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# Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities

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# Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the *Convention on the Rights of Persons with Disabilities*

Sheila Wildeman

The World Health Organization (WHO) has in the last decade identified mental health as a priority for global health promotion and international development, to be targeted through promulgation of evidence-based medical practices, health systems reform, and respect for human rights. Yet these overlapping strategies are marked by tensions as the historical primacy of expert-led initiatives is increasingly subject to challenge by new social movements — in particular, disabled persons' organizations (DPOs). These tensions come into focus upon situating the WHO's contributions to the analysis of global mental health in light of the negotiation and early stages of implementation of the *Convention on the Rights of Persons with Disabilities* (CRPD),<sup>1</sup> particularly as it applies to persons with mental disabilities. To clarify, I distinguish "mental" from "intellectual" disability (as does the CRPD<sup>2</sup>) and use the former term interchangeably with "psychosocial" disability, a term favored within the disability community to denote mental health conditions without rooting these in individual pathology. The focus of my analysis is psychosocial or mental disability; however, at times the analysis has clear application also to intellectual disability or to forms of state action to which persons with intellectual disabilities may also be subject.<sup>3</sup>

Commentators have remarked upon the importance of the CRPD in bringing together in one instrument civil and political with economic, social and cultural rights, supplemented by state obligations to support political participation.<sup>4</sup> Yet, arguably as a function of unprecedented participation of those most directly affected, the CRPD has generated controversies about the implications of recognizing persons with disabilities, and in particular, psychosocial disabilities, as bearers of these inter-related human rights. These controversies may be regarded as inevitable byproducts of the CRPD's fragile reconciliation of historically polarized ideas and interests. My discussion makes particular note of contestation around Articles 14 and 17 (liberty and integrity of the person) and Article 12 (equal legal capacity).

I argue that the inclusive negotiation history of the CRPD, and more immediately, the important obligations this convention imposes with regard to participatory implementation, hold out much promise for vindicating the rightful status of persons with psychosocial and intellectual disabilities as political

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actors and so equal legal subjects rather than objects of others' (well- or ill-intentioned) interventions.<sup>5</sup> The controversies discussed herein may be regarded as illustrative of the CRPD's function in operationalizing political agency among persons historically relegated to categories of disability deemed inconsistent with agency. But the question remains: what are the implications for global mental health policy?

The article proceeds in five parts. Part I introduces certain tensions, as well as points of convergence, between global mental health policy as articulated at the WHO and the attentiveness to social context (including relationships of power and oppression) and to subjective experience that is essential to human rights analysis. Part II introduces the social model of disability — forged in opposition to the dominance of professional knowledge — and positions the anti-psychiatry movement in relation to both the social and human rights models of disability. Part III turns to the CRPD, noting the key role played by DPOs (including those representing persons with psychosocial disabilities and those representing persons with intellectual disabilities) in the negotiation and drafting of this instrument, and briefly introducing the substantive rights and implementation measures included in it. Part IV examines two controversies engendered by the CRPD: first, concerning the legitimacy of involuntary psychiatric hospitalization and treatment, and second, concerning the meaning or implications of the right to equal legal capacity. These controversies illustrate the radical challenges to global mental health policy that have gained new legitimacy and momentum through the participation of DPOs in the CRPD process.

Part V concludes with reflections on the prospects for carrying forward the CRPD's commitments to inclusive or participatory mental health policy-making at the global and domestic levels. While there is a risk of continued polarization and of a retrenchment of historic patterns of exclusion, states parties — along with international agencies, civil society organizations including DPOs, and academics — should seek to deepen mutual engagement around the imperatives of the CRPD in order to shift global mental health policy from coercive approaches toward innovative supports, in accordance with the interlocking values of autonomy, equality, and political participation.

## I. Global Mental Health Policy

The last decade has seen a remarkable intensification of international policy discourse directed at global mental health, after a long period of relative silence. The growth in international attention is largely justified within this discourse by way of a relatively

straightforward utilitarian calculus. On that analysis, estimates of prevalence — typically focused on conditions classed as neuropsychiatric disorders<sup>6</sup> — are paired with estimates of associated costs, followed by observations about systemic inefficiencies and calls for reform. One prominent expression of this line of analysis in the WHO literature highlights the contribution of a set of mental disorders to the “global burden of disease”: a term of art which factors premature death together with diagnosis-specific discounting of years lived with disability.<sup>7</sup> Recent estimates suggest that mental disorders contribute 14% of the total calculated global burden of disease,<sup>8</sup> with depression ranking as top contributor in high income nations and as third contributor worldwide.<sup>9</sup> Other WHO documents focus upon global economic losses linked to mental health conditions, based on impact on economic growth,<sup>10</sup> loss of income, and direct and indirect medical and non-medical costs.<sup>11</sup> In this vein, the WHO's executive committee has endorsed the estimate that “the cumulative global impact of mental disorders in terms of lost economic output will amount to US \$16,000 billion over the next 20 years.”<sup>12</sup>

