly rejecting the earlier paradigm, finding that:

[T]he needs of persons with incapacities are as diverse and complex as they are unique to the individual. The current system of conservatorship and committee does not provide the necessary flexibility to meet those needs . . . a committee, with its judicial finding of incompetence and the accompanying stigma and loss of civil rights, traditionally involves a deprivation that is often excessive and unnecessary.

Replacing the old, "one-size-fits all" medical model, N.Y. Mental Hyg. Law 81.01 continues:

[I]t is desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention which assists them in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable.

[We thus establish a guardianship system] which takes into account the personal wishes, preferences and desires of the person, and which affords the person the greatest amount of independence and self determination and participation in all the decisions affecting such person's life.<sup>85</sup>

The basis for determining incapacity also represents a dramatic shift from the centrality of medical diagnosis to an individualized, functional analysis employing a three-step process.<sup>86</sup>

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85. See discussion *infra* at Part IV.C. These assumptions are largely reflected in the choice of primary language: "incapacitated persons" ("IPs") or, prior to the imposition of guardianship, "allegedly incapacitated persons" ("AIPs"). The person is thus *defined by her disability* which is, in turn, used to justify removal of, or limitation on, legal capacity. By contrast, human rights language refers to a *person* with disabilities, affirming personhood as paramount, and disability as one of many aspects possessed by an individual. The preamble to Article 81 of the N.Y. Mental Hygiene Law reflects this newer view, but the definitions and operative provisions revert to an earlier model. See N.Y. Mental Hyg. Law § 81 (McKinney 2012).

86. In the submissions, hearings, and conversations leading up to the final statute this three-step approach was deemed essential to ensure that guardianship would not be sought for, or imposed upon persons (especially older persons) because of eccentricity, failure to comply with generalized standards of accepted behavior, or simply making "bad decisions." This constitutes an explicit rejection of the "outcomes test of incapacity." See Dhanda, *supra* note 12, at 432-33.

The court is directed to begin from the presumption that all adults possess full legal capacity unless and until it has been proven, by clear and convincing evidence,<sup>87</sup> that

- 1) the person is likely to suffer harm;
- 2) the person is unable to provide for personal needs and/or property management; and
- 3) the person cannot adequately understand and appreciate the nature and consequences of such inability.<sup>88</sup>

The statute re-emphasizes the functional inquiry critical to capacity: "In reaching its determination the court shall give primary consideration to the functional level and functional limitations of the person."<sup>89</sup>

The mandatory hearing provides a host of procedural safeguards, including appointment of an independent court evaluator,<sup>90</sup> right to counsel,<sup>91</sup> required or presumptive presence of

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87. The burden of proof, which falls on the person seeking to impose a guardianship, is deliberately greater than the usual preponderance of the evidence utilized in most civil proceedings, instead requiring clear and convincing evidence. N.Y. Mental Hyg. Law § 81.12(a) (McKinney 2006).

88. *Id.* at § 81.02(s)(b)(1)–(2).

89. N.Y. Mental Hyg. Law § 81.02(c) (McKinney 2011). The Law Revision Commentaries to various relevant sections of Article 81 note changes in medical and psychological practice, especially for older persons, in making comprehensive functional assessments:

For years specialists in geriatric medicine have advocated the practice of comprehensive assessments of frail and elderly patients . . . [that] go beyond the usual medical workup and specifically test the physical function, cognition, and affect and the social support system.

Law Revision Commission Notes to N.Y. Mental Hyg. Law § 81.02 (McKinney 2012) (citing Bobbe Shapiro Nolan, *Functional Evaluation of the Elderly in Guardianship Proceedings*, 12 L., Med. & Health Care 210 (1984)).

The Commentaries also note the ways in which courts, including New York's highest court, have moved to a functional assessment of capacity: "The New York Court of Appeals has endorsed this new functional approach, recognizing that the presence of a particular [medical or psychiatric] condition does not necessarily preclude a person from functioning effectively." Law Revision Commission Notes to N.Y. Mental Hyg. Law § 81.02 (McKinney 2012) (citing *Matter of Grinker* (Rose), 77 N.Y.2d 703 (N.Y. 1991) and *Rivers v. Katz*, 67 N.Y.2d 485 (N.Y. 1986), *reargument denied*, 68 N.Y.2d 808 (N.Y. 1986)).

For an excellent example of forensic functional capacity assessment, see Y. Drogin, *Guardianship for Older Adults: A Jurisprudent Science Perspective*, 35 J. Psychiatry & L. 553, 559 (2007).

90. N.Y. Mental Hyg. Law § 81.08.

the AIP,<sup>92</sup> the rights of cross-examination and confrontation,<sup>93</sup> general adherence to the rules of evidence,<sup>94</sup> and right to a trial by jury on demand.<sup>95</sup>

Assuming a finding, under the three-part test, of danger of harm, functional incapacity, and inability to understand and appreciate, the court's functional evaluation, limited to replace *only* those functional incapacities that have been established by clear and convincing evidence, then dictates the powers granted the guardian.<sup>96</sup> This is "limited" or "tailored" guardianship.

Unlike the earlier "committee" model in New York, a person for whom a guardian has been appointed is not adjudicated an "incompetent" and "retains all powers and rights *except* those powers and rights which the guardian [has been] granted."<sup>97</sup> Guardians of the person and property are required to file extensive reports, the first within ninety days of appointment, and then yearly.<sup>98</sup> The reports are reviewed by persons appointed by the court, denominated "court examiners."<sup>99</sup>

Without question, the statute represents a profound change—indeed a paradigm shift—from the relatively cursory medical model, a diagnosis-driven determination that rendered

91. N.Y. Mental Hyg. Law § 81.10. As a matter of case law this includes a constitutional right to court appointed counsel when involuntary commitment to a nursing home is sought. *In re St. Luke's-Roosevelt Hosp. Ctr.*, 607 N.Y.S.2d 574 (Sup. Ct. 1993), *modified and remanded on appeal*, 627 N.Y.S.2d 357 (App. Div. 1995), *aff'd*, 640 N.Y.S.2d 73 (App. Div. 1996); *aff'd*, 89 N.Y.2d 889 (N.Y. 1996).

92. N.Y. Mental Hyg. Law § 81.11(c).

93. N.Y. Mental Hyg. Law § 81.11(b).

94. N.Y. Mental Hyg. Law § 81.12(b).

95. N.Y. Mental Hyg. Law § 81.11(f).

96. The statute directs that "a guardian shall exercise only those powers that the guardian is authorized to exercise by court order." N.Y. Mental Hyg. Law § 81.20(a)(1). In exercising powers over the person, or the property, the guardian shall:

[A]fford the incapacitated person the greatest amount of independence and self determination with respect to property [and personal needs] management, in light of that person's functional level, understanding and appreciation of his or her functional limitation; and personal wishes, preferences and desires with regard to managing the activities of daily living.

*Id.* § 81.20(6)–(7).

97. N.Y. Mental Hyg. Law § 81.29(a).

98. N.Y. Mental Hyg. Law § 81.31.

99. N.Y. Mental Hyg. Law § 81.32.

a person for whom a guardian was appointed essentially “legally dead.”<sup>100</sup>

The New York statute and others like it have also encouraged change in the way psychiatrists and psychologists conduct their capacity evaluations;<sup>101</sup> and while these statutes are frequently more progressive on paper than they are in practice,<sup>102</sup> legal recognition of an individual as a bundle of capacities, presumptively able to make most decisions, whose “wishes, preferences and desires” are nevertheless to be honored when a guardian exercises power in a domain in which the person has proven incapacity, has inexorably changed our perception of people with intellectual disabilities.

#### D. Guardianship Reform: Round Two—Surrogate Decision-Making

Functional assessments, limited guardianships, and legislative directions to consider the preferences, wishes, and desires of a person under guardianship may (and sometimes do) decrease the state’s erasure of legal personhood. Nonetheless, the appointment of a guardian necessarily involves stripping the person under guardianship of the legal right and power to make certain—or all—decisions and choices about her life and property. The current, civil rights-inspired paradigm shift has attempted to soften—or has resulted in softening—the impact of such imposition through the concept of substituted decision-making.

Early committee and conservatorship statutes gave little direction to guardians on how to exercise their decision-making

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100. Teaster et al., *supra* note 76, at 14, n.8.

101. See ABA Comm’n on L. & Aging & Am. Psychological Ass’n, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers* (2005); ABA Comm’n on L. & Aging & Am. Psychological Ass’n, *Judicial Determination of Capacity of Older Persons in Guardianship Proceedings* (2006).

102. Guardianship cases are generally only a small portion of the mix of cases carried by individual Supreme Court Justices but if done right can be extremely time consuming. The combination of an over-burdened judicial system, petitioners who routinely request plenary authority, inadequate resources for independent evaluation, and the likelihood that the AIP will be unrepresented, result in far too little of the “tailoring” to specifically proven functional incapacities that is the heart of the statute. In addition, where the AIP suffers, or appears to suffer from a progressive dementia, petitioners will request—and courts often grant—full plenary powers to avoid the necessity of repeated future hearings as the individual’s capacity (inevitably) deteriorates.

powers. These statutes sometimes, but not always,<sup>103</sup> imposed an indeterminate “best interests” standard. The 1969 Uniform Probate Code provided that a “guardian of an incapacitated person has the same powers, rights and duties respecting his ward that a parent has respecting his un-emancipated minor child”<sup>104</sup> and fourteen states retain this quite literally *paternalistic* standard.<sup>105</sup> The primary, and arguably more autonomy-promoting, alternative to best interests has been “substituted judgment”—that is, the guardian’s best guess as to what the person under guardianship herself would have chosen under the circumstances.<sup>106</sup>

By 1997, the UGPPA was amended<sup>107</sup> to include the following directive language: “A guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian. A guardian at all times shall act in the ward’s best interest and exercise reasonable care, diligence, and prudence.”<sup>108</sup>

While the UGPPA is ambiguous about the relative weight guardians should give to substituted judgment versus best interest,<sup>109</sup>

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103. In a comprehensive and recent article, Linda Whitton and Lawrence Frolik examined the history, present status, and practical consequences of statutory standards of decision-making, finding that, even today, twenty-eight jurisdictions have *no* general decision-making standards for guardians (there are sometimes more specific standards for end-of-life decisions). Six states make reference to “best interests,” and thirteen combine best interests with substituted judgment. Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardian: Theory and Reality*, Val. U. L. Studies Research Paper No. 11–22, 10 (forthcoming November 2012).

104. Unif. Probate Code Official Text with Comments § 5-312 (West 1969).

105. Whitton & Frolik, *supra* note 104, at n.37.

106. When, however, a person has (arguably) *never* had capacity, pure substituted decision-making would not seem available.

107. The Uniform Probate Code similarly emphasizes the ward’s input in decision-making, and goes even further than the UGPPA in supporting the ward’s autonomy where feasible. It reads:

Except as otherwise limited by the court, a guardian shall make decisions regarding the ward’s support, care, education, health, and welfare. A guardian shall exercise authority only as necessitated by the ward’s limitations and, to the extent possible, shall encourage the ward to participate in decisions, act on the ward’s own behalf, and develop or regain the capacity to manage the ward’s personal affairs.

Unif. Probate Code § 5–314 (amended 2010), 8 U.L.A. 172 (Supp. 2011).

108. Unif. Guardianship and Protective Proceedings Act § 314(a).

109. Whitton & Frolik, *supra* note 104, at 13. The applicable standard has often been highly contested, with judges settling any ambiguity in the statute.



the National Guardianship Association (NGA) Standards of Practice, adopted three years later, in 2002, provides that substituted judgment is “the principle of decision-making that substitutes, as the guiding force in any surrogate decision made by the guardian, the decision the ward *would have made when competent*.”<sup>110</sup>

This clear preference for substituted decision-making is, however, qualified (if not entirely eviscerated) by the provision that it “is not [to be] used when following the ward’s wishes would cause substantial harm to the ward or when the guardian cannot establish the ward’s prior wishes.” In either of these circumstances, best interests become the controlling standard.<sup>111</sup>

Whitton and Frolik have surveyed various statutory standards, with the interpretive glosses placed on them by judicial decisions,<sup>112</sup> and have categorized them as: strict substituted judgment;<sup>113</sup> expanded substituted judgment;<sup>114</sup> strict best interest;<sup>115</sup> expanded best interest;<sup>116</sup> and hybrid models, in which there is either hierarchy in which substituted judgment is favored,<sup>117</sup> or as an un-

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See, e.g., *Matter of Pflueger*, 693 N.Y.S.2d 419 (Sur. Ct. 1999) (describing the conflict between “objective” and “subjective” substituted decision-making).

110. Nat’l Guardianship Ass’n Standards of Practice, Standard 7 (2007) (emphasis added). This formulation is intended to apply only to those situations in which a previously capacitated adult has lost capacity, not to persons with intellectual disabilities deemed never to have possessed capacity.

111. *Id.*

112. Whitton & Frolik, *supra* note 104, at 5.

113. Here the guardian is directed to base decisions “on the incapacitated person’s prior decisions and expressed wishes.” *Id.*, n.71 (citing Ursula K. Braun et al., *Reconceptualizing the Experience of Surrogate Decision Making: Reports vs Genuine Decisions*, 7 *Annals Fam. Med.* 249, 249–50 (2009)).

114. Under this model, “[d]ecisions may be based on the incapacitated person’s prior statements, actions, values and preferences.” *Id.* at 23 (citing Bart J. Collopy, *The Moral Underpinning of the Proxy-Provider Relationship: Issues of Trust and Distrust*, 27 *J.L. Med. & Ethics* 37, 40 (1999)).

115. Here, the standard would require decisions to “be based on a comparison of the benefits and burdens from the viewpoint of a reasonable person in the incapacitated person’s circumstances.” *Id.* at 26.

116. Here, the prior standard is expanded by the direction that decisions “may include considerations of consequences for significant others if a reasonable person might ordinarily consider such consequences.” *Id.* at 29–30.

117. Under a hybrid model, “[d]ecisions should be based on substituted judgment if there is evidence of what the incapacitated person would have wanted; if not, then based on best interest.” *Id.* at 32.

ranked, more ambiguous, amorphous blending of substantial judgment and best interest.<sup>118</sup>

The recent Third National Guardianship Summit<sup>119</sup> brought together interdisciplinary delegates with decades of experience in guardianship to evaluate and rethink the appropriate standard for decision-making. The debate that ensued repeated and reiterated almost three decades of struggle.

The final recommendations from the Summit generally require substituted decision-making but also express a preference for supported decision-making in certain contexts.<sup>120</sup> For example, as to health care decision-making, the guardian is required to:

- a) Acquire a clear understanding of the medical facts;
- b) Acquire a clear understanding of the health care options and the risks and benefits of each; and
- c) Encourage and support the individual in understanding the facts and *directing a decision*.<sup>121</sup>

Substituted decision-making comes into play only “to the extent the person cannot currently direct the decision.”<sup>122</sup>

The standards for a guardian’s “residential decision-making” are similar, though more detailed:

- First, the guardian shall ask the person what he or she wants;
- Second, if the person has difficulty expressing what he or she wants, the guardian shall do everything possible to help the person express his or her goals, needs, and preferences;

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118. Here, “[d]ecisions should be based on substituted judgment if there is evidence of what the incapacitated person would have wanted *and the decision also promotes the incapacitated person’s best interest*. If there is no evidence to support substituted judgment, then the decision should be based on best interest.” *Id.* at 32–33 (emphasis added).

119. The Summit focused specifically on the duties of guardians, including guardian decision-making. The Whitton & Frolik article was originally written as a “framing” document for the Summit. The papers written for the summit and recommendations of the Summit are available at <http://www.guardianshipsummit.org>.