Against this background come critiques of current approaches to mental health promotion and treatment. Evidence of high rates of untreated mental health conditions<sup>13</sup> are juxtaposed with low resourcing of mental health in comparison to somatic conditions.<sup>14</sup> This pattern is identified worldwide; moreover, WHO data indicate that significantly less is spent on mental health by low-income nations than by high-income ones, both in per capita and proportionate budgetary terms.<sup>15</sup> This includes strikingly lower expenditures on psycho-pharmaceuticals.<sup>16</sup> The attendant policy critiques are aimed not simply at resourcing but, in addition, at inefficiencies, including lack of coordination among existing mental health and social services, and the concentration of resources on hospital versus community-based services.<sup>17</sup> In response, initiatives launched by the WHO<sup>18</sup> and other organizations such as the strategically expert-steered Movement for Global Mental Health<sup>19</sup> seek to promote evidence-based mental health treatment<sup>20</sup> (focused primarily, though not exclusively, on psychopharmaceutical interventions)<sup>21</sup> in tandem with systemic reforms that aim to be sensitive to variances in economic conditions and human resource capacities.<sup>22</sup> Moreover, and specifically in response to the data suggesting high prevalence combined with low resourcing among low-income countries, WHO policy is increasingly directed toward linking global mental health to the work of international development, for instance, through calls to integrate mental health targets into the Millennium Development Goals.<sup>23</sup>

But let us pause to consider some critiques that may be raised to the utilitarian calculus that underpins the recent prominence of global mental health on the international health policy stage. One critique goes to prevalence, or to the conceptual and analytical constructs through which mental health and mental disability are mapped in the first place. There is as yet no standardized method for assembling data about the prevalence of disability generally or mental disability in particular, and comparisons across existing methods of data collection are highly unreliable.<sup>24</sup> This has inspired intensive efforts to select among available tools, both to orient global health policy and to enable human rights monitoring with respect to disability.<sup>25</sup> Yet such efforts are beset by complexities, rooted in part in the fact that prevalence estimation is not value- or interest-neutral.<sup>26</sup> Rather, the assessment of disability prevalence requires selection and prioritization among various features of complex social and individual phenomena. As such, the conceptual and normative frame that one brings to prevalence estimation is likely not only to affect the results, but moreover, to play a profound role in structuring subsequent processes of decision-making about strategic action.

Further complexities arise specifically with respect to estimating the prevalence of psychosocial disability. For instance, not all individuals who may be diagnosed with a mental health condition will self-identify as such<sup>27</sup> — whether because of social stigma or because alternative frameworks (whether spiritual or other interpretive frameworks)<sup>28</sup> present more compelling ways of integrating one's experience. Such complexities only deepen in the face of cultural difference. Indeed, drawing upon the thesis that important differences may register across cultures, not only with respect to how mental health conditions are understood but how they manifest (both symptomology and prognosis),<sup>29</sup> one may speculate that prevalence estimation on Western disease-based models may potentially contribute to population-wide alterations in the experience of mental disability. This in turn raises the prospect (a highly profitable one from the vantage of international pharmaceutical interests) of replicating among developing nations/emerging markets the accelerating incidence of psychiatric disorders and attendant “shrinking of the normal”<sup>30</sup> that characterizes the nations now exporting neuropsychiatric knowledge.<sup>31</sup> Viewed in this light, the work of mapping prevalence begins to blur uncomfortably with the imperatives of BigPharma. Thus one may ask: should, or could, prevalence estimation take account of alternative perspectives — individual, cultural, also politi-

cal or ideological — on the nature of mental disability? What would this mean for the design and implementation of instruments and for the uses of assembled data?