120. See Nat’l Guardianship Network, Third National Guardianship Summit Standards and Recommendations (2011).

121. *Id.*, standard 5.2 (emphasis added). The decision is, however, still made by the guardian.

122. *Id.*, standard 5.3.

- Third, only when the person, even with assistance, cannot express his or her goals and preferences, the guardian [shall seek information necessary to make a substituted decision].<sup>123</sup>

Thus, the current paradigm has seen significant movement along what Whitton and Frolik call the “continuum framed by protection on one end and self-determination on the other,”<sup>124</sup> which is intended to maximize the incapacitated person’s dignity and autonomy. What remains unquestioned is that once a person is deemed incapacitated, however defined or established, said person is deprived of the right and power to make—and act on—her own decisions, instead conferring that power on another. That is, regardless of the procedural protection she is afforded, the respect given her past views, and the commitment to enhancing or re-establishing capacity, as to her *incapacity*, the person under guardianship is *not, or is no longer, a legal actor*.

#### IV. THE EMERGING PARADIGM

##### Vignette # 3: 2010

*In 2005, after a ten-year hiatus in legal education, I returned to the bench as Surrogate of New York County. As such, I have jurisdiction not only over wills, trusts, and estates, but also over guardianship of people with intellectual disabilities (statutorily denominated “mental retardation” and “developmental disabilities”) under Article 17-A of the New York Surrogate’s Court Procedure Act.*<sup>125</sup>

*The statute was first enacted in 1966, and clearly reflects the old paradigm. When the legislature was considering reform of New York’s conservator and committee laws in the late 1980s and early 1990s, it directed a study of Article 17-A in light of changing medical knowledge and legal standards, but the study was never completed, and the legislature never returned to the need to reform Article 17-A.*

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123. *Id.*, standard 6.1. Only after these three steps have been taken may the guardian proceed to a decision based on best interest.

124. Whitton & Frolik, *supra* note 104, at 18.

125. N.Y. Sur. Ct. Procedure Act, Art. 17-A (McKinney 2005). New York is one of only six states that have separate statutes for persons with intellectual disabilities and adults who have lost capacity. The others are California, Connecticut, Idaho, Kentucky, and Michigan. See Cal. Prob. Code § 1850; Conn. Gen. Stat. § 45a; Idaho Code Ann. § 55; Ky. Rev. Stat. Ann. § 387; Mich. Comp. Laws § 700.

*As such, the statute offers only plenary (as opposed to limited or tailored) guardianship over the person and/or property, based on a purely diagnosis-driven determination.<sup>126</sup> The person for whom guardianship is sought need not be present at the hearing,<sup>127</sup> and, indeed, if the petitioners are her parents, or her parents consent, there is no requirement of any hearing at all!<sup>128</sup> Once a personal guardian is appointed the court has no further contact with her<sup>129</sup> unless and until she instigates it, or she dies or otherwise ceases to serve as a guardian and someone petitions to replace her.<sup>130</sup> On extremely rare occasions, a ward (as the statute refers to her) may petition to have a guardian*

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126. Two health care professionals, one of whom must be an M.D., must certify that the person for whom guardianship is sought suffers either from mental retardation or developmental disability, that the condition is likely to continue indefinitely, and that s/he cannot manage her personal affairs and/or property. See N.Y. Sur. Ct. Procedure Act Law § 1750-a (McKinney 2005); Affidavit (Certification) of Examining Physician or Licensed Psychologist (GMD-2A) and Affirmation (Certification) of Examining Physician (GMD-2B) are included in the Petition for Appointment of Guardian (N.Y. Sur. Ct. Procedure Act Law, Art. 17-A, available at <http://www.nycourts.gov/forms/surrogates/omni/gd17A.pdf> (last visited Mar. 2, 2012)). The certifications made on these forms only require the provider to check yes or no as to whether the person meets the requirements for appointment of a guardian. Her presence is not required at any hearing that may be held and, as a practical matter, she never appears and so is unavailable for cross-examination. See *supra* note 86.

127. Presence may be (and usually is) dispensed with in circumstances where the court finds it would not be in the prospective ward's best interests. N.Y. Sur. Ct. Procedure Act Law § 1754 (McKinney 1989).

128. N.Y. Sur. Ct. Procedure Act Law § 1754(1) (McKinney 1989). The Judge may appoint a Guardian ad Litem to report with recommendations, but appointment is limited to attorneys on the Office of Court Administration's approved fiduciary list; while such attorneys are often excellent, or at least competent trust and estates practitioners, there is no requirement that they possess any expertise or special knowledge about intellectual disability and, with rare exceptions, they do not.

129. Guardians of the property, however, are required to file annual accountings which the court presumably reviews. N.Y. Sur. Ct. Procedure Act Law § 1719 (McKinney 1989); *Id.* 1761 (applying general guardianship provisions to Art. 17-A guardianships).

130. The statute makes substitution easy by permitting, in the original application, designation of a standby guardian and often, as well, a first alternative standby. N.Y. Sur. Ct. Procedure Act Law § 1757.01 (McKinney 1989).

If the guardian is unable to function, the standby immediately assumes all the powers and responsibilities of the guardian (without additional court action) even though the court may never have seen her. These standby powers last for 180 days, after which the standby must come to court to seek permanent letters of guardianship, which are generally granted solely on the papers. N.Y. Sur. Ct. Procedure Act Law § 1726 (McKinney 1989).

removed.<sup>131</sup> *There is no requirement of periodic reporting by guardians of the person, nor is there any mechanism for inquiry into the ward's situation over the years and often decades after a guardian is appointed.*<sup>132</sup>

*Armed with righteous zeal, from the beginning of my term, I insisted on conducting full hearings, always with the proposed "ward" present. Because of the many failures of the statute,<sup>133</sup> I applied it narrowly, requiring petitioners who did not clearly fit within its parameters to use M.H.L. Art. 81 instead, which better reflects the current paradigm by retaining most decisions for the ward and requiring regular reporting.<sup>134</sup> I wrote a decision holding the statute unconstitutional in the absence of periodic reporting and review<sup>135</sup> and*

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131. In seven years this has occurred only twice in my court, once instigated by a phone call from a parent/guardian who had received a letter requesting her (years overdue) financial accounting. The woman reported being surprised since her daughter, the "ward," had long since moved away, was holding a full time job, and was supporting herself and her own two children. The guardianship clerk gently suggested that perhaps the ward might wish to petition for termination of her guardianship.

132. Periodic reporting and review is critical because of the court's ultimate responsibility for legally empowering someone—the guardian—often to exercise total control over the life and property of another—the "ward" or person under guardianship. The court has a constitutional obligation, as well as a moral responsibility, to ensure that the ward is, at the very least, no worse off than she would have been without the guardianship and, optimally, that the guardian is, in fact, consistently acting in her best interest. In the absence of reporting and review, an incapacitated person may suffer from neglect or abuse, may lack adequate medical treatment, rehabilitative services, appropriate reassessment, and adjustment of medications, or may be inadequately or inappropriately housed or unnecessarily confined. The guardian may have misappropriated her ward's property, may have died or herself become incapacitated, or even, as in one actual case I heard, been imprisoned for sexual abuse of a person other than his ward.

133. These failures were recognized by the legislature as early as 1990. *See supra* note 86.

134. While MHL Art. 81 may, at least in theory, be utilized for persons whose lack of capacity results from intellectual disability, the many procedural protections it affords made it less attractive and arguably more expensive and time-consuming for petitioners. *See Matter of Chaim A.K.*, 885 N.Y.S.2d 582 (Sur. Ct. 2009) (comparing provisions and protections of Art. 17-A and N.Y. Mental Hyg. Law Art. 81 and finding that the mental illness of the person for whom guardianship was sought required that a proceeding be brought under the latter statute with its greater procedural protections and concern for autonomy and self-determination).

135. *Matter of Mark C.H.*, 906 N.Y.S.2d 419 (Sur. Ct. 2010) (requiring, at a minimum, a yearly report from the guardian).

*instituted a procedure for such reporting and court examination on a yearly basis.*<sup>136</sup>

*I was publicly advocating for a complete overhaul of Article 17-A, and working with the New York City Bar Association ("NYCBA") on a report and proposed statute<sup>137</sup> more focused on least restrictive means through tailored guardianship; utilizing substituted judgment, not a best interest standard, for those decisions which the guardian was authorized to make; maximizing autonomy; and providing greater procedural protections.<sup>138</sup> Things were moving slowly but, we hoped, surely. I was feeling pretty pleased with myself.*

*Then I got a call from a student in the CUNY Law School International Women's Human Rights Clinic asking if she could come and talk to me about Article 17-A. I agreed and scheduled a meeting. She was extraordinarily bright, engaging, and passionate and had become interested and involved in disability rights issues because she had a sibling with significant intellectual disabilities.*

*But!*

*She told me, in no uncertain terms, that I was on a completely wrong track. She said that people with intellectual disabilities, all people with intellectual disabilities, have the human right to make all their own decisions and not, regardless of how well intentioned, to have those decisions made for them.*

*I was totally taken aback. I explained, somewhat patronizingly, that she simply did not know or understand the diversity of persons for whom guardianship was sought or the degree and severity of some of their disabilities. She had not seen, as I had, a woman in her twenties, strapped to a gurney, suffering from cerebral palsy, epilepsy, and severe mental retardation who had never spoken,*

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136. Recognizing the limitations of many of the 17-A guardians appointed, a significant number of whom are immigrants, non-English speaking, and often poor, the court mails a relatively simple questionnaire to the guardian each year on the anniversary date of her/his appointment.

137. The Committee on Disability of the New York City Bar Association ("NYCBA") began work on the issue in 2010. The project was subsequently taken up by the Committee on Mental Health where a report is in progress. A separate, more informal group of diverse statewide stakeholders also began to meet to consider possible changes to the statute.

138. It has been generally understood that although all the principles of the current guardianship paradigm should be incorporated in such a statute, the difference in populations of petitioners and of persons for whom guardianship is sought suggests that there be appropriate variations from the specific provisions of Article 81.

*could not feed herself or perform any activities of daily living, and who appeared entirely non-communicative. Surely there was no way this woman was capable of understanding choices about her personal situation, much less making those choices. The student was obviously both uninformed and naive. (Does this sound like someone in Vignette #2?)*

*The student held her ground. Everyone can make choices, she insisted. It's just that they need assistance in understanding and in communicating those choices. Substituted decision-making is not permissible, and the real issue is the support necessary to enable every person with an intellectual disability to function as a legal actor.*

*I asked what her authority was for this extreme and clearly wrong-headed position. The United Nations Convention on the Rights of Persons with Disabilities, which President Obama had recently signed, she replied. Specifically, she cited Article 12, which guarantees full legal capacity as a fundamental human right.*

*I was embarrassed to admit that I knew nothing of the Convention. Where had it come from, and what did it mean?*

#### A. More Changing Times: The Disability Rights Movement 1970–1990

The shift from a view of persons under guardianship as limited rights-bearers, embodied in the current paradigm, to that of persons with full legal capacity, is not merely semantic or rhetorical; it is, rather, a paradigm shift brought about, in large part, by decades of activism by the disability community.

Just as the civil rights movement brought about changes in constitutional law and legal thinking and advocacy that influenced attitudes toward, and legislation about, guardianship, so too it provided the impetus for an entirely new disability rights movement.<sup>139</sup> This new movement, often led by self-advocates,<sup>140</sup> saw

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139. See, e.g. Matthew Diller, *Judicial Backlash, the ADA, and the Civil Rights Model*, 21 Berkeley J. Emp. & Lab. L. 19, 34 (2000) (“[I]t is not surprising that other groups sought to adopt the [African-American] civil rights model for advocacy, legislation and litigation to their own struggles for equality.”).

140. Particularly in the area of persons with intellectual disabilities, previous advocacy was done primarily by individuals’ parents who argued for greater resources for their children including even, in later periods, “normalization” and “inclusion,” but who never challenged (and, indeed, often reinforced) the paradigm of incapacity and protection. See Donato Tarulli & Carol

disability, like race, not as an inherent defect or condition, but rather as socially constructed<sup>141</sup> and thus subject, as well, to dismantlement.

As Arlene Kanter writes, like the Civil Rights Movement<sup>142</sup> this movement represented a break with the past:

The social model places the responsibility squarely on society (and not on the individual with a disability) to remove the physical and attitudinal barriers that “disable” people with various impairments and prevent them from exercising their rights and fully integrating into society. In other words, a person’s impairment does not diminish the right of that person to exert choice and control about his or her life or to fully participate and contribute to communities through full integration in the economic, political, social, cultural, and educational mainstream of society. By *relying on the social model of disability, it is impossible to say that any person is “unable” or “unqualified” to exercise rights or to participate fully in society.*<sup>143</sup>

In the early 1970s, people with a whole range of disabilities, most commonly sensory and mobility, began to come together with an explicitly civil rights agenda. The first of what were to become Centers for Independent Living (CIL) was established in 1972.<sup>144</sup> In New York City, Disabled in Action began using the direct-action tactics of the civil rights movement, including street demonstrations, to promote the rights of people with disabilities. People First organizations emerged from conferences held in Canada and the United States in 1973 and 1974. The formal self-advocacy movement

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Sales, *Self-Determination and the Emerging Role of Person-Centered Planning in A Dialogical Framework*, in Owen et al., *supra* note 49, at 105–08.

141. Some commentators have styled this a “socio-political model.” See, e.g., Nicholas A. Dorsey, *Mandatory Reassignment under the ADA: The Circuit Split and Need for a Socio-Political Understanding of Disability*, 94 Cornell L. Rev. 443, 446 (2009) (“[T]he socio-political model situates as the ‘problem’ of disability externally, in stereotypical attitudes and an environment that fails to meet the needs of the disabled, rather than within disabled individuals themselves.”).

142. Kanter, *supra* note 5, at 422 (noting that “the Disability Rights Movement, like the Civil Rights Movements before it, focuses on issues of identity and power relationships.”).

143. *Id.* at 427 (emphasis added).

144. Carey, *supra* note 24, at 137. By the late 1980’s there were more than 300 CILs operating across the country. *Id.*



“burgeoned through the 1980s and 1990s.”<sup>145</sup> In 1990, the same year the ADA was passed, a national organization, Self-Advocates Becoming Empowered (“SABE”), was founded.<sup>146</sup>

While the effort to change guardianship laws had focused primarily on promoting autonomy and establishing procedural protections, the disability rights movement had a more radical and explicit equality agenda, premised both on the Civil Rights Act of 1964, which prohibited discrimination based on race, sex, and national origin,<sup>147</sup> and the equal protection clause of the Constitution.<sup>148</sup>

Section 504 of the Rehabilitation Act of 1973 adopted the language of the Civil Rights Act of 1964, which prohibited discrimination<sup>149</sup> against “otherwise qualified handicapped individuals,”<sup>150</sup> but its coverage extended only to federal programs and federally funded entities, in contrast to the private sector coverage of the Civil Rights Act. This limitation significantly impeded equality of access and opportunity in non-public programs, and, in 1984, Congress directed the National Council on Disability (the “Council”) to study and evaluate the effectiveness of various federal enactments in achieving the full integration of people with disabilities.<sup>151</sup> In 1986, the Council issued a report highlighting the

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145. Frances Owen, Dorothy Griffiths, Donato Tarullio & Jacqueline Murphy, *Historical and Theoretical Foundations of the Rights of Persons with Intellectual Disabilities: Setting the Stage*, in Owen et al., *supra* note 49, at 38.

146. Self-advocacy was hardly a U.S. phenomenon. In 1981, people with disabilities from around the world assembled in Singapore to found Disabled People’s International (DPI). Kanter, *supra* note 5, at 471.

147. Carey, *supra* note 24, at 183. 42 U.S.C. § 2000d–2000d-4a (2006).

148. Since non-discrimination is a necessary condition for equality, comprehensive anti-discrimination laws have long been the goal of equality advocates, including racial minorities and women. Non-discrimination is not, however, always enough, as the struggle between formal and substantive equality demonstrates.