A second critique of the utilitarian calculus animating global mental health policy discourse takes aim at the characterization of mental health conditions as burdens or economic losses. Here we may start with calculation of the global burden of disease. That calculation, as noted, is based in part in the construct of the disability-adjusted-life-year, arrived at by assigning specific diseases or disorders fixed life-year-discounting effects.<sup>32</sup> This does not factor in available supports, subjective attitudes or values, or other matters that may affect whether an individual flourishes or languishes.<sup>33</sup> Such estimates therefore lack the attentiveness to context essential to appreciating the nature, causes and consequences of disability, including mental disability — from either a health or human rights perspective.

**In short, the danger of the sort of utilitarian calculus that has become a centerpiece of global mental health policy is that it may encourage pre-existing tendencies to discount the complexity of both the subjective experience and social foundations of mental disability.**

Turning to the calculation of economic loss, it may be argued that such an approach is the necessary handmaiden of policy analysis and reform. Yet translation of the complex social and subjective dimensions of mental health problems into economic burdens<sup>34</sup> — at least, without significant care in devising and relaying those calculations — risks encouraging a dangerous strategic reductionism. That is, particularly when paired with broad claims about the effectiveness of psycho-pharmaceutical treatments (in the absence of attention to such factors as high rates of inefficacy,<sup>35</sup> intercultural elements, and the range of reasons for treatment resistance<sup>36</sup> including but not limited to health-compromising side effects),<sup>37</sup> such analysis may reinforce widely-held beliefs that there are simple ways to “fix” the individual and social problems identified. This in turn has the potential to reinforce widespread attitudes of resentment and recrimination as well as reflexive attributions of incapacity or lack of insight<sup>38</sup> aimed at those who refuse or discon-

tinue psychiatric treatments.<sup>39</sup> What may be lost along the way is attentiveness to the interweaving of mental health conditions with individual values and identity, as well as social determinants — not only “stigma” but political economy (for instance, the increasing concentration of wealth and concomitant assignment of ever-growing numbers to unemployment or dehumanizing work and so to increased vulnerability to mental health problems).<sup>40</sup> In short, the danger of the sort of utilitarian calculus that has become a centerpiece of global mental health policy is that it may encourage pre-existing tendencies to discount the complexity of both the subjective experience and social foundations of mental disability.

It is debatable whether the concerns raised regarding estimations of prevalence and of associated burdens may be alleviated in some measure by the classificatory model promoted by the WHO for informing assessment of disability prevalence and policy responses thereto: the International Classification of Functioning, Disability, and Health (ICF).<sup>41</sup> In contrast to the symptom-based schema of the DSM-IV<sup>42</sup> or ICD-10,<sup>43</sup> the ICF enables a multi-dimensional description of the interaction of individual impairments and the social environments that promote or diminish individual functioning. In this it advances a “bio-psycho-social” model of disability, which some have argued is well suited to data-gathering at the intersection of public health policy and human rights.<sup>44</sup> However, in addition to criticism regarding the complexity and so practicability of this classificatory scheme,<sup>45</sup> other concerns touch again upon power and oppression. Some argue that the ICF allows too much scope for continued prioritization of a disease model of impairment, thus undercutting the most critical or radical social analyses of disability;<sup>46</sup> this was suggested by some DPOs at the CRPD negotiations.<sup>47</sup> Others raise the Foucauldian concern that the ICF’s unparalleled attention to the details of disabled persons’ attitudes and activities enables unprecedented surveillance,<sup>48</sup> and with this, new (if unintended) possibilities for incursions upon autonomy as well as new bases for disentanglement from social benefits.<sup>49</sup>

If, as suggested, estimations of disability prevalence and interpretations of the data generated thereby are always informed by a prior normative framework, then one question to be pursued is what that normative framework is or should be. (Let us shelve for the moment the question of whether any such normative or justificatory framework might mask the operation of a different, and perhaps more sinister, functionality). Here we may turn to a further important element in the discourse of contemporary global mental health policy: human rights.<sup>50</sup> A fitting starting-point is the