149. Ironically, according to Carey, H.E.W.’s resistance to issuing regulations under the Act energized and emboldened the activism of cross-disability organizations. Carey, *supra* note 24, at 137. For a description of the demonstrations conducted by disability rights activists against Joseph Califano, Secretary of Health, Education, and Welfare, see Joseph Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* 65–70 (1994).

150. See 29 U.S.C. § 794(a) (2000).

151. Pub. L. No. 8-221, § 143(a) (1984). Between the Rehabilitation Act and this Congressional direction, a number of legislative acts had provided protection for differing groups of people with disabilities in various areas. These included the Education for All Handicapped Children Act, Pub. L. No. 94-142, 89 Stat. 773 (which was later supplanted by the Individuals with Disabilities Education Act

way in which societal barriers limited the participation of people with disabilities in social and economic life and called on Congress to enact a comprehensive law to require and ensure equality of opportunity.<sup>152</sup> Congress answered the call by enacting the Americans with Disabilities Act ("ADA") in 1990.<sup>153</sup>

The ADA has been understood as a milestone in the struggle for inclusion and integration, explicitly recognizing that socially-created conditions and barriers, rather than disabled peoples' individual "defects," are the cause of exclusion and non-participation.<sup>154</sup> The statute prohibits discrimination in employment (Title I), public activities, services, and programs (Title II), and public accommodations and services provided by private entities (Title III), requiring instead "reasonable accommodation." As Rovner describes it, the reasonable accommodation mandate:

[M]ay be generally understood as requiring both public and private entities to make those changes to the 'built environment' that are necessary to ensure that people with disabilities are able to participate in society's institutions (so long, of course, as those changes are not too expensive or burdensome to make).<sup>155</sup>

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[IDEA], 20 U.S.C. § 1400-1487); the Civil Rights of Institutional Persons Act of 1980, 42 U.S.C.A. § 1997 *et seq.*; and the Voting Accessibility for the Elderly and Handicapped Act of 1984, 42 U.S.C.A. § 1973 *et seq.*

152. National Council on Disability, *Toward Independence* (1986), available at <http://www.ncd.gov/publications/1986/February1986>.

153. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 *et seq.*

154. A leading commentator has noted:

The enactment of the Americans with Disabilities Act (ADA), was viewed as a watershed in the disability community, not only because of the substantive rights it guaranteed to disabled people, but also because it reflected a departure from the medical model and an adoption of the movement's socio-political model of disability.

Laura L. Rovner, *Disability, Equality and Identity*, 55 Ala. L. Rev. 1043, 1044 (2004) (citations omitted).

155. *Id.* at 1063-64, (describing the reasonable accommodation mandate as "transformative"). Rovner quotes Linda Krieger, who wrote that disability is no longer "a container holding tragedy, or occasion for pity, charity, or exemption from the ordinary obligations attending membership in society" but now "also, or to a certain extent instead, contains rights to and societal responsibility for making enabling environmental adaptations." Linda Hamilton Krieger, *Afterward: Socio-Legal Backlash*, 21 Berkeley J. Emp. & Lab. L. 476, 481 (2000).

Regulations for governmental action under Title II issued by the Attorney General embraced an inclusion model in what is generally known as the “integration mandate”<sup>156</sup> requiring public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>157</sup>

The ADA has not been an unqualified success. On the one hand, while it has resulted in removal of physical barriers to public, civic, and economic life, it has been far less successful in effectively reducing discrimination in employment,<sup>158</sup> and the “reasonable accommodation” mandate has been substantially weakened.<sup>159</sup> On the other hand, the ADA has been, and continues to provide, the basis for litigation on behalf of groups with specific disabilities<sup>160</sup> and individuals who have suffered discrimination because of their disabilities. Notably, however, it has not been widely utilized to enhance the rights of persons with intellectual disabilities.<sup>161</sup>

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156. See *infra* Section IV(B) and note 162 for discussion of the “integration mandate” in the context of education.

157. 28 C.F.R. § 35.130(d) (2008) (“Non Discrimination on the Basis of Disability in State and Local Government Services”). Michael Perlin argues that this constitutes a legislative/administrative adoption of the principle of least restrictive alternative which courts had previously been unwilling to locate in the Constitution. Perlin, *supra* note 68, at 1010–11.

158. See Eilionoir Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* 412 (2011) (citing Samuel Bagenstos, *Law and the Contradictions of the Disability Rights Movement* 117 (2009) (“[T]he statute has failed significantly to improve the employment position of people with disabilities. Indeed, by virtually all reports the employment rate of people with disabilities has declined over the time the statute has been on the books.”)).

159. See, e.g., *Alabama v. Garrett*, 531 U.S. 356 (2001) and discussion in Rovner, *supra* note 155, at 1069–81; see also Diller, *supra* note 140, at 24–31 for a discussion of judicial hostility to a reasonable accommodation. But see Michael E. Waterstone et al., *Disability Cause Lawyers*, 55 Wm. & Mary L. Rev. 1287, 1357–58 (2012) (describing victories of disability rights lawyers in public services and accommodations cases using a variety of state and federal statutes).

160. See, for example, the work of the National Federation for the Blind in utilizing the ADA to require corporations using websites—a public accommodation—to make those websites accessible to the visually impaired. See generally Katherine Rengel, *The Americans with Disabilities Act and Internet Access for the Blind*, 25 J. Marshall J. Computer & Info. L. 543 (2008); see also Michael A. Schwartz, *America’s Transformation: The Arc of Justice Bends Toward the Deaf Community*, 45 Val. U.L. Rev. 845 (2011).

161. There is a major exception. The Supreme Court’s decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) applied the ADA in a challenge to institutional, rather than community, placement for individuals with mental disabilities, and

Professor Leslie Saltzman has made an insightful and provocative argument that legal guardianship violates the ADA because it isolates persons with intellectual disabilities, preventing them from making and acting on their own decisions, thus removing them from participation in the larger world, and inhibiting the growth of which they are capable.<sup>162</sup> Her discussion of the applicability of the ADA to guardianship also segues to a possible argument couched in the language of international human rights and the CRPD.<sup>163</sup>

#### B. The Integration Presumption, Normalization, and Person-Centered Planning

Besides civil rights advocacy and self-advocacy leading to legislative reforms culminating in the ADA, at least three other trends have contributed to the emerging paradigm and deserve brief mention: the integration presumption, “normalization,” and person-centered planning.

In response to the deinstitutionalization movement of the 1950s and 1960s, parents and advocates for persons with intellectual disabilities advocated for more community-based services and, in the case of education, that children with disabilities should be taught in the community rather than in specialized institutions.<sup>164</sup> At the same time that litigators and advocates were arguing for “least restrictive means,” Congress codified this “integration presumption” in the Individuals with Disabilities Education Act (“IDEA”) “to hasten *structural change* in the alternatives available to children with disabilities.”<sup>165</sup> In order for states to receive funding under the IDEA

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recognized the perceptions and stigmatizations which occur outside an inclusion model. “Institutional placement of persons and who can handle and benefit from community settings perpetuate unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life . . .” *Id.* at 584.

162. Leslie Saltzman, *Rethinking Guardianship (Again): Substituted Decision-Making as a Violation of the Integration Mandate of the Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157, 160 (2010).

163. *Id.* at 161. See also Leslie Saltzman, *Guardianship for Persons With Mental Illness—A Legal and Appropriate Alternative?*, 4 St. Louis U. J. Health L. & Pol’y 279 (2011) (arguing a similar thesis).

164. See Ruth Colker, *The Disability Integration Presumption: Thirty Years Later*, 154 U.Pa. L. Rev. 789, 789–90 (2006).

165. *Id.* at 795. Colker is critical of what she sees as essentially unexamined adherence to an integration presumption in the face of empirical evidence suggesting that integrating children with intellectual disabilities into “regular” classrooms may often not serve their best interests educationally.

they were required to provide criteria for an appropriate free public education, create individualized programs, and abide by the integration presumption, described as follows:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.<sup>166</sup>

The integration presumption, with its assumption that persons with disabilities, including intellectual disabilities, are most likely to grow and thrive in a community, went hand-in-hand with a formalized notion of “normalization,” which first arose in the Scandinavian countries in the 1960s.<sup>167</sup> “Normalization” involved “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.”<sup>168</sup> The purpose of normalization was to help persons with intellectual disabilities develop into well-adjusted members of society by giving them the same opportunities and experiences as other citizens.<sup>169</sup> The principle of normalization, as a “philosophy to guide the delivery of services and encourage

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166. 20 U.S.C. § 1412(a)(5)(A) (2006).

167. Among the leaders in this effort were Niels Erik Bank-Mikkelsen in Denmark and Bengt Nirje in Sweden. See, e.g., Bengt Nirje, *The Normalization Principle and Its Human Management Implications*, in *Changing Patterns in Residential Services for the Mentally Retarded* 179, 181 (R.B. Kugel & W. Wolfensberger, eds., President’s Committee on Mental Retardation, 1969) (describing the theoretical content and analyzing the benefits of the normalization principle as implemented in Sweden for the purposes of a U.S. audience). In the United States, normalization understood as “focus[ing] on creating environments for people with learning and intellectual disabilities that are as ‘culturally normative as possible’” was first championed by Wolf Wolfensberger in *The Principles of Normalization in Human Services*. Kanter, *supra* note 4, at 421 (2011) (quoting Wolf Wolfensberger et al., *The Principles of Normalization in Human Services* 28 (1972)). For a fuller discussion of Wolfensberger’s contributions, see Frances Owen et al., *Historical and Theoretical Foundations of the Rights of Persons with Intellectual Disabilities: Setting the Stage*, in *Challenges to the Human Rights of People with Intellectual Disabilities* 23, 29–30 (Frances Owen & Dorothy Griffiths eds., 2009).

168. Nirje, *supra* note 168, at 181.

169. See Carey, *supra* note 24, at 141.

learning,<sup>170</sup> in turn influenced the development of “person-centered planning” (“PCP”).

Without specifically adopting a social construction model of disability, the integration presumption and normalization principles shifted emphasis from the “defective” condition suffered by people with intellectual disabilities to the social supports—and elimination of social barriers—that were necessary for their full and equal participation in society.<sup>171</sup> The movement for community inclusion took these concepts a step further by incorporating the demand for self-determination.<sup>172</sup>

As such, PCP “was designed to serve as a starting point for the provision of individualized support by assisting people with disabilities in defining, planning for, and pursuing their desired futures, including housing arrangements, employment, relationships, and leisure activities.”<sup>173</sup> PCP was incorporated into the all-important funding process for services for people with disabilities, the Centers for Medicare and Medicaid Services (CMS), whose regulations provide, *inter alia*:

Person-Centered Planning Process: CMS requires that a person-centered planning process and assessment be used to develop a person-centered plan. The process *is directed by the individual, with assistance as needed or desired from a representative of the individual's choosing*. It is intended to identify the strengths, capacities, preferences, needs, and desired measurable outcomes of the individual. The

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170. *Id.*

171. Here it is useful to note the distinction, generally and regrettably absent in the literature as well as in this Article, between “impairment,” the defect or condition suffered by an individual, and “disability,” which is the restriction or restrictions resulting from the impairment. See World Health Org., International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease 47, 143 (1980).

172. John and Connie O'Brien, leading advocates for community inclusion for persons with developmental disabilities and among the founders of PCP, argued for individualized services, as opposed to “prepackaged group services,” whose purpose was, *inter alia*, to assist individuals to develop their individual abilities and personal interests and to discover and respond to their individual choices. Carey, *supra* note 24, at 193; see also Connie Lyle O'Brien & John O'Brien, *The Origins of Person Centered Planning: A Community of Practice Perspective*, Center on Human Policy 2 (2000), available at [http://thechp.syr.edu/PCP\\_History.pdf](http://thechp.syr.edu/PCP_History.pdf) (offering an “account of how the family of approaches to person-centered planning developed”).

173. Carey, *supra* note 24, at 193.

process may include other persons, freely chosen by the individual, who are able to serve as important contributors to the process. . . .<sup>174</sup>

The principles of self-direction, being embedded in community, and support (assistance) for making choices about one's life are fundamental to the guarantee of legal capacity in the CRPD. Rather than understanding this new iteration as something suddenly thrust upon us by the Convention, we should see how the history of civil rights activism, deinstitutionalization, the rise of self-advocacy movements and integration, normalization, and PCP have all contributed to an organic process from which the newest paradigm is now emerging.

### C. The Rise of Human Rights

The concept of human rights, and of institutions responsible for their enunciation and implementation, took form after the horrors of World War II, with the founding of the United Nations in 1945 and adoption of the Universal Declaration of Human Rights ("UDHR")<sup>175</sup> on December 10, 1948. The UDHR contains the fundamental principles of international human rights law: "the equal and inalienable rights of all members of the human family"<sup>176</sup> and every person's inherent dignity. No distinction is drawn in the entitlement to the rights and freedoms enumerated in the UDHR on the basis of "birth or other status." The UDHR is, however, only aspirational, and is not legally binding on signatories (which include the United States).

Treaties, however, are binding,<sup>177</sup> and in 1966 the United Nations General Assembly adopted two major treaties, the

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174. *Self Directed Services*, Medicaid.gov, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html> (last visited October 24, 2012). *See also* 42 C.F.R. § 440.167 (2011); State Medicaid Manual § 4480.

175. Universal Declaration of Human Rights, G.A. Res. 217 (III) A, U.N. Doc. A/RES/810 (Dec. 10, 1948).

176. *Id.* at 207.

177. Application of conventions is incumbent on the legislative, political, and judicial bodies of signatory States, and the Vienna Convention affirms the primacy of international law over national law. *See Vienna Convention on the Law of Treaties*, art. 26–30, *adopted* May 23, 1969, 1155 U.N.T.S. 331. The United States has not ratified the Vienna Convention, but the Supremacy Clause of the U.S. Constitution makes ratified treaties binding on states. *See United States v. Pink*, 315 U.S. 203, 230 (1942).

International Covenant on Civil and Political Rights ("ICCPR")<sup>178</sup> and the International Covenant on Economic, Social and Cultural Rights ("ICESCR"),<sup>179</sup> dividing what have come to be called first and second generation rights.<sup>180</sup> The treaties's parallel language in the UDHR guaranteeing equal protection of the law and "equal and effective protection against discrimination on any ground such as . . . birth or other status." In 1994 the meaning of "status" was clarified in General Comment 5 of the U.N. Committee on Economic, Social and Cultural Human Rights, the U.N. treaty-created body overseeing the ICESCR, which noted explicitly that "[a]ll human beings are born free and equal *including persons with a disability*."<sup>181</sup>

### 1. Shifts in International Human Rights Discourse on Disability

The international community began to shift from a medical to a social model of disability in the 1970s<sup>182</sup> and 1980s.<sup>183</sup> Significant

178. International Covenant on Civil and Political Rights, Dec. 16, 1966, 999 U.N.T.S. 171.

179. International Covenant on Economic, Social and Cultural Rights, Dec. 16, 1966, 993 U.N.T.S. 3.

180. First generation rights are "civil" rights, which primarily protect individuals against infringements on their freedom by the state and parallel the rights incorporated into the U.S. Constitution Bill of Rights. Second generation rights involve affirmative governmental obligations to provide autonomy-enhancing conditions or services—adequate food, health care, shelter, etc.—as opposed to refraining from prohibited actions. The United States has consistently rejected the imposition of second generation affirmative rights and was largely responsible for the U.N. creating two separate treaties, only one of which (ICCPR) the United States would ratify. See Harold Koh, *A United States Human Rights Policy for the 21st Century*, 46 St. Louis U. L.J. 293, 308 (2002); see also Connie de la Vega, *Protecting Economic Social and Cultural Rights*, 15 Whittier L. Rev. 471, 472 (1994).