acknowledgement, in the 2010 WHO report on Mental Health and Development,<sup>51</sup> of a “bi-directional” relationship between mental health and human rights.<sup>52</sup> This recognizes, on the one hand, that mental health problems render one vulnerable to denial of human rights, including subjection to violence — for girls and women with mental disabilities, particularly sexual violence<sup>53</sup> — as well as discrimination manifesting in disproportionately low access to health and other social supports and attendant exposure to poverty and homelessness. On the other hand, the bi-directionality thesis recognizes that human rights violations have a causal effect in rendering one vulnerable to mental health problems.<sup>54</sup> Here the acknowledged determinants again include violence, inequality, and lack of accessible social supports, including income supports and adequate housing. In acknowledging that factors such as socio-economic inequality (including gender and racial inequality) may give rise to mental health problems, the bi-directionality thesis simply tracks scientific consensus.<sup>55</sup> But what is of note is the WHO’s adoption of the normative framework of human rights as a mechanism for calling down a political response. In this it is important that the discourse adopted is not exclusively or even in the main directed at establishing a right to individualized medical treatment. Rather, the central claim is that states must promote the social determinants of mental health. This is complemented by development discourse linking mental health with productive and responsible citizenship and so with the social and economic health of nations.<sup>56</sup> In this way, global mental health is positioned as a unifying ideal traversing the domains of medicine, law, economics and politics. Moreover, it is positioned in a manner that both fundamentally challenges and fundamentally preserves the global political-economic status quo — effectively nesting a rights-based egalitarianism within a capitalist ethic of productivity and attendant concern for reliable and ever-expanding supplies of human capital.

It is important, however, also to note a more targeted approach to mental health and human rights taken by the WHO. Its *Resource Book on Mental Health, Human Rights and Legislation*<sup>57</sup> assembles a set of human rights instruments relevant to mental disability, and offers specific guidance on the legal standards and procedural protections required in order to reconcile human rights with involuntary psychiatric interventions. The guidance ranges from substantive criteria for involuntary hospitalization, to rights to independent review, to a range of other entitlements and protections featured in the dedicated mental health laws of many nations. As context, in 2010, one-third of nations lacked such dedicated mental health



laws, the majority being low-income nations<sup>58</sup> (though it may be noted that many of these also have little in the way of psychiatric infrastructure).<sup>59</sup>

But are involuntary psychiatric interventions (ever) consistent with human rights?<sup>60</sup> This section has noted tensions between subjective as well as culturally-variegated perspectives on mental disability, and an approach, reflected in the WHO literature, that gives exclusive authority to professional knowledge — particularly with respect to prevalence and global burdening. The continued privileging of professional perspectives along with liberty-constraining legal frameworks in WHO mental health policy — or the continued preservation of these frameworks from culturally and politically informed deliberative reassessment — risks reinforcing the skeptical critique that, despite the best of intentions, both global mental health policy and the international human rights model to which it has recently been wedded are liable to function less to enhance human well-being within a framework of respect for diversity than to expand professional power along with the global capitalist/pharmaceutical markets within which professional power is inscribed. In what follows, I examine one (albeit partial) response to the skeptical critique, namely that the nexus of human rights and mental health policy made possible in the wake of the CRPD offers opportunities to forge new, more inclusive forums for re-conceptualizing the ideals of both human rights and mental health. But first, let us further unpack the premises implicit in the idea of taking a human rights approach to mental disability.

## II. Human Rights and Mental Disability: Background to the CRPD

The roots of a human rights approach to disability — or the human rights approach that informs the CRPD — may be traced to what has been termed the “social model” of disability. The central ideas are present in the following statement advanced in the early 1970s by members of the U.K. movement, Union of the Physically Impaired Against Segregation (UPIAS):

[I]t is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.<sup>61</sup>

This description of (physical) disability as arising through the interaction of individual impairments and social environments was pitched in opposition to what has been termed the medical model of disability, wherein disability is conceptualized as a form of

individual dysfunction and the means of ameliorating disability are understood to lie primarily or exclusively within the knowledge of medical professionals.<sup>62</sup> As such, the social model marks an effort to wrest disability policy from the dual dominance of medical and charity-based frameworks and to position it as a matter of politics.<sup>63</sup>

The social model has exercised a formative influence on disability advocacy and the field of critical disability studies, even as it has attracted controversy — for instance, concerning the relative primacy of historical-materialist critique (aimed at capitalist market systems and attendant distributive inequalities as they affect persons with disabilities) versus postmodern critique (addressing the discursive construction of both disability and impairment).<sup>64</sup> Further controversy has arisen around the implications of the social model for psychosocial disability; e.g., whether mental health conditions are properly described either as socially produced or as “disabilities.”<sup>65</sup> Yet as Judi Chamberlain and others have demonstrated, persons with psychosocial disabilities have travelled long roads of political advocacy<sup>66</sup> in order to achieve recognition as central actors within the disability movement, asserting critiques of social-systemic oppression with particular force.<sup>67</sup>

This returns us to the question: what have human rights to do with disability, and in particular with psychosocial disability? From the historical-materialist side of disability activism comes a strong tradition of suspicion of human rights, rooted in the concern that the liberal-individualist assumptions in which rights are steeped will necessarily undermine more radical socialist programs of dismantling the normative and institutional underpinnings of personal property and capitalist market systems regarded as at least partly constitutive of disability-based oppression. Even so, human rights discourse has proven to be a powerful mechanism for linking critiques based in the social model of disability to claims immediately cognizable in politics and in law.

The emergence of human rights-based reasoning in the critique of psychosocial disability has followed its own unique path. Beginning in the 1960s and 70s, political agitation regarding the treatment of persons with psychosocial disabilities was predominately libertarian in flavor, centered as it was upon freedom from unwanted psychiatric interventions.<sup>68</sup> This form of political critique was fostered in great part through processes of consciousness-raising within the anti-psychiatry movement. Through testimonials of intense physical and psychological suffering brought on by forced psychiatric treatment,<sup>69</sup> typically tracing a path through suffering to anger and then on to social

and political insight and activism, this movement has done much to root the critique of state-sanctioned psychiatric power in the right to liberty, conceived as the right to be left alone. At the same time, anti-psychiatry has served a community-building function among the socially and ideologically diverse collectivity of persons identifying as psychiatric survivors.<sup>70</sup> Today, anti-psychiatry continues to denounce involuntary or coercive psychiatric interventions as fundamental infringements of liberty; however, the human

lence, including systemic sexual violence and punitive or managerial uses of restraint and seclusion, to subjection to appalling institutional conditions, including extreme heat or cold and unsanitary facilities endangering life and health.<sup>75</sup> Nor could these instruments apparently reach beyond custodial institutions to assist persons subjected to familial uses of restraint or seclusion<sup>76</sup> or to capricious dissolution of the capacity to exercise basic legal rights.<sup>77</sup> Similar critiques were made of international policy statements concerning

Despite a few rare victories reflecting the extraordinary efforts of individuals and advocacy groups, none of the international human rights instruments preceding the CRPD had succeeded in grounding systemic reforms broadly supportive of inclusion and equal citizenship among persons with either psychosocial or intellectual disabilities. All this arguably added credence to the skeptical claim that human rights, and particularly international human rights, are but hollow promises perhaps assisting in the work of political posturing among nations but doing little or nothing to improve the lives of persons with disabilities and in particular those with psychosocial or intellectual disabilities.

rights analysis adopted is increasingly grounded not simply in negative freedom but in a broader set of positive rights. Increasingly, that is, the grassroots-based human rights approach to mental or psychosocial disability, like the human rights approach to disability more generally, has come to draw upon a social model of disability in order to identify inequitable distributions of social burdens and benefits as both disabling and as legal wrongs.

The comprehensive critiques advanced in the name of anti-psychiatry have for the most part been marginalized within mainstream mental health policy-making processes, domestic and international. A similar marginalization may be said to have occurred with respect to the efforts of human rights advocacy organizations over the years to systematically document abuses occurring in and beyond mental health facilities and social care homes.<sup>71</sup> Perhaps most disappointingly, as various commentators have noted, the international human rights instruments in place prior to the CRPD appear to have been incapable of grounding any significant or comprehensive challenges to the range of harms historically identified.<sup>72</sup> International instruments of general application<sup>73</sup> were rarely if ever applied to sanction the egregious harms documented within institutions<sup>74</sup> — from vio-

the human rights of persons with mental disabilities, here additionally targeting the weak normative force of these instruments<sup>78</sup> and, in some instances (as with the *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*), their giving wide berth to medical discretion regarding involuntary interventions.<sup>79</sup> The latter critique has been directed also to regional human rights instruments (in particular, Art. 5 of the *European Convention on Human Rights*),<sup>80</sup> although commentators have recognized a few important examples of vindication of the human rights of persons with psychosocial disabilities under the regional instruments.<sup>81</sup> To these substantive criticisms may be added concerns about the lack of participation of persons with disabilities in the processes leading to the international and regional human rights instruments preceding the CRPD.<sup>82</sup> In sum, despite a few rare victories reflecting the extraordinary efforts of individuals and advocacy groups,<sup>83</sup> none of the international human rights instruments preceding the CRPD had succeeded in grounding systemic reforms broadly supportive of inclusion and equal citizenship among persons with either psychosocial or intellectual disabilities.<sup>84</sup> All this arguably added credence to the skeptical claim that human rights, and particularly international human rights,