181. Gen. Comment No. 5 on Persons with Disabilities, U.N. Comm. on Econ., Soc. & Cultural Rights, Rep. on its 11th Sess., Nov. 21–Dec. 9, 1994, U.N. Doc. E/1995/22, Supp. No. 3, para. 5 (1995) (emphasis added).

182. A 1972 Declaration apparently qualified the principle of the universality and indivisibility of human rights in stating that "[a]ll mentally retarded persons have, *to the maximum degree of feasibility*, the same rights as all other human beings." Dec. on the Rights of Mentally Retarded Persons, G.A. Res. 2856 (XXVI), U.N. GAOR, 26th Sess., Supp. No. 29, U.N. Doc. A/18429, at 93 (Dec. 20, 1971) (emphasis added); see also Dec. on the Rights of Disabled Persons, G.A. Res. 3447 (XXX), U.N. GAOR, 30th Sess., Supp. No. 34, U.N. Doc. A/10034, at 88 (Dec. 9, 1975) (both calling for the equality of persons with intellectual disabilities while, at the same time, continuing assumptions that such persons were disabled



progress was made in the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities,<sup>184</sup> which highlighted the concept of disability as a social construct, and in the Vienna Declaration and Program of Action.<sup>185</sup> The latter, asserting the right of equal opportunity, called for its realization via the elimination of all physical, financial, social, psychological, and other socially constructed barriers that effectively exclude or restrict persons with disabilities' full participation in society.

By 2004, the Montreal Pan-American Health Organization (PAHO) and the World Health Organization (WHO) Conference on Intellectual Disability generated a document that presages the CRPD, the Montreal Declaration on Intellectual Disabilities.<sup>186</sup> Reaffirming the right to equality and non-discrimination for persons with intellectual disabilities, and adopting a paradigm of equality of opportunity,<sup>187</sup> the Montreal Declaration announced the shift to legal capacity and supported decision-making, with Article 6 calling for the

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as the result of specific medical problems that require separate social services and institutions).

183. In 1982, the U.N. General Assembly enacted the World Programme of Action Concerning People with Disabilities, G.A. Res. 37/52, U.N. GAOR, 37th Sess., Supp. No. 51, U.N. Doc. A/RES/37/52, at 185–86 (Dec. 3, 1982) [hereinafter WPA]. While maintaining a medical model in its goals of prevention and rehabilitation, it noted that the equal opportunities it advocated would also require positive action to make the physical and cultural environment accessible to people with disabilities.

184. G.A. Res. 48/96, U.N. GAOR, 48th Sess., U.N. Doc. A/RES/48/96 (Dec. 20, 1993). These rules supplemented the WPA by focusing on equality for persons with disabilities.

185. World Conference on Human Rights, June 14–25, 1993, *Vienna Declaration and Programme of Action*, ¶¶ 63–65, U.N. Doc. A/CONF.157/23 (July 12, 1993).

186. See Pan Am. Health Org./World Health Org., *Montreal Declaration on Intellectual Disabilities* (adopted Oct. 6, 2004), available at <http://www.mdri.org/mdri-web-2007/pdf/montrealdeclaration.pdf>.

187. As commentators on the Montreal Declaration have noted, “[e]quality of opportunity, along with equality of result and equality of resources, is a variant of the concept of formal equality. Equality of opportunity is a matter of creating conditions where the same opportunities for social participation are available to all, including persons with an intellectual disability.” See Jocelin LeComte & Celine Mercier, *The Emergence of the Human Rights of Persons with Intellectual Disabilities in International Law: The Case of the Montreal Declaration on Intellectual Disabilities and the United Nations Convention on the Rights of Persons with Disabilities*, in Owen et al., *supra* note 49, at 53; see also Kanter, *Disability Studies*, *supra* note 4, at 445 (describing “bridg[ing] the gap between civil rights and human rights and between formal and substantive equality”).

establishment of common standards on supported decision-making. It reads, in part:

6. (a) Persons with intellectual disabilities have the same right as other people to make decisions about their own lives. Even persons who have difficulty making choices, formulating decisions and communicating their preferences can make positive choices and decisions that further their personal development, relationships and participation in the communities. . . . [P]ersons with intellectual disabilities should be supported to make their choices and decisions, to communicate them and to have them respected. Accordingly, where individuals have difficulty making independent choices and decisions, laws and policies should promote and recognize supported decision-making. States should provide the services and the necessary support to facilitate persons with intellectual disabilities in making meaningful decisions about their own lives;

(b) Under no circumstance should an individual with an intellectual disability be considered completely incompetent to make decisions because of his or her disability. It is only under the most extraordinary of circumstances that the legal right of persons with intellectual disabilities to make their own decisions can be lawfully interrupted. Any such interruption can only be for a limited period of time, subject to periodic review, and pertaining only to those specific decisions for which the individual has been found by an independent and competent authority to lack legal capacity . . . .<sup>188</sup>

## 2. The Convention

The CRPD,<sup>189</sup> adopted by the U.N. General Assembly in 2008, is an extraordinary document, created through an extraordinary

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188. See LeComte & Mercier, *supra* note 188, at 59–60 (discussing the principles underlying the Montreal Declaration generally and Art. 6 in particular).

189. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006). In addition to the general principles and Article 12, discussed below, and the implementation articles discussed in Part V, *infra*, the Convention clarifies, in the disability context, the entire panoply of human rights, including education (Art. 24), employment (Art. 27), political participation (Art. 29), access to justice (Art. 13), freedom of

process.<sup>190</sup> Unique among international human rights treaties, from the beginning the conceptualization and drafting process included people with disabilities, rallying behind the slogan: “Nothing about us, without us!”<sup>191</sup>

The Preamble begins in part with a declaration that States Parties to the Convention, *inter alia*:

- (b) [Agree that] . . . everyone is entitled to all the rights and freedoms set forth [in the Universal Declaration of Human Rights and the International Covenants on Human Rights] without distinction of any kind; [and]
- (c) Reaffir[m] the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment *without discrimination*; [and] . . .
- (e) Recogniz[e] that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society *on an equal basis with others*; and . . .
- (n) Recogniz[e] the importance for persons with disabilities of their individual autonomy and independence, including *the freedom to make their own choices* . . . .<sup>192</sup>

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expression and opinion (Art. 21), privacy (Art. 22), personal integrity (Art. 17), liberty of movement and nationality (Art. 18), liberty and security of the person (Art. 14), and an adequate standard of living (Art. 28).

190. The convention was the culmination of almost two decades of advocacy by individuals, disabled people’s organizations (DPOs), non-governmental organizations (NGOs) with and without status at the United Nations, and government representatives. See Arlene S. Kanter, *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities*, 34 Syracuse J. Int’l. L. & Com. 287, 288 (2007).

191. See, e.g., Rosemary Kayess & Phillip French, *Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities*, 8 Hum. Rts. L. Rev. 1, 34 (2008). This negotiating slogan—“Nothing about us, without us!”—was adopted by the International Disability Caucus. See Michael L. Perlin, “A Change is Gonna Come”: *The Implications of the United Nations Convention on the Rights of Persons with Disabilities for the Domestic Practice of Constitutional Mental Disability Law*, 29 N. Ill. U.L. Rev. 483, 489–90 (2008–2009).

192. CRPD, *supra* note 19, at Preamble (emphasis added).

The paramount themes of equality and dignity are repeated in Article 1,<sup>193</sup> in Article 3, General Principles,<sup>194</sup> and, more fully, in Article 5.<sup>195</sup>

The heart of the Convention's protection of persons with intellectual disabilities<sup>196</sup> is found in Article 12, "Equal Recognition before the Law," which contains the paradigm-shifting assertions that

- (1) . . . persons with disabilities have the right to recognition everywhere as persons before the law [and]
- (2) States Parties *shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life* [and that]
- (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*.<sup>197</sup>

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193. "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." *Id.* Art. 1.

194. Those principles include "respect for inherent dignity, individual autonomy including *the freedom to make one's own choices*, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility." *Id.* Article 3 (emphasis added).

195. "States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law." Article 5 continues by imposing certain affirmative obligations on States Parties, including, "in order to promote equality and eliminate discrimination," the obligation to "take all appropriate steps to ensure that reasonable accommodation is provided." *Id.* Article 5(1), (3).

196. It should be noted that persons with intellectual disabilities include those persons whose disabilities have arisen later in life or are related to the aging process. See Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Rights of Elderly People Under International Law*, 25 Ga. St. U.L. Rev. 527 (2009); see generally *supra* note 1.

197. CRPD, *supra* note 19, Article 12 (emphasis added). Article 12 goes on to provide for protections against limitation on the exercise of legal capacity. *Id.* It is useful to clarify what "supportive services" means, and might entail. Michael Bach and Lana Kerzner, leaders in the law reform effort to bring Canadian guardianship law into compliance with the CRPD, have suggested three main kinds of supports for decision-making pursuant to Article 12: supports to assist in formulating one's purposes, to explore the range of choices and to make a decision; supports to engage in the decision-making process with other parties to make agreements that give effect to one's decision, where one's decisions requires this; and supports to act on the decisions that one has made, and to meet one's

This language represented the culmination of a hard fought battle around the meaning of legal capacity,<sup>198</sup> with some states introducing a distinction between legal capacity *for* rights and legal capacity *to act*,<sup>199</sup> as well as a tension between substituted and supported decision-making.<sup>200</sup> On December 13, 2006, however, the General Assembly adopted the final version of the Convention, including Article 12, which, as the International Disability Coalition (“IDC”) pointed out, “spell[ed] a paradigm shift” with “the right to enjoy legal capacity in all aspects, including the capacity to act [determined] fundamental to basic equality and participation in all aspects of life.”<sup>201</sup>

Thus, in a sweeping pronouncement, already ratified by more than 100 countries,<sup>202</sup> the Convention redefined persons with

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obligations under any agreements made for that purpose. Bach and Kerzner, *supra* note 2, at 73.

198. See generally Dhanda, *supra* note 12.

199. This distinction was the subject of a highly contested footnote, purportedly based on different meanings of the term “legal capacity” in different languages. *Id.* at 451–53. The footnote was strongly opposed by the International Disability Coalition (“IDC”), which argued that the formulation of legal capacity in the Women’s Convention, *supra* note 10, had already adopted the more expansive definition and so could not be derogated by inclusion of a lesser standard in the CRPD. According to Dhanda:

Human Rights instruments by their nature are universal and non-derogable. Thus, according to proper U.N. protocol, state parties who seek national exemptions from conventions are free to file reservations, such exemptions do not derogate from the universal consensus but only allow individual state parties to choose their time of accession.

Dhanda, *supra* note 12, at 443–444, 454–55. Dhanda characterizes the disputed footnote as “a substantive reservation described as a linguistic one.” Dhanda, *supra* note 12, at 454.

200. Dhanda characterizes this as “the opposition between paternalism and participation set up in the Working Group text.” *Id.* at 441. She describes the position of the IDC (an umbrella group for more than 70 disability rights organizations) as explicitly arguing for a “paradigm shift” in its insistence that “while supported decision-making was premised on the competence of people with disabilities, substituted decision-making was based on their incompetence, and hence the two concepts could not subsist together.” *Id.* at 448.

201. *Id.* at 456 (quoting U.N. Enable, Statements Made on the Adoption of the Convention on the Rights of Persons with Disabilities, International Disability Caucus, <http://www.un.org/esa/socdev/enable/convstatementgov.htm#idc> (last visited Sept. 30, 2012)).

202. For the latest total of countries signing and ratifying the Convention, see <http://www.un.org/disabilities/countries.asp?navid=17&pid=166> (last visited Mar. 7, 2012).

As of this writing, Mozambique was the 110th country to ratify.

intellectual disabilities not merely as legal subjects with certain defined rights, but as legal actors with full capacity, equal to that of all other, non-disabled persons. Of equal significance, it places responsibility for facilitating and supporting that capacity squarely on the state.<sup>203</sup>

And, within the right to legal capacity, as the CUNY student told me, *substituted* (and, of course, best interests) decision-making has been supplanted by *supported* decision-making.

Vignette #4: October 2011. Conversion.

*I am in Salt Lake City as a delegate to the Third National Guardianship Summit, which has been called to generate standards for guardian decision-making.<sup>204</sup> The organizing committee has commissioned a number of “framing” scholarly papers in various areas, with a primary paper<sup>205</sup> focusing on analysis of substituted versus best interests decision-making. The clear consensus of those present is that these appear to be the two choices—with a fairly strong consensus in favor of the more “progressive” position of substituted decision-making.*

*I am in the working group on medical decision-making, where debate is mainly about whether, in substituted decision-making, the guardian is to consider only what the person under guardianship<sup>206</sup>*

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203. In this respect, Dhanda points out:

[T]he Disability Convention has [also] demonstrated the falseness of the dichotomy between civil-political and social-economic rights. . . . Just as some civil-political rights, such as the freedom of speech and expression, are meaningless without reasonable accommodation of the physical infrastructure; other social-economic rights, such as the right to health, become oppressive without informed consent and freedom of choice. The need to establish an inclusive and universal paradigm of legal capacity is necessary . . . for persons with disabilities to move from systems of welfare to regimes of rights.

Dhanda, *supra* note 12, at 456–57.

204. Most of the delegates and observers come out of the elder law community and are most familiar with guardianship for adults who have previously possessed, but then lost or lack “capacity.” There are only a few people who work primarily with persons with intellectual disabilities and, not surprisingly, there are no persons with intellectual disabilities.

205. Frolik & Whittson, *supra* note 104.

206. There is at least majority opinion that the objectifying term “ward” should be replaced, though “person under guardianship,” with its acronym “PUG,” gives some people pause.

would have chosen when she was capacitated, or whether to take a more contextualized view, considering the wishes and values of those close to her and involved in her care. During a break, I fall into conversation with a lawyer from the Bazelon Center for Mental Health Law and the topic of the CRPD comes up. “What’s wrong with this picture?” we ask each other, and return to the group primed to call into question the entire approach that has been taken, both in the group and in the Symposium itself.

*There must be supported decision-making, we proclaim. All persons are entitled equally to legal capacity as a matter of human right. Much discussion ensues. The group adopts recommendations for medical decision-making with a hierarchy of directives to guardians: first, the person under guardianship must be supported in making her own decision, which “directs” the guardian’s decision;<sup>207</sup> only if this is impossible should substituted decision-making be employed; and, finally, where neither is possible, for example where there is no information about an unconscious person, or a person in a persistent vegetative state, may best interests be employed.*

*To our great surprise, although the initially favored substituted judgment model remains as the overarching principle, our recommendation is adopted in the general voting session by the largest majority given any recommendation. A similar recommendation privileging and requiring supported decision-making on the issue of where to reside<sup>208</sup> is also adopted. Supported decision-making thus has made it into the influential recommendations—and pre-eminent discourse—of the National Guardianship Summit.*

*I can hardly wait to call the CUNY student . . .*

## V. SUPPORTED DECISION-MAKING IN PRACTICE

There is no legal system in the world that requires only supported decision-making to the complete exclusion of substituted

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207. See *supra* note 122. This formulation is considerably different from requiring the guardian to “take into account” the person’s “wishes,” “desires,” or “preferences” as she makes the decision. There may, however, be some semantic ambiguity as to whether the guardian simply communicates the decision “directed” by the person under guardianship, or whether she *makes* a directed decision.

208. For a powerful discussion on the importance of “home” for equal participation in society, see Anita Hill, *Reimagining Equality: Stories of Gender, Race and Finding Home* (2012).

decision-making, as some would argue the CRPD requires.<sup>209</sup> There are, however, a number of models that provide for supported decision-making, that reserve substituted decision-making for the most extreme cases of incapacity<sup>210</sup> and that change the very definitions of capacity and incapacity.