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### III. The CRPD — Process and Substance

#### *The Process*

The processes of advocacy and negotiation leading to the CRPD's adoption at the UN in 2007 and its coming into force in 2008 have been described by a number of commentators, some of whom were active participants.<sup>85</sup> In its first session, the *ad hoc* UN committee charged with overseeing negotiations decided that NGOs, including disabled persons and their representatives, should be extended significant rights of participation in the process.<sup>86</sup> The depth of that commitment was indicated in a subsequent decision that the working group charged with producing a draft text to orient the negotiations should include twelve NGOs, in addition to twenty-seven government representatives and one national human rights body.<sup>87</sup> The twelve selected included seven international and five regional DPOs.<sup>88</sup> One of these was the World Network of Users and Survivors of Psychiatry [WNUSP],<sup>89</sup> which throughout the negotiations took a leadership role in advocating for persons with psychosocial disabilities.

Following the working group process, the negotiations leading to the final text again featured unprecedented civil society (mainly DPO) participation.<sup>90</sup> This included novel opportunities for commentary in the course of formal plenaries as well as participation at side events.<sup>91</sup> The roster of participants in the sixth session of the *ad hoc* committee featured over sixty DPOs, each of which was represented by delegates ranging from one to over thirty in number.<sup>92</sup> Recognition of the potential for fragmentation and dilution of DPO perspectives led to the formation of the International Disability Caucus [IDC]:<sup>93</sup> a group of DPOs and supporting NGOs that made behind-the-scenes efforts to forge consensus on key issues and that strategically intervened throughout the negotiations by way of oral and written advocacy. Beyond WNUSP, members of the IDC representing persons with psychosocial disabilities included Support Coalition International (since renamed MindFreedom International) and the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP).<sup>94</sup> Representing persons with intellectual disabilities and their families were the Canadian Association for Community Living<sup>95</sup> and Inclusion International.<sup>96</sup> These and other former members of the IDC have continued to vigorously air the perspectives advanced in the negotiations

in order to inform the interpretation and implementation of the CRPD.

John McCarthy, founder of Mad Pride Ireland and representative of MindFreedom International at the negotiations, described an incident that captures the energy and sense of having infiltrated the very center of power that many DPO delegates must have felt, in addition to a profound sense of responsibility toward those still languishing at the capillaries of power. Having accepted an invitation to sit at a national delegate's table, McCarthy took the opportunity to stage a moment of political theatre:

Maradonna then offered me a place at his countries desk, I really did not understand the implications of this until I told my fellow delegates, and the excitement was something to see. I am very proud to say I did make a statement from the floor and that I then shuffled around that enormous chamber to show those delegates the reality of over medication. Have you any idea how embarrassing it is to shuffle like I did, and see the faces of those delegates as I passed in front of each countries desk all 196 of them, some with looks of sympathy and understanding others with looks of anger at this breach of protocol. But I kept Helens face to the forefront of my mind as the tears welled up at the back of my eyes and I finished the circuit as the business of the convention carried on. The point was made.<sup>97</sup>

#### *The Content*

The CRPD does not define disability.<sup>98</sup> However, it articulates a commitment to the social model in a preambular statement that recognizes

that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.<sup>99</sup>

In distinguishing “disability” from “impairment,” the tensions within the social model are reproduced.<sup>100</sup> Yet the emphasis on inclusion conveyed in this interactive conception of disability is what nonetheless underlies and informs the whole of the CRPD, in particular the normative commitments expressed in the rest of the preamble, the purposes and definitions (Arts 1 & 2), and the general principles stated in Articles 3-9. In these sections, the central principle that persons with disabilities are entitled to equal enjoyment of human rights is elaborated through statements affirming that the coordinate values of equality,



autonomy, and respect for difference ground rights to dedicated social and economic supports and participatory opportunities.<sup>101</sup>

The substantive rights articulated in Articles 10–30<sup>102</sup> include familiar civil and political rights, such as the right to physical and mental integrity (Art 17), freedom of expression and opinion (Art 21), and the right to vote (Art 29). Yet the CRPD elaborates upon the implications of these rights for persons with disabilities in a manner that brings positive state obligations to the fore.<sup>103</sup> In addition, the CRPD articulates distinct economic, social, and cultural rights — for instance, the right to education (Art 24), the right to “the highest standard of health without discrimination on the basis of disability” (Art 25), the right to work

In sum, the CRPD’s substantive guarantees affirm the fundamental interrelationship of civil and political with economic, social, and cultural rights, and of both these traditionally distinct classes of right with participatory rights.<sup>104</sup> It is important to note in particular the vital function of the right to (and duty of states parties to support) political participation under this comprehensive human rights scheme. That is, the guarantee of political participation is essential to ensure that the fundamental public values of equality and autonomy — along with the whole set of civil and political, and economic, social, and cultural rights — are given specificity in a manner that reflects the perspectives and aspirations of a pluralistic citizenry, including in particular persons with disabilities.