## A. Guardianship Reform in Europe

### 1. Sweden

Two important articles by the late Stanley S. Herr<sup>211</sup> describe the Swedish model in which guardianship is replaced<sup>212</sup> by two forms

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209. The World Network Users of Psychiatry (WNUSP) has argued that Art. 12 is a total prohibition of substituted decision-making except perhaps where a person is unconscious, or in a persistent vegetative state. *But see* Dhanda, *supra* note 12, at 460–61 (citing U.N. Enable, Statements Made on the Adoption of the Convention on the Rights of Persons with Disabilities, Canada) (“The text of Article 12 does not prohibit substituted decision-making and there is language which could even be used to justify substitution.”).

210. As Michael Bach, a leading Canadian law reform advocate has argued: At some point in our lives, we might need some form of substitute decision-making, because for whatever reason the supports we need to make decisions (friends, family, and trusted others, assistive technologies, etc., are unavailable) [sic].

But in such cases, wardship or guardianship should be absolutely limited, tied to specific decisions, with due process, a right to challenge, and rigorous monitoring systems to ensure everything possible is being done to re-establish the supports needed for a person to exercise their legal capacity.

However, substitute decision-making should always be a last resort. The problem is that for far too many people with intellectual disabilities it has become the first. Families are being forced by health care, financial and community service systems into placing their adult family members under wardship or guardianship simply because alternative supported decision-making provisions and community services are not yet in place.

Michael Bach, *Supported Decision-Making under Article 12 of the UN Convention on the Rights of Persons with Disabilities: Question and Challenges*, Notes for Presentation to Conference on Legal Capacity and Supported Decision-Making Parents’ Committee of Inclusion Ireland 1–2 (Nov. 3, 2007), available at <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>.

211. Stanley S. Herr, *Law and Mental Retardation: International Trends and Reforms*, 38 Int’l Digest of Health Legislation 849 (1987); Stanley S. Herr, *Self-Determination, Autonomy and Alternatives to Guardianship*, in Braddock & Parish, *supra* note 42, at 429. See also Israel Doron, *Elder Guardianship*



of support, the *god man*, or mentor, and the *forvaltare*, or administrator or trustee. The former, mentorship, is the preferred method of support services, mixing support with a state-imposed mentorship which, however, in no way diminishes the civil rights of the person for whom the mentor is appointed. In the vast majority of cases, the *god man* or mentor acts only with the consent of the person, with rights and duties similar to a power of attorney in assisting the person with legal, personal or financial affairs. The procedure for appointment is fast, simple and free,<sup>213</sup> and the *god man*, usually a friend or relative,<sup>214</sup> is paid for his services, if necessary, by the government. Unlike a power of attorney, however, a *god man* may also be appointed for a person unable to give consent. While this may look more like traditional guardianship, it is intended to avoid the stigma and loss of rights that previously accompanied appointment of a guardian. Moreover, importantly, the person for whom a *god man* is appointed has legal remedies when the *god man* oversteps the boundaries of his authority or acts when the individual would have been able to give her consent but did not.<sup>215</sup>

As a matter of last resort, when other forms of assistance are insufficient,<sup>216</sup> the court may appoint a *forvaltare*, or administrator, who may act without the person's consent or in opposition of her wishes. The appointment of a *forvaltare* results in the loss of legal capacity for the person for whom a *forvaltare* is appointed, to the extent of the powers the court assigns to the *forvaltare*, although she always maintains the right to vote.

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*Kaleidoscope—A Comparative Perspective*, 16 Int'l J.L. Policy & the Family 368 (2002).

212. In 1989 the Swedish legislature (*Riksdag*) amended the *Foraidrabalken* or parent-law, which dealt with parent-child relations, to restrict guardianship to persons under 18 years of age, thus abolishing guardianship for adults with disabilities. Herr, *Self-Determination*, *supra* note 212, at 432.

213. According to Herr, "Since most cases are based on direct consent and a review of the documents by the court, no personal hearing or appearance is necessary. In routine cases, the appointment process takes only two to three weeks to complete with the judge writing the court order in about ten minutes." *Id.* at 434.

214. The most common practice is a one-to-one relationship with a relative or friend, though professionals may have small caseloads, and *god men* are also recruited from the citizenry, with service viewed as a civic-minded obligation. *Id.*

215. *Id.* at 433.

216. The law provides a strong preference for the appointment of a *god man* over that of a *forvaltare*, with the latter utilized only when the person objects to the decisions or appointment of a *god man* and there is serious danger to the person or her property. *Id.* at 433, 435.

These legal interventions are minimized, however, by Sweden's comprehensive disability services, which provide paid "contact persons" to provide companionship to persons with disabilities who are otherwise isolated or uninvolved in the community<sup>217</sup> and personal assistants, who are hired, and may be fired, by the person and paid for by the government.<sup>218</sup> These disability services "improve freedom of choice, autonomy and continuity in the personal living situation."<sup>219</sup>

Herr applauds the Swedish system's vigorous commitment to least restrictive alternatives and greater autonomy for individuals with disabilities, noting that "[m]entorship arrangements and other protective services that do not legally disable the individual can be realized in other countries. Although the mechanics, procedures, and nomenclature will vary from country to country, these concepts are certainly 'exportable.'"<sup>220</sup>

## 2. Germany

Other European countries have modified their guardianship laws to provide for at least some measure of supported decision-making. In 1992, for example, the German Parliament replaced procedures for interdiction (legal incapacitation), guardianship, and curatorship with a more flexible measure, the *Betreuung*. Through this measure, the agent, a *Betreuer*, acts to maximize autonomy and the person with a disability is given substantial procedural protections.

The applicable law, or *Betreuungsgesetz*, includes four key principles, described by Herr as follows:

*The principle of necessity*: which bars appointment if the person can manage independently or with the support of other social services.

*The principle of flexibility*: which limits the scope of the *Betreuer's* authority in order to conform to the

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217. *Id.* at 436 ("It is a mark of the comprehensiveness of Sweden's disability services that this need for recreation and emotional outlets is identified as a matter of right.").

218. A personal assistant is a mandated support service for persons under 65 who are living in the community and require at least 20 hours of services per week. This service is either provided directly by the state or by a cash allowance to the person. *Id.* at 436-37.

219. *Id.* at 437 (quoting Disability Commission, Report of the Disability Commission, Disability, Welfare, Justice: Summary 22 (1989)).

220. *Id.* at 440.

constitutional principle of the least-restrictive alternative, because the *Betreuer* is to “follow the wishes of the supported individual as long as the well-being of the handicapped person is not likely to be impaired,” and recognizes that the person’s well-being includes “the possibility to lead a self-determined life to the highest possible degree”;

*The principle of self-determination*: which permits a durable power of attorney as a substitute for a *Betreuer*;

*The principle of rights preservation*: expressed in “the principle of subsidizing sufficient practical support” and the “avoidance of formal legal incapacitation” with the result that, unlike the old law, the appointment of a *Betreuer* does not automatically deprive the person with an intellectual disability of such fundamental rights as the rights to vote, to marry, and to make a will.<sup>221</sup>

The law also provides significant and, in some cases, creative procedural protections, including:

- (1) a personal interview by the judge of the Guardianship Court with the person with the disability, generally at the person’s permanent residence;<sup>222</sup>
- (2) the power of the person to bring appeals from a guardianship and to participate fully in the proceedings, regardless of legal capability;
- (3) the certificate of an expert that describes the person’s medical, social, and psychological condition and offers recommendations regarding the tasks and duration of the *Betreuer*’s role;
- (4) the requirement of a “final conversation” between the Judge and the individual to explain the investigation’s results, the expert’s findings, and the *Betreuer*’s identity and scope of authority; and

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221. *Id.* at 441 (citing Ulrich Hellman, Speech at Minimizing Guardianship, Maximizing Autonomy: Least Restrictive Alternatives in Surrogate Decision-Making Panel in Lisbon, Portugal (June 14, 1993)).

222. This provision nicely demonstrates an accommodation that can be made to minimize a person’s discomfort and/or intimidation, which may substantially diminish or remove a person’s ability to understand and communicate in a more formal judicial setting.

- (5) a durational limit of no more than five years for the *Betreuer's* appointment.<sup>223</sup>

Under the *Betreuer* system, a person represented does not lose her legal status or any of her legal rights. However, when the *Betreuer* and the person disagree, the *Betreuer* must obey the person's wishes only if her decision is in her best interests.<sup>224</sup> This limitation clearly results both in a potentially significant loss of autonomy and also returns, in a default situation, to the best interest standard of decision-making. The *Betreuer* system has thus been labeled one of "shared decision-making"<sup>225</sup> rather than true supported decision-making.<sup>226</sup>

### 3. Russia

Russian guardianship law has been particularly restrictive, requiring plenary guardianship on a finding of any incapacity. The law has been subject to challenge since 2007 when the Mental Disability Advocacy Center in Budapest issued a report on guardianship and human rights in Russia, and in June of 2012 the Russian Constitutional Court struck the Russian guardianship statute down, ordering the Parliament to enact a new law which better respects people's decision making capacity, citing the CRPD.<sup>227</sup>

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223. Herr, *Self-Determination*, *supra* note 212, at 442.

224. Anna Arstein-Kerslake, *Legal Capacity and Supported Decision-Making: Good & Bad Practices*, 24 n.89 (on file with author) (citing Bürgerliches Gesetzbuch [BGB][Civil Code], Aug. 18, 1896, Reichsgesetzblatt [RGL.] 195, as amended, §1901, para. 3).

225. Doron, *supra* note 212, at 379.

226. It has also been criticized for the number of poorly trained and poorly qualified people appointed as *Betreuer* because of efforts to reduce the costs of the system, and for the lack of adequate monitoring to prevent abuse. Arstein-Kerslake, *supra* note 225, at 25.

227. Mental Disability Advocacy Ctr., Russian Constitutional Court Criticizes "Abusive" Guardianship Law, June 28, 2012, [http://mdac.info/en/28/06/2012/Russian\\_Constitutional\\_Court\\_criticises\\_abusive\\_guardianship\\_law](http://mdac.info/en/28/06/2012/Russian_Constitutional_Court_criticises_abusive_guardianship_law) (last visited Oct. 25, 2012). To support the Russian legislature in reforming its law, MDAC has issued an instructive and thoughtful report, see [http://mdac.info/sites/mdac.info/files/English\\_Analysis\\_of\\_the\\_Russian\\_legal\\_capacity\\_system\\_for\\_persons\\_with\\_mental\\_disabilities\\_Towards\\_implementation\\_of\\_Article\\_12\\_of\\_the\\_UN\\_CRPD.pdf](http://mdac.info/sites/mdac.info/files/English_Analysis_of_the_Russian_legal_capacity_system_for_persons_with_mental_disabilities_Towards_implementation_of_Article_12_of_the_UN_CRPD.pdf) (last visited Nov. 14, 2012).

## B. Guardianship Reform in North America

### 1. Canada

Canada has been a leader in advancing the human rights of persons with intellectual disabilities,<sup>228</sup> and there is much to learn from our neighbor to the North.

Because Canada is a federal system, over the past decade or so its provinces have developed a number of different models. While none represent pure supported decision-making, a number of provinces have moved, in various degrees, away from the prior model of substituted decision-making, toward a more autonomy-producing regime.<sup>229</sup> The Supreme Court of Canada has clearly enunciated the right to autonomy of persons with intellectual disabilities, noting that “[u]nwarranted findings of incapacity severely infringe upon a person’s right to self-determination”<sup>230</sup> and has recently emphasized the value of autonomous decision-making for allegedly incapable people.<sup>231</sup>

The province which has moved furthest toward supported decision-making,<sup>232</sup> British Columbia (“B.C.”), has done so through

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228. Interestingly, until recently, guardianship reform in Canada basically followed the same timeline as that of the United States, and movement to the current paradigm in the United States was also driven by the AP exposé in 1987, *supra* note 75, which was reprinted in Canadian newspapers. One province, Alberta, moved to the functional/due process statutory model more than a decade earlier in 1976. Sarah Birmingham, *Developments in Canadian Adult Guardianship and Decision-Making Law*, 18 Dalhousie J. Legal Stud. 119, 130–32 (2008).

229. See R.M. Gordon, *The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making*, 23 Int’l J.L. & Psychiatry 61 (2000) (describing this paradigm shift).

230. *Starson v. Swayze*, [2003] 1 S.C.R. 722, 759 (Can.).

231. *Nova Scotia (Minister of Health) v. J.J.*, [2005] 1 S.C.R. 177, 185–86 (Can.).

232. In 2007 the British Columbia (“B.C.”) Legislative Assembly passed Bill 29, the Adult Guardianship and Planning Statutes Amendment Act 2007, which would have substantially modernized B.C.’s guardianship laws. While some portions of the legislation have recently come into effect, they are not critical to the overall guardianship scheme, which remains basically unchanged. Lana Kerzner, *Paving the Way to Full Realization of the CRPD’s Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective* 36 (2011), prepared for In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century (April 2011), available at [http://www.anth.ubc.ca/fileadmin/user\\_upload/CIC/documents/In\\_From\\_The\\_Mar](http://www.anth.ubc.ca/fileadmin/user_upload/CIC/documents/In_From_The_Mar)

the use of what are called “representation agreements.”<sup>233</sup> The Representation Agreement Act (the Act),<sup>234</sup> enacted with significant participation by disability and aging organizations,<sup>235</sup> provides for voluntary agreements through which people with intellectual disabilities can designate a person or group of persons to assist them in making specific decisions or kinds of decisions.<sup>236</sup> While superficially like powers of attorney, representation agreements grant some legitimacy to “people who provide supports . . . vis-à-vis third parties, such as banks and medical professionals”<sup>237</sup> and require significantly less mental capacity than is generally the case for powers of attorney.

Agreements pursuant to Chapter 7 of the Act enable persons with disabilities to name someone “to help the [person] make decisions or to make decisions on behalf of the [person]”<sup>238</sup> on issues involving routine management of the person’s financial affairs<sup>239</sup>

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gins\_Paper-Lana\_Kerzner-FINAL-April\_22\_2011\_\_2\_.pdf (last visited April 4, 2012).

233. There have been a number of reports and bills proposed, including legislation that would go far toward a true assisted decision-making model, but for various reasons they have not passed, or, if passed, have not yet received “royal assent.” Kerzner, *supra* note 233, at 23.

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

235. For example, the Canadian Association for Community Living (CACC), and its oft-cited Executive Vice President, Michael Bach, have been in the forefront of developing strategies for supported decision-making and promoting reform of legal regimes for substituted decision-making. Since 1991, the self-advocacy group People First Canada has called for an end to guardianship because of its violation of the right to self-determination. *See* Bach and Kerzner, *supra* note 2, at 33. Beginning in 2000 the 3Rs: Rights, Respect, Responsibility Project (CRPD) has committed to research, evaluate and educate about the human rights of people with intellectual disabilities. Owen et al., *supra* note 49, at 16–18. The Montreal Declaration, which involved much Canadian participation, presaged the CRPD itself.

236. That is, an individual is able to appoint different people (or a group of people) for a variety of different areas, like health, finances, place of abode, etc. If more than one representative is appointed in a specific area the representatives can only act unanimously in exercising their delegated authority.

237. Kerzner, *supra* note 233, at 38.

238. Where the representation agreement provides for financial management, a “monitor” is appointed to ensure that the representative is exercising his responsibilities in an appropriate manner. The monitor may visit and/or question the representative, and if anything is amiss, must report to the Public Guardian and Trustee. Representation Agreement Act, R.S.B.C. 1996, c. 405, § 20 (Can.).

239. Section 7 excludes the purchase or sale of real property and refusing life-supporting care. *Id.* § 7. Section 9, which applies the usual test for capacity—

(paying bills, receiving and depositing of pension payments, purchasing of food, accommodations, and other services necessary for personal care, making investments, etc.), major and minor health care decisions, obtaining legal services, and other areas of personal care.

Capacity is presumed for persons with mental illness and/or intellectual disabilities. Persons who would be found to lack capacity under traditional contract law provisions may nonetheless make representation agreements, amend such agreements, and revoke them.<sup>240</sup>

The test for enforceability of representation agreements includes the following:

Whether the adult communicates a desire to have a representative make, help make, or stop making decisions;

Whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;

Whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;

Whether the adult has a relationship with the representative that is characterized by trust.<sup>241</sup>

For many situations, therefore, court involvement is entirely unnecessary. Of equal importance, the binary model of capacity/incapacity is replaced with a spectrum of competencies, and relationships of trust are given legal significance.

The construct of capacity in Chapter 7 has thus been favored by disability advocates as follows:

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the ability to understand information and to appreciate consequences—allows for a much broader range of authority. *Id.* §§ 9–10. However, section 9 agreements “do not allow for a role of supporters; the section refers to the representative being authorized to do certain things, but there is no mention of a role for helping in decision-making.” Kerzner, *supra* note 233, at 38.

240. The Act specifically provides that, for the purposes of creating Section 7 agreements, a person is not deemed incapable because s/he may not have the capacity to enter into contracts or manage her/his personal or financial affairs. Representation Agreement Act, R.S.B.C. 1996, c. 405, § 8(1) (Can.).

241. Kerzner, *supra* note 233, at 39. Representation Agreement Act § 8 (2).

[O]ne area of the law in which interdependent personal relationships involving a person with a disability are recognized, and in a manner which promotes the legal right of self-determination of a person (by creating more flexible standards of competency to make a decision, and by acknowledging that the defining feature of the relationship is one of trust rather than simply care giving or dependence).<sup>242</sup>

The B.C. system is not, however, even close to a pure supported decision-making model<sup>243</sup> because state intervention and the use of substituted or best interest surrogate decision-making are retained. If an individual does not, or cannot, enter into a representation agreement, the Public Guardian<sup>244</sup> is authorized to make decisions on her behalf.<sup>245</sup>

Other Canadian provinces have made significant inroads, on paper at least, toward supported decision-making, in moving from the medical model to a social model of capacity and incapacity.<sup>246</sup> For example, legislation in Manitoba has been designed both to protect *and* to empower people with intellectual disabilities who are defined as “vulnerable persons” under the Act<sup>247</sup> and to recognize the role of

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242. Kerzner, *supra* note 233, at 39 (internal citation omitted).

243. For example, the legislation does not provide for centralized registration of Section 7 agreements, though in B.C. a non-profit, charitable organization, NIDUS ([www.nidus.ca](http://www.nidus.ca)), does so. *Id.* at 40.

244. The Public Guardian and Trustee of British Columbia is a corporation established by the Public Guardian and Trustee Act, which administers trust assets for juveniles, adults who require assistance in decision making, and certain trust beneficiaries, and exercises quasi-judicial authority over guardianship and trust matters in the province. See *Who We Are*, Public Guardian and Trustee of British Columbia, available at [http://www.trustee.bc.ca/who\\_we\\_are/index.html](http://www.trustee.bc.ca/who_we_are/index.html) (last visited Oct. 25, 2012).

245. Anecdotally, when persons with representation agreements choose to make “bad” decisions, they may also be overridden by the Public Guardian. (Personal conversation, Third National Guardianship Summit, Salt Lake City, Utah, October 2011).

246. The full range of statutory provisions in Canada’s provinces is set out in Kerzner, *supra* note 233, at 44–57.

247. The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90 § 7(1) (Can. 2012) (stating that “vulnerable person” means an adult living with a mental disability who is in need of assistance to meet his or her basic needs with regard to personal care or management of his or her property”). Note the emphasis on “need of assistance” rather than on being “unable to make decisions about.” The Act, however, excludes persons with psychological disabilities, and many elderly persons, from its coverage. Kerzner, *supra* note 233, at 42.



support networks in assisting vulnerable persons to exercise their legal capacity. The Preamble is instructive:

WHEREAS Manitobans recognize that vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise;

AND WHEREAS it is recognized that vulnerable persons should be encouraged to make their own decisions;

AND WHEREAS it is recognized that the vulnerable person's support network should be encouraged to assist the vulnerable person in making decisions so as to enhance his or her independence and self-determination;

AND WHEREAS it is recognized that any assistance with decision making that is provided to a vulnerable person should be provided in a manner which respects the privacy and dignity of the person and should be the least restrictive and least intrusive form of assistance that is appropriate in the circumstances;

AND WHEREAS it is recognized that substitute decision making should be invoked only as a last resort when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself or with the involvement of members of his or her support network . . . .<sup>248</sup>

The Act recognizes a role for support networks to help people with intellectual disabilities exercise their decision-making rights, and it considers substituted decision-making to be only appropriate when necessary.<sup>249</sup> Unfortunately the Act is seriously limited by its application only to persons with what it more narrowly defines as mental disability—"significantly impaired intellectual functioning existing concurrently with impaired adaptive behavior and manifested prior to the age of 18 years"<sup>250</sup>—thus

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248. The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90 at Preamble (Can. 2012).

249. Kerzner, *supra* note 233, at 40–41. The statute provides that a substitute decision maker may only be appointed where the person is incapable *despite* the involvement of a support network. *Id.* at 43.

250. The Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90 § 1(1) (Can. 2012).

excluding persons with psycho-social disabilities or adult-onset intellectual disabilities.<sup>251</sup>

Unlike much other Canadian legislation, however, the Act actually provides for support services in some situations. Where an application for substitute decision-making is made and the person does not have a support network, the Vulnerable Persons' Commissioner may request assistance, provided by Manitoba's Supported Living Program, to create and involve a support network for the applicant.<sup>252</sup> While the Act provides "several procedural and administrative mechanisms to ensure access to and respect for the role of supports" support networks *per se* are not legally recognized and third parties are not bound to honor their role.<sup>253</sup>

Legislation in Yukon<sup>254</sup> provides for a spectrum of approaches to decision-making including supported decision-making agreements,<sup>255</sup> representation agreements, substitute decision-making for health care decisions, and guardianship.<sup>256</sup> Supported decision-making agreements provide legal status to those who provide support "to be with the [person with an intellectual disability] and participate in discussions with others when the [person with an intellectual disability] is making decisions or attempting to obtain information."<sup>257</sup> Reverting to an earlier paradigm, however, the law also authorizes the representative to make substituted decisions.<sup>258</sup>

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251. The limited coverage is attributed to the strong lobbying role played by the associations for community living, which serve that population, and the corresponding absence of participation in enactment of the law by representatives of the other major groups. Gordon, *supra* note 230, at 67.

252. Vulnerable Persons Living with a Mental Disability Act, C.C.S.M. c. V90 §§ 50(2), 85(2) (Can. 2012); Kerzner, *supra* note 233, at 43.

253. Kerzner, *supra* note 233, at 45.

254. Decision Making, Support and Protection to Adults Act, S.Y. 2003, c. 21 (Can.).

255. In order to enter into a legally recognized supported decision-making agreement, the person with an intellectual disability must demonstrate a certain level of capacity, understanding the nature of the agreement and its effect. *Id.* at Sched. A, Adult Protection and Decision-Making Act, §§ 5–6.

256. A chart of the planning and decision-making tools available in the Yukon may be accessed at <http://www.hss.gov.yuk.ca/downloads/decision-making-tools.pdf>.

257. Decision Making, Support and Protection to Adults Act, S.Y. 2003, c. 21, Sched. A, § 4(b) (Can.).

258. These decisions include routine financial management as well as some personal care issues. Adult Protection and Decision-Making Act, O.I.C. 2005/78 (Can.).

The “associate decision-maker’s” roles are enumerated in the statute as follows:

5(1) Except as a supported decision-making agreement otherwise provides, the responsibilities of the associate decision-maker are

- (a) to assist the adult to make and express a decision;
- (b) to assist the adult to obtain relevant information;
- (c) to advise the adult by explaining relevant information and considerations;
- (d) to ascertain the wishes and decisions of the adult and assist the adult to communicate them; and
- (e) to endeavour to ensure that the adult’s decision is implemented.<sup>259</sup>

Like Manitoba and Yukon, Saskatchewan recognizes the role of supports but only in the context of court appointments rather than voluntary agreements. While guardians are appointed for persons found incapable of managing their personal and/or financial affairs under a traditional cognitive capacity test, the Saskatchewan Adult Guardianship and Co-Decision-Making Act also provides for appointment of a “co-decision-maker” for people the court determines need assistance in making decisions.<sup>260</sup> As such, the co-decision-maker’s role is to assist the person in making decisions and share with the person the authority to make decisions.<sup>261</sup> The co-decision-maker does not, therefore, assist in furthering a person’s full legal capacity, though in some, but not all circumstances, she is required to acquiesce in the person’s decision.<sup>262</sup>

The most recent movement away from guardianship and toward some form of supported decision-making has been Alberta’s adoption of two new statutes: the Adult Guardianship and

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259. Decision Making, Support and Protection to Adults Act, S.Y. 2003, c. 21, Sched. A (Can.); Adult Protection and Decision-Making Act, O.I.C. 2005/78 § 5 (Can.).

260. Adult Guardianship and Co-Decision-Making Act, S.S. 2000, c. A-5.3 (Can.).

261. *Id.* §§ 17, 42.

262. That is, she must do so if a reasonable person could have made the impugned decision and no harm or loss is likely to result. *Id.* §§ 17(2), 42(2). Thus, protectionism clearly trumps autonomy and legal capacity is sacrificed to the “reasonableness” standard.

Trusteeship Act<sup>263</sup> and the Personal Directives Act.<sup>264</sup> Taken together they represent a “spectrum of decision-making options” that “provide legal mechanisms for individuals to appoint people to make decisions for them, appoint people to assist them in making decisions, as well as allowing a court to appoint a co-decision-maker, guardian or trustee.”<sup>265</sup>

Supported decision-making authorizations and co-decision-making orders, however, only apply to personal, as opposed to financial decisions.<sup>266</sup> On the other hand, unlike in most other Canadian jurisdictions, these authorizations and orders can be officially registered.<sup>267</sup>

Finally, efforts to enact legislation in Prince Edward Island directed specifically to supported decision-making,<sup>268</sup> which have been stalled for some time, have been revitalized<sup>269</sup> and there is significant activity toward similar reform in the provinces of Newfoundland and Labrador.<sup>270</sup>

Thus, unlike any existing statutory scheme in the United States, Canadian provinces have been experimenting with laws that provide persons with intellectual disabilities the right to choose a person or persons to assist them, and in some cases make decisions for them. The goal is not to give those representatives legal status, but to provide a decision-making hierarchy for guardians, “associates,” “co-decision makers,” or other surrogate decision makers that stresses facilitation, communication, and support for the intellectually disabled person’s own decisions, thereby making substituted decision-making a last resort. Equally important, both by statute and through the larger social service system, Canadian provinces recognize and provide at least some of the assistance and accommodation necessary to permit persons with intellectual

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263. Adult Guardianship and Trusteeship Act, S.A. 2008, c. A-42 (Can.).

264. Personal Directives Act, R.S.A. 2000, C. P-6 (Can.).

265. Kerzner, *supra* note 233, at 33.

266. *Id.* at 35.

267. Personal Directives Act, R.S.A. 2000, C. P-6, s.7.2 (Can.); Personal Directives Regulation, A. Reg. 99/2008, 4(1) (Can.).

268. The Supported Decision-Making and Adult Guardianship Act, 1997 C. 49 received Royal Assent in May 1997, but has not yet been proclaimed in force.

269. A new Supported Decision-Making Coalition of PEI has come together and is in dialogue with the provincial government in an effort to move the legislation forward. Supported Decision Making and Adult Guardianship Act, S.P.E.I. 1997, c. 49 (Can.); Kerzner, *supra* note 233, at 59.

270. *Id.* at 57.

disabilities to function as legal actors, whose decisions are respected and whose autonomy is encouraged and preserved.

## VI: NEXT STEPS

So, how to move forward?

For the world legal community, transition from the current paradigm of incapacity and guardianship to the emerging paradigm of full legal capacity and support for decision-making has become an imperative. In 2009, the Office of the United Nations High Commissioner for Human Rights wrote:

In the area of civil law, interdiction and guardianship laws should represent a priority area for legislative review and reform. Legislation currently in force in numerous countries allow the interdiction or declaration of incapacity of persons on the basis of their mental, intellectual or sensory impairment and the attribution to a guardian of the legal capacity to act on their behalf. Whether the existence of a disability is a direct or indirect ground for a declaration of legal incapacity, legislation of this kind conflicts with the recognition of legal capacity of persons with disabilities enshrined in Article 12, paragraph 2.<sup>271</sup>

This necessary transition has already been acknowledged by the First World Conference on Adult Guardianship, a group of guardianship experts, representatives of guardianship organizations,

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271. The High Commissioner's report continued, with emphasis as well on the affirmative steps necessary for compliance with Article 12:

Besides abolishing norms that violate the duty of States to represent the human right to legal capacity of persons with disabilities, it is equally important that measures that protect and fulfill this right are also adopted, in accordance with Article 12, paragraph 3, 4 and 5. This includes: legal recognition of the right of persons with disabilities to self-determination; of alternative and augmentative communication; of supported decision-making, as the process whereby a person with disability is enabled to make and communicate decisions with respect to personal or legal matters; and the establishment of regulations clarifying the legal responsibilities of supporters and their liability.

UN Office of the High Commissioner of Human Rights, Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, U.N. Doc. A/HRC/10/48 at ¶ 45 (Jan. 26, 2009).

and government representatives from around the globe organized by the International Guardianship Network, who gathered in Yokohama, Japan in October 2010. Their meeting generated the Yokohama Declaration (the "Declaration"), which explicitly affirms the "guiding principles and provisions" of the CRPD.<sup>272</sup> Notwithstanding this general affirmation, the words "legal capacity" are never used, nor is the right of every person to make his or her own decisions explicitly affirmed. In the context of adult guardianship, however, the Declaration provides:

- (1) a person must be assumed to have the mental capacity to make a particular decision unless it is established that he or she lacks capacity;<sup>273</sup>
- (2) a person is not to be treated as unable to make a decision unless all practicable steps to help him or her do so have been taken without success.<sup>274</sup>

Implicitly then, supported decision-making is required whenever possible. The Declaration, however, imposes no obligation to *provide supports* that may be necessary (as opposed to those which "are practicable"). While it reiterates many of the reforms of the current paradigm,<sup>275</sup> the Declaration is an important first step in "re-orienting" adult guardianship, even as the participants in the conference hope that:

[T]his Yokohama Declaration should be disseminated and communicated to public bodies and national governments to raise awareness of the issues involved and to obtain the support required to implement the provisions that we have acknowledged, affirmed and declared herein.<sup>276</sup>

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272. First World Conference on Adult Guardianship, Yokohama Declaration I(2)[2], Oct. 4, 2010, <http://www.international-guardianship.com/yokohama-declaration.htm> [hereinafter Yokohama Declaration]. The Declaration is divided into two parts, the first (I) the "International Part," and the second, II, the "Japanese Part" with provisions directed specifically to that country's guardianship system, including "urg(ing) the Japanese government to ratify at the earliest opportunity the [CRPD]." *Id.* § II.

273. Capacity, however, is nowhere defined.

274. Yokohama Declaration, *supra* note 273, §§ I.3.(1) and (2).

275. Somewhat peculiarly, the Declaration backtracks from the current paradigm in its provision that, "any restriction on an adult's capacity to make decisions should only be imposed where it is shown to be necessary for his or her own protection, or *in order to protect third parties.*" *Id.* § I.3.(4) (emphasis added).