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(Art 27), and the right to “an adequate standard of living,” including “adequate food, clothing and housing” (Art 28). Article 19 guarantees a right to independent living and inclusion in the community, complemented by state duties to provide “residential and other community support services, including personal assistance necessary to support” the exercise of this right.

Rights to political participation are additionally acknowledged — first, through a general guarantee of “[f]ull and effective participation and inclusion in society” (Art 3(c)). That guarantee gains specificity in Article 4(3), which requires that states parties actively involve persons with disabilities in decision-making about the laws and policies affecting them, including decisions regarding implementation of the CRPD. Moreover, Article 29 provides a right to “participation in political and public life,” and places a duty on states to “encourage” the participation of disabled persons in political parties, NGOs and specifically DPOs.

It is important to note in addition the CRPD’s extensive implementation mechanisms.<sup>105</sup> These include a mechanism now common among international human rights conventions: that of instituting a committee to oversee international implementation (Art 34).<sup>106</sup> Like other such bodies, the CRPD committee is to receive and respond to the compliance reports of states parties (Art 36). Also familiar from precedent conventions is the committee’s authority to make general observations on the convention’s implementation in the course of reporting to the General Assembly and the Economic and Social Council (Art 39). The committee is further vested with authority, under the Optional Protocol, to hear individual complaints relating to signatories of that instrument (Art 1 OP)<sup>107</sup> and to initiate inquiries into “grave or systematic violations” of CRPD rights among the signatories (Art 6 OP).

Also relevant to implementation are obligations of states parties which reach beyond the core obligation to bring domestic law and practice into conformity

with the convention (Art 4(1)(b)). These include the duty to submit compliance reports (Art 35) — supplemented, in the CRPD, by a duty to widely distribute those reports and the committee's responses (Art 36(4)).<sup>108</sup> Additionally, states parties must designate one or more focal points to take responsibility “for matters relating to the implementation” of the Convention (Art 33(1)), and must give “due consideration” to effecting a “coordination mechanism” for integrating the implementation-related activities of different levels or departments of government (33(1)).<sup>109</sup> As or more important is the obligation to vest an independent body with responsibility “to promote, protect and monitor implementation” (Art 33(2)),<sup>110</sup> so as to ensure that non-compliant laws, policies or practices are identified and actively challenged domestically.<sup>111</sup> The same section states an expectation that “[c]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process” (Art 33(3)).

Article 31 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. This provision does not specify a duty to consult with disabled persons in designing data-collection policies or instruments (the importance of which was discussed in Part I herein).<sup>112</sup> It does impose obligations to comply with relevant international human rights norms, including those concerning protection of privacy and confidentiality (31(1)(a)&(b)), and to share the data with disabled persons and others (31(3)). Finally, Article 32 imposes duties of international cooperation, including an obligation on states parties to work with international, regional and civil society organizations, including DPOs, to facilitate “capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices.”<sup>113</sup>

#### IV. Two Controversies

##### *The Expressive Function of Human Rights*<sup>114</sup>

Two debates of particular relevance to persons with psychosocial disabilities arose during CRPD negotiations. These concerned the legitimacy of involuntary psychiatric interventions and, separately, the legitimacy of substitute decision-making. Both debates were pressed to the point of negotiation impasse and then resolved by way of textual silence — leaving considerable scope for interpretive controversy in their wake. This may be regarded as a failing of the negotiations and of the resulting text, effectively undermining the consensus required to generate practi-

cal reforms.<sup>115</sup> I argue instead that the controversies in question illustrate an important positive function of the CRPD, and of human rights guarantees more generally: one that Oliver Lewis, drawing upon the work of Sandra Fredman and others,<sup>116</sup> describes in his work on the CRPD as the “expressive” function of human rights law. On this account, human rights law (international or domestic) does not operate on a simple command and control basis.<sup>117</sup> Rather, it creates “a normative framework, a vocabulary and a set of open concepts to structure normative discussion,”<sup>118</sup> along with “institutions and procedures that promote further discussion.”<sup>119</sup> That is, on this account, human rights norms are best understood as mechanisms for opening dialogue among authorities and those subject to authority on central questions concerning the basic requisites of political legitimacy. This promotes mutual education, and ultimately, action, the transformative potential of which rests in the value of “encouraging actors to rethink assumptions, evaluate positions and shift existing concepts or paradigms.”<sup>120</sup>