276. *Id.* § I 5(2).

### A. CRPD Provisions

The CRPD itself provides an implementation mechanism through which transition to the new paradigm can be achieved. First, it requires States Parties to “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the . . . convention.”<sup>277</sup> It calls for international cooperation between states “and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities.”<sup>278</sup>

In a departure from other human rights conventions,<sup>279</sup> the CRPD calls upon States Parties to “designate one or more focal points within government for matters relating to implementation . . . and . . . give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.”<sup>280</sup>

To coordinate these international and national efforts, the Convention establishes a Committee on the Rights of People with Disabilities (the “Committee”)<sup>281</sup> and envisions an ongoing conversation and cooperation<sup>282</sup> between the Committee and States Parties, who are required to report on their efforts and achievements

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277. CRPD, *supra* note 19, Art. 31.

278. *Id.* Art. 32(1). Measures which might be taken include: “[f]acilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmers and best practices,” sharing research, and technical knowledge, sharing technologies and technical advances, and providing “as appropriate” economic assistance, *Id.* Art. 32(1)(b)–(d).

279. The Convention’s “attention to the national level . . . represents a particular innovation for international human rights conventions, although it is a standard feature of environmental and other international agreements.” Lord & Stein, *supra* note 20, at 462–63.

280. CRPD, *supra* note 19, Art. 33(1). Beside the “focal points,” Art. 33 calls for a “framework, including one or more independent mechanisms . . . within government to promote, protect and monitor implementation.” *Id.* Art. 33(2).

281. *Id.* Art. 34. The Committee’s membership is elected by States Parties, with consideration to be given to “equitable geographical distribution, representation of the different forms of civilization and the principal legal systems, balanced gender representation and participation of experts with disabilities.” *Id.* Art. 34(4).

282. *Id.* Art. 37.

every four years.<sup>283</sup> There is also provision for regular meeting of all states parties in a Conference of States Parties (the “Conference”) whose purpose is “to consider any matter with regard to the implementation of the . . . convention.”<sup>284</sup>

In addition to this mixed international/national structure for implementation, the Convention as a whole recognizes both substantive rights recognized in other international human rights treaties generally (such as healthcare and education) and more broadly-conceived rights such as liberty and, in the context of Article 12, supports for decision-making. These latter, socio-economic rights are necessary because “it is . . . not enough to remove formal obstacles to persons with disabilities”—for example, to abolish guardianship laws and determinations of legal incapacity—“it is also necessary to equip [people with disabilities] with the means necessary to make new opportunities a reality.”<sup>285</sup>

The Convention recognizes that, unlike political rights, for which states parties have “obligations of results,” socio-economic rights take time for implementation and realization. Consequently, as

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283. *Id.* Art. 35–36. The Committee then issues “suggestions and general recommendations on the report” which are forwarded to the member state. In 2011, the Committee considered the reports of Spain and Tunisia and, in both cases, expressed concern “that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity.” See Comm. on the Rights of Pers. with Disabilities, Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations, Spain, Oct. 19–23, 2011, U.N. Doc. CRPD/C/ESP/CO/1, ¶ 33 (Oct. 19, 2011), *available at* [http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1\\_en.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc); Comm. on the Rights of Pers. with Disabilities, Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations, Tunisia, Apr. 11–15, 2011, U.N. Doc. CRPD/C/TUN/CO/1, ¶ 22 (May 13, 2011), *available at* [http://www2.ohchr.org/SPdocs/CRPD/5thsession/CRPD-C-TUN-CO-1\\_en.doc](http://www2.ohchr.org/SPdocs/CRPD/5thsession/CRPD-C-TUN-CO-1_en.doc). The Committee recommended that both countries review the laws allowing for guardianship and trusteeship and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will, and preferences. More recently, in April 2012 the Committee made a similar finding as to Peru Comm. on the Rights of Pers. with Disabilities, Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations, Peru, Apr. 16–20, 2012, U.N. Doc. CRPD/C/PER/CO/1, ¶¶ 22, 24–25 (May 9, 2012), *available at* <http://www.ohchr.org/Documents/HRBodies/CRPD/7thsession/CRPD.C.PER.CO.1-ENG.doc>.

284. CRPD, *supra* note 19, Art. 40.

285. Gerard Quinn, *The United Nations Convention on the Rights of Persons with Disabilities*, 15 Tex. J. C.L. & C.R. 33, 43 (2009).



to such rights, States Parties have “obligations of conduct,” that is, the obligation “to lay down a positive dynamic of change that will lead to results in a reasonable time frame.”<sup>286</sup> The Convention, therefore, specifically acknowledges the inescapable reality that resources are finite and some change takes time in Article 4(2), which reads:

With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.<sup>287</sup>

Taken as a whole, the Convention requires States Parties to create “focal points” and national coordination mechanisms to collect and share information and best practices through the innovative mechanisms<sup>288</sup> of the Committee, with the goal of the “progressive achievement” over a reasonable period of time, of full equality for persons with disabilities. And, as it emphasizes again and again, this process must include and incorporate people with disabilities and their organizations.<sup>289</sup> This, then, is the model from which transition to the new paradigm of legal capacity can realistically emerge.

286. *Id.*

287. CRPD, *supra* note 19, Art. 4(2).

288. As two leading commentators have noted, [T]hose involved in the drafting of the CRPD attempted to build a framework within which the Convention’s eventual domestic incorporation would evolve beyond current human rights practice. . . . This explains . . . some of the more innovative structural . . . elements of the CRPD. . . . Moving beyond the traditional frameworks of human rights conventions, the CRPD lays out a template for comprehensive action, providing catalysts for socialization and outlining integrative mechanisms. . . .

Lord & Stein, *supra* note 20, at 455–56. *See also* World Network of Users and Survivors of Psychiatry, Implementation Manual for the United Nations Convention on the Rights of Persons with Disabilities 16–17 (2008), available at <http://www.WNUSP.net/>; World Network of Users and Survivors of Psychiatry, Legal Capacity as Right, Principle and Paradigm (2011) (discussing the practical implementation of Article 12).

289. *See, e.g.*, CRPD, *supra* note 19, Art. 32 (requiring all international cooperation and development efforts to include persons with disabilities and to be accessible to them). *See also* World Network, Legal Capacity as Right, *supra* note 289 (submission to the Committee on the Rights of Persons with Disabilities in

## B. Europe

Enactment (and, in many countries, ratification) of the CRPD is empowering disability advocates to push for radical reform of existing guardianship protective systems with, already, some notable success. In Europe, a network of scholar-advocates has been funded to examine current guardianship/curatorship regimes and to propose reform to bring them into compliance with CRPD Article 12.<sup>290</sup> In Ireland, for example, where the National University of Ireland, Galway, has been a center of disability research and advocacy, scholars and disability advocates have drawn up “Principles and Key Issues for Capacity Legislation,” which is intended as a framework for a new “capacity law” to replace the law currently in effect, dating from 1871. Among its principles and “key issues”:

The title of the law should be non-discriminatory. Taking into account the CRPD, the title of the law should be “legal capacity” rather than “mental capacity.”<sup>291</sup>

The law must protect people’s rights to make decisions about all aspects of their lives—as outlined in Article 12 of the CRPD—including [for example] decisions about healthcare, finances, relationships and where and with whom to live.<sup>292</sup>

People who need support to make decisions have a right to be provided with that support by the state, e.g. advocate supports should be recognized and assist the person in understanding options and expressing their “will and preferences.”<sup>293</sup>

Reasonable accommodation should be made to help the person understand the decision. Different ways of providing information must be explored (including sign language, alternative communication, flexibility with regard to time and location for

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response to its call for papers on theoretical and practical implementation of Article 12, providing a thoughtful example of such participation).

290. The network, funded by the EU Marie Curie (FP7) funding scheme, is called DREAM (Disability Rights Expanding Accessible Markets) and may be reached at <http://nuigalway.ie/dream>.

291. Centre of Disability Law and Policy, *Essential Principles: Irish Legal Capacity Law*, Principle 2, Key Issue (a) (Apr. 2012), available at [www.nuigalway.ie/cdlp/documents/principles\\_web.pdf](http://www.nuigalway.ie/cdlp/documents/principles_web.pdf).

292. *Id.* Principle 2, Key Issue (b).

293. *Id.* Principle 4.

delivering information, pacing, repetition, and a trusted source for information, etc.).<sup>294</sup>

There should be a range of advocacy supports, including state-appointed advocates with statutory powers, as well as other forms of individual advocacy (e.g. citizen advocacy, peer advocacy, self-advocacy support).<sup>295</sup>

Decisions made by someone else is a last resort when all supports have been considered (facilitated decision-making). It should only apply for specific decisions and for the length of time necessary for that purpose.<sup>296</sup>

Most European countries have signed, and in many cases ratified, the CRPD, and are working through the Council of Europe<sup>297</sup> on implementation strategies. Significantly, the European Union (“EU”) itself has also signed the Convention.<sup>298</sup> The primary EU body working on implementation is the High Level Group of Member

294. *Id.* Principle 4, Key Issue (a). This has made me think about the entirely *inappropriate* processes we use to decide who has capacity to make decisions. That is, a person with intellectual disabilities is brought into an unfamiliar, often extremely intimidating, courtroom, and asked questions by a stranger at ordinary speed, such as, under N.Y. Sur. Ct. Procedure Act Law § 17-A, where she would be asked, “Do you understand what end-of-life decision-making is?” and is then expected to answer immediately thereafter. How different could it be if a trusted advocate spent time, at home or in another familiar setting, breaking down that question into constituent parts, explaining each as many times as necessary, using cues appropriate to the person to assess understanding, and then “translating,” if necessary, in the courtroom. The practical application of this is reflected in Principle 9: “All information . . . must be easy to understand, must have the person [not the judge!] at the centre of the process, and must meet *that person’s* individual needs. This means that an entirely court based system that determines capacity is not appropriate.” *Id.* Principle 9 (emphasis added).

295. *Id.* Principle 4, Key Issue (b).

296. *Id.* Principle 8. The principles thus confront one of the major objections to a radical reading of Art. 12, that there are some people who simply cannot, regardless of supports, make decisions, and that for such persons, substituted decision-making will still be necessary.

297. The Council of Europe is an intergovernmental body that works to promote common, democratic principles across Europe. The body responsible for promoting, implementing and monitoring its disability plan is the European Coordination Forum for the Council of Europe Disability Action Plan 2006–2015 (CAHPAN). Flynn, *supra* note 159, at 58–59 (2011).

298. This was the first time a supranational structure of a group of nation states has signed a UN Human Rights Convention. *Convention and Optional Protocol Signatories and Ratifications*, Secretariat for the Convention on the Rights of Persons with Disabilities, <http://www.un.org/disabilities/countries.asp?navid=12&pid=166> (last visited October 25, 2012).

States' Representatives on Disability ("HLG"), which collaborates with civil society in identifying common challenges and potential solutions devised by individual member states, monitoring progress and assisting in follow-up. The HLG has already published three reports describing steps taken to date.<sup>299</sup> The Irish effort, discussed above, is part of this process.

These efforts are, of course, directed at improving the condition and enhancing of persons with many different kinds of disabilities. However, because of the relative success of a decades-long commitment to anti-discrimination efforts, and the greater visibility of persons with intellectual disabilities, the greatest changes in national laws and policy are likely to be directed to that group, prominently including changes in, or a total revamping, if not repeal, of guardianship legislation.<sup>300</sup>

### C. The Americas

Regardless of whether individual states in the Americas have ratified the CRPD, there is significant pressure to begin movement toward laws and policies that embrace its legal capacity mandate. For example, the monitoring committee of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities<sup>301</sup> has recently issued its General Observation on the interpretation of that treaty in light of the CRPD urging its state parties:

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299. Flynn, *supra* note 159, at 75. As previously noted, this focus on development of natural implementation plans and regional cooperation, including sharing "best practices," is uniquely built into the CRPD itself. CRPD, *supra* note 19, Art. 33; Lord & Stein, *supra* note 20, at 463.

300. The movement is hardly confined to Europe. Advocates all over the world have already begun to use the convention to challenge discriminatory practices against people with many different kinds of disabilities. See Paul Harpur, *Time to be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change*, 45 Val. U. L. Rev. 1271, 1287–88 (2011) (detailing challenges in Australia, Cambodia, China, Germany, the South Pacific Island States, and Vietnam).

301. Organization of American States, Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, entered into force Sept. 14, 2001, AG/Res. 1608 (XXIX-O/99) (June 7, 1999), available at <http://www.oas.org/juridico/english/ga-res99/eres1608.htm>. This Convention, which was a precursor to the CRPD, has been ratified by nineteen states, though not by either Canada or the United States. Notably, one of the earliest countries to ratify, Mexico, was also the initial driving force for the CRPD.

[T]o adopt measures, in keeping with Article 12 of the United Nations Convention, to guarantee recognition of universal legal capacity, including that of all persons with disabilities, regardless of the type or extent of disability, and consequently, to initiate without delay a process for replacing the practice of declaring legal incompetence, guardianship, or any other form of representation that impairs the legal capacity of persons with disabilities, with a practice based on decision-making with support.<sup>302</sup>

#### D. The United States

The United States has signed, but not yet ratified the CRPD. However, the Senate Committee of Foreign Relations passed the treaty in July 2012 and there are hopes for subsequent passage.<sup>303</sup> At the same time that Ambassador Susan Rice signed the Convention, the Obama administration announced the creation of a new position, the Special Advisor for International Disability Rights within the State Department, and named long-time disability activist Judith Heumann, herself a person with a disability, to that position.<sup>304</sup> The National Council on Disability, an independent federal agency whose members are appointed by the President, undertook a study of the implications of CRPD ratification, finding that “as a general matter, the aims of the CRPD are consistent with the U.S. disability law” but noting that, as to the provisions of Article 12, which affirms the right of persons with disabilities to recognition of their legal capacity “on

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302. Organization of American States, Inter-American Committee for the Elimination of All Forms of Discrimination against Person with Disabilities, General Observation of the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities on the need to interpret Article I.2(b) in line with the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities in the context of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, OEA/Ser.L/XXIV.3.1 CEDDIS/doc.12(I-E/11) rev.1 (May 4–5, 2011).

303. See, e.g., Press Release, U.S. Senate Comm. on Foreign Relations, In Bi-Partisan Vote, Foreign Relations Committee Passes Disabilities Treaty (July 26, 2012), available at <http://www.foreign.senate.gov/press/chair/release/bi-partisan-vote-foreign-relations-committee-passes-disabilities-treaty>; Press Release, U.S. Senator John McCain, Bipartisan Group of Senators Announce Support for Disability Treaty (May 25, 2012), [http://www.mccain.senate.gov/public/index.cfm?FuseAction=PressOffice.PressReleases&ContentRecord\\_id=84b3c564-d49f-0cf5-7742-9ff158d8ef7e](http://www.mccain.senate.gov/public/index.cfm?FuseAction=PressOffice.PressReleases&ContentRecord_id=84b3c564-d49f-0cf5-7742-9ff158d8ef7e).

304. See *Biography of Judith E. Heumann*, U.S. Dep’t of State, <http://www.state.gov/r/pa/ei/biog/144458.htm> (last visited Mar. 12, 2012).

an equal basis with others in all aspects of life,”<sup>305</sup> “[l]egal capacity is governed primarily by state-level law.”<sup>306</sup> In 2011 the administration prepared a ratification package to be transmitted to the Senate, where, with three reservations, five understandings, and a declaration clarifying the application of the Convention in domestic courts, it now awaits that body’s “advice and consent.”<sup>307</sup> At present, then, the United States is not yet bound to implement Article 12, but if and when ratification occurs, both current guardianship laws and the current paradigm of incapacity will be up for grabs. All that has seemed clear—and right—about our medically informed, functional understanding of capacity, our careful balancing of autonomy and protection, and our attention to procedural protections in any determination of incapacity is, in light of the Convention, deeply problematic. Catching the wave of the emerging paradigm is disorienting, uncomfortable, even frightening. It will require not only changes in our laws, but also profound changes in how we see and understand people with intellectual disabilities. This kind of change is explored through the lens of “expressive law” which considers the way in which “[l]egal instruments affect preferences and behavior by altering social perceptions and conventions.”<sup>308</sup> But, regardless of how we feel about it, to quote Professor Perlin’s hero Bob Dylan, “Change is a-Comin’.”<sup>309</sup>

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305. CRPD, *supra* note 19, Art. 12(2).

306. National Council on Disability, Finding the Gaps: A Comparative Analysis of Disability Laws in the United States to the United Nations Convention on the Rights of Persons with Disabilities 4 (2008), available at <http://www.ncd.gov/publications/2008/May122008#a12>.

307. Press Release, U.S. Dep’t of State, Conversations with America: International Disability Rights (Feb. 17, 2011), <http://www.state.gov/r/pa/prs/ps/2011/02/156748.htm>.

308. See Lord & Stein, *supra* note 20, n.141 (citing Alex Geisinger, *A Belief Change Theory of Expressive Law*, 88 Iowa L. Rev. 35 (2002)); see also Michael Ashley Stein, *Under the Empirical Radar: An Initial Expressive Law Analysis of the ADA*, 90 Va. L. Rev. 1151 (2004) (providing a literature review of expressive law).

309. Professor Perlin is a leading figure in mental disability law and studies and a prolific writer. He admits to a lifetime fascination with the music of Bob Dylan, and often titles his articles using the names or lyrics of Dylan’s songs. See, e.g., Perlin, *Change is Gonna Come*, *supra* note 192; see also Perlin, *Their Promises of Paradise*, *supra* note 68.

## VII. THE CHALLENGES AHEAD

As in Europe, disability advocacy groups and civil society are likely to press for repeal or very significant reform of existing guardianship laws; some sort of legal recognition of representation agreements or similar arrangements; education and awareness in developing decision-making capacities in persons with intellectual disabilities and respect for those capacities,<sup>310</sup> and various kinds of supports, from assisted communication, to more enriched community living, to alternative judicial proceedings. Because of the work going on elsewhere in the world, the United States will not be entering into the emerging paradigm alone, or without the experiences—good and bad—of other nations.<sup>311</sup> The apparent enormity of the task need not overwhelm us.

Inclusion Europe, a large and influential umbrella group, has proposed an incremental process of replacing traditional guardianship by a system of supported decision-making that asks States Parties to, *inter alia*:

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310. “Being able to take one’s own decisions requires . . . that family members, careers, professional staff and others recognize the ability of people with intellectual disabilities to take their own decisions. These are the objectives of the self-advocacy movement . . .” *Key Elements of a System for Supported Decision-Making*, Inclusion Eur., available at [http://www.inclusion-international.org/wp-content/uploads/Position\\_Paper-Supported\\_Decision\\_Making1.pdf](http://www.inclusion-international.org/wp-content/uploads/Position_Paper-Supported_Decision_Making1.pdf).

311. Indeed, this should come within the coordinating role of the entities created by the CRPD, *supra* note 19. As Gerard Quinn has written:

Now, there is an inherent danger with assisted decision making and let’s beware of it. Assisted decision making might cross the elusive line to become—in effect—substitute decision making. I am no expert in how to configure effective ‘assisted decision making’ regimes. But lack of knowledge about how it can be done, or a fear about how to police the line between assisted and substitute decision making is no excuse for not moving in the right direction. There are plenty of countries out there—or States or Provinces within countries such as Canada, Australia and Sweden—that have very practical experience in doing this over many years. Let’s get the information and skills flowing to make sure we can embed best practice [sic] here in Europe. Incidentally, the Conference of States Parties under the UN Convention could be an excellent platform for transferring this know-how.

Gerard Quinn, European Foundation Centre: Consortium on Human Rights and Disabilities, *An Ideas Paper* 18 (June 4, 2009) available at [www.nuigalway.ie/cdlp/documents/events/EFCGQfinal.doc](http://www.nuigalway.ie/cdlp/documents/events/EFCGQfinal.doc).

[First], review all national laws in light of Article 12 and to ensure that the right to self-determination and to equal recognition before the law without discrimination on the basis of disability is enshrined in the law;

[Second], to abolish without delay all legislation and practices that (sometimes automatically) lead to a legal incapacitation once a person with intellectual disability becomes of age; [and]

[Third], to set up a plan to implement gradually the newly adopted supported decision-making system: . . . traditional guardianship measures on the basis of appropriate law reforms should be reviewed for all cases and should progressively be replaced by the supported decision-making system.<sup>312</sup>

Anticipating the kind of resistance that will undoubtedly be raised in the United States as well, Inclusion Europe wisely notes:

This system will take time to develop and would run the risk of becoming dysfunctional if all existing measures of traditional guardianship were declared illegal at the same time, without the conditions in place that made supported decision-making effective for a particular individual. The system of guardianship and the system of supportive decision-making should therefore exist in parallel during the period of time until the transition is completed.<sup>313</sup>

And, although this Article has focused on the paradigm shift to legal capacity, it is also surely the case that, even within the primacy of autonomy there is always the possibility of exploitation and/or abuse, and appropriate protective mechanisms must be designed and enacted.<sup>314</sup> This is a process in which the active

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312. See Inclusion Europe, *supra* note 312, at 4–5 (discussing the replacement of traditional guardianship with supported decision-making).

313. *Id.* at 5.

314. As Michael Bach and Lana Kerzner note, “[a]n important component of any decision-making regime would be the inclusion of a high level of review and oversight to address . . . concerns about abuse and undue influence.” Bach & Kerzner, *supra* note 2, at 37. They point, however, to a recent U.N. report on issues of older persons from a global perspective that “[c]alls for addressing elder abuse and other issues within a proactive human rights approach, and recommends a new international human rights mechanism for that purpose.” *Id.*



participation of persons with intellectual disabilities is crucial to avoid the re-imposition of a protectionist model of incapacity.<sup>315</sup> Perhaps the greatest conceptual obstacle to full implementation of Article 12 is the deeply ingrained belief that there are some persons who are, simply, just beyond reach. This perception<sup>316</sup> tends to undermine the entire claim of legal capacity and the equality of all persons, including those with intellectual disabilities, before the law. This, too, has been addressed by others who are farther along in adoption of the human rights paradigm.<sup>317</sup> As Gerard Quinn writes:

Now what about those whose will is undetectable or for whom it is not possible to ascribe a will or preference? These would include people who have been institutionalized and for whom the “mystic cords of memory” that bind them to others, to family, to friends, to community, is gone . . . and people in what is described as a “persistent vegetative state”. . . . I think the hard reality which is that sometimes decisions will be made “for” and not “with” does not mean that substituted decision-making *as usual* is the correct response.<sup>318</sup>

But what’s worse: stretching a fiction (100% support) to the point that it is visibly at odds with reality . . . or admitting the obvious and then using

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*See also* Chinsung Chung, United Nations, Human Rights Council Advisory, The Necessity of Human Rights Approach and Effective United Nations Mechanism for the Human Rights of the Older Person (Dec. 2009), *available at* <http://www2.ohchr.org/english/bodies/hrcouncil/advisorycommittee/session4/docs/A-HRC-4%20crp-1.doc>.

315. *See, e.g.,* Tina Minkowitz, The Paradigm of Supported Decision Making, <http://nagano.dee.cc/tinalegal.htm> (last visited Oct. 25, 2012) (exemplifying the thoughtful and provocative work done by people with intellectual disabilities and their organization).

316. Inclusion Europe has noted that the “[p]erception of a person with severe disabilities or complex needs as being incapable of taking on socially accepted mainstream roles in life . . . goes hand in hand with prejudices and negative attitudes against this group and their families. . . .” resulting in their “[s]pend[ing] their lives with little support at home . . . or being confined to [institutional] services. . . .” Inclusion Europe, People with Severe Disabilities and/or Complex Needs and the U. N. Convention 1 (2009), *available at* [http://inclusioneurope.org/images/stories/documents/PositionPapers/Position\\_paper\\_r\\_Complex\\_Needs\\_EN.pdf](http://inclusioneurope.org/images/stories/documents/PositionPapers/Position_paper_r_Complex_Needs_EN.pdf).

317. Quinn, *supra* note 313, at 18.

318. Quinn, *supra* note 11, at 14.

our talents to lock in the exception<sup>319</sup> and transform how decisions are “made for” people.<sup>320</sup>

That is, neither Article 12 nor national (or in the case of the United States, state) legislation implementing it means that there can *never* be a situation in which some form of substituted or best interest decision-making will be necessary. But, even while acknowledging the truly “hard cases,” Quinn urges us to employ the paradigm shift in a different manner “for those 5% for whom there should be an added obligation to divine the will if at all possible and create social embeddedness that allows some flash of the will to emerge.”<sup>321</sup>

He explains:

As a last resort, when all other less restrictive support mechanisms have failed to resolve an individual situation, [prospective legislation] should outline the circumstances in which substituted decision-making can be used. Types of substitute decision-making, which would be compliant with UN Convention, are often referred to as co-decision-making or facilitated decision-making, and these systems have a number of striking differences from guardianship or out-dated wardship mechanisms. Co-decision-making and facilitated decision-making mechanisms have as their core principle the “will and preferences” of individuals and are not focused on “best interests”—as this is often interpreted simply as a persons “best medical interests.” Instead, a facilitator or co-decision maker is appointed and must make the decision which comes closest to the “will and preferences” of the person and one which can augment the future development of that person’s decision-making capacity, however limited this capacity may at first appear to be. Understanding the “will and preferences” of the person can be a lengthy process, especially where individuals do not use easily recognised systems of communication. However, the outcome is predicated

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319. That is, according to Quinn, limiting it to *only* those persons for whom no amount of supports are enough (while, simultaneously, understanding the obligation to explore all possibilities), and drawing lines to identify “toe holds on the slippery slopes” in which the new *exception*—decisions “for”—could, without vigilance, revert to the current paradigm and become, instead, the norm. *Id.* at 77–88.

320. *Id.* at 78.

321. *Id.*

on a human rights-based approach to legal capacity, as enshrined in Article 12 of the UN Convention.<sup>322</sup>

As lawyers, judges, psychiatrists, psychologists, educators, and other care providers,<sup>323</sup> we need to be open to what Kuhn called the “change in the perception and evaluation of familiar data” so as to “reorient” our understanding and practice as we engage with this emerging paradigm shift that will necessarily “alte[r] the historical perspective of [our collective] community that experiences it.”<sup>324</sup>

Vignette #5: 2012

*As I learn more about the CRPD, I read and am moved by some of its leading advocates, including the previously quoted Gerard Quinn. He reiterates:*

Take the person for whom there is no—or at least no obvious—will or preference. Bad substitute-decision-making is no longer acceptable. Or put another way, the necessity of making some decisions “for” rather than “with” the person has to be accompanied by a parallel and serious commitment to put in place the necessary ingredients to help spark the will and preference . . . . [T]hat means connecting the individual with social capital, with community. This is especially important with respect to those who have been institutionalized and for whom the “mystic chords of memory” that connect them with family and acquaintances are shattered . . . .<sup>325</sup> [T]his is the essence of the paradigm shift in action.<sup>326</sup>

*I think about “seeing and lighting the spark within” persons who have previously seemed beyond reach. I remember what the*

322. *Id.* at 35.

323. Quinn points out the prior “compartmentalization” of persons in different fields with different focuses working on issues of intellectual disability. He notes that “one result of this compartmentalization was that legal capacity was seen as a technical issue, marginalized on the fringes of disability law and calling for technical solutions. Not any more. If the Convention has done one thing it has enabled a common language to emerge—producing a unified field theory, if you will, of disability laws.” Gerald Quinn, *Seminar on Legal Capacity 8* (Ctr. for Disability Law & Policy, Ideas Paper, 2009).

324. Kuhn, *supra* note 16, at 11–12.

325. For a moving description of the “re-connection” of two individuals who were de-institutionalized as a result of the *Olmstead* decision, *supra* note 162, see Samantha A. DiPolito, *Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation’s Conscience?* 58 Mercer L. Rev. 1381, 1383 (2007).

326. Quinn, *Rethinking Personhood*, *supra* note 15, at 61.

psychiatrist and psychologist wrote about Mark,<sup>327</sup> a young man for whom I appointed an Art. 17-A guardian in 2008. According to their certifications, Mark was suffering from “profound mental retardation and autism.” Testing done that year showed that he had “the receptive communication skills of someone less than two years old and the expressive skills of a three month old.” The legal services attorney who visited Mark confirmed that “effective communication was not possible.” Mark was unable to perform any of the activities of daily living; he could not feed, bathe, or dress himself. He was given to aggressive and sometimes violent outbursts, was heavily medicated and frequently confined to his room, sometimes in restraints, in the institutional “school” in which he had resided for the past five years.

Mark’s mother died when he was 14, shortly after his institutionalization. She left a trust for his care, but neither of the trustees had ever visited Mark, inquired of the institution as to which of Mark’s needs might be met by expenditures from the trust, or, indeed, spent a single dollar from the trust on him, the sole beneficiary. When this tragic story came to light, I directed the trustees to retain a trained social worker/care manager who had experience working with people with intellectual disabilities.

Once hired, the care manager, who was both skilled and empathetic, got to work. Using funds from the trust, she purchased a facilitated communication device for Mark, and worked with his care providers to educate and train them—and Mark—in its use. She arranged consultations with specialists that resulted in significant reduction in the amount of medication Mark was receiving and in changes in medication that dramatically reduced the seizures from which he suffered. She purchased a computer and outdoor play equipment for Mark’s use (and that of other young people in the institution), arranged for him to be taken out to restaurants and other public places with aides, and in many ways began to create supports for Mark to express his wishes, to become part of a community and to begin to make—and act on—decisions about his life.

During the last three and half years, Mark has “graduated” from his special education program (in which he had previously been continuously restrained) and moved into transitional supportive group housing. Now he has his own room, cleans, shops and cooks, communicates with his housemates and support staff, and participates in activities in the larger community. His aggression is markedly

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327. Matter of Mark C.H., 906 N.Y.S.2d 419, 420 (Sur. Ct. 2010).

*decreased, and he has learned to “self soothe.” He has preferences about what to eat, what to wear, with whom to spend his time and how, and he has the capacity to act on those preferences. He has expressed the desire to see his brother, from whom he was separated almost a decade ago when he was institutionalized and steps are being taken to facilitate that reunion.*

*As I read the quarterly reports filed by the care manager I am incredibly happy about this near miraculous transformation. They describe the emergence of a real person, one who is learning autonomy and living with dignity, a person who is beginning to enjoy some equality of access to the “social economic and political institution of society.” I notice that I am beginning to internalize the new paradigm, to “see” Mark, and others like him, in an entirely different light, with “capacities” that were previously invisible.*

*Now, as I conduct guardianship hearings involving young people who have been labeled “severely retarded” and who do not speak—but who, if you watch carefully, are constantly communicating feelings and choices to their trusted family members—I begin to see the spark that Quinn describes. I wonder how much more fully these apparently “totally incapacitated” young people could live their lives in a society that provided them and their caretakers with the supports necessary for them to enjoy and exercise that full legal capacity which, as Quinn writes, “is only the tool by which the ‘person’ asserts him or herself in the lifeworld—in the myriad of tiny daily transactions that make up who we are.”<sup>328</sup>*

It may not be easy, but it’s time to get started . . .

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328. Quinn, *Rethinking Personhood*, *supra* note 15, at 54.