Viewed in this light, the debates described below illustrate the depth of the challenges and opportunities introduced by the CRPD for global mental health policy.

##### *The Legitimacy of Involuntary Psychiatric Hospitalization and Treatment*

The first controversy is rooted in Article 14, and also 17 (other provisions, including Article 19, are implicated as well).<sup>121</sup> Article 14(1)(a) requires states parties to ensure that persons with disabilities enjoy the right to liberty and security of the person on an equal basis with others. Under Article 14(1)(b), states must ensure that persons with disabilities are not “deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.”

It is the final clause that was the focus of debate at the negotiations. Some states delegates sought to revise the draft text to specify that deprivation of liberty should not be based “solely” or “exclusively” on disability.<sup>122</sup> Their intent was to affirm the legitimacy of laws grounding involuntary hospitalization not on mental disorder alone, but rather on mental disorder plus other criteria, such as risk of serious harm to self or others or risk of serious physical or psychological deterioration.<sup>123</sup> Mexico and Thailand raised the concern that positioning disability among multiple factors to be relied upon in restricting liberty is itself a form of disability-based discrimination.<sup>124</sup> The next day, IDC representatives endorsed this critique and registered their support for the original Working

Group text.<sup>125</sup> Ultimately, the proposed qualifications aimed at explicitly condoning involuntary psychiatric hospitalization were rejected.

Relatedly, Article 17 (the right to “physical and psychological integrity”) was at one point the subject of proposed textual amendments in an effort to specify legal safeguards proper to involuntary psychiatric interventions. This proposal was rejected as well, consistent with the position of the IDC,<sup>126</sup> making Article 17 noteworthy for its relative lack of elaboration in comparison with other sections of the CRPD.<sup>127</sup> At the negotiations, the IDC made clear its concern that this right not be qualified or circumscribed in a manner that singles out persons with disabilities.<sup>128</sup> Some commentators have since argued that Article 17 stands as a missed opportunity to have mandated procedural and substantive protections often disregarded in state laws and practices concerning involuntary hospitalization.<sup>129</sup> In any case, the failure of the text to advert to involuntary hospitalization has facilitated competing interpretations as to whether Article 17 strictly prohibits involuntary psychiatric interventions or merely fails to state (but does not preclude) a range of conditions under which such interventions are permitted.<sup>130</sup>

Let us explore further the IDC’s position that laws permitting involuntary psychiatric interventions are necessarily inconsistent with Articles 14 and 17, read in light of the wider values of the CRPD.<sup>131</sup> That position is at its base rooted in the fairly uncontroversial thesis that the liberal rights-guarantees of liberty and physical/psychological integrity encompass not only freedom from arbitrary incarceration but also freedom from arbitrary, unwanted state-sanctioned interventions. The question is what counts as “arbitrary,” or on what if any basis these guarantees may be justifiably circumscribed. There is significant consensus among rights-respecting constitutional democracies that anticipated risk should not in itself be a basis for restricting liberty, either in health care settings or in the ordinary exercise of criminal law powers.<sup>132</sup> Is there, then, any reasonable basis for singling out persons with mental health conditions for liberty-restricting or intrusive interventions based in apprehended risk? Here it is salient that persons without mental health diagnoses may, for instance, neglect medical advice so as to jeopardize their own health (sometimes on bases that others deem irrational), or may present risk factors more predictive of dangerousness than is a psychiatric diagnosis.<sup>133</sup> In this way, assertions based in the inviolability of liberty and personal integrity may be supplemented by the equality-based concern that regimes of involuntary psychiatric hospitalization and treatment arbitrarily single out some persons for disproportionate burdening, based

in stereotypical assumptions equating mental health diagnoses with dangerousness and/or incapacity.<sup>134</sup> As Tina Minkowitz has suggested, a further twist to the argument is provided by Article 19’s guarantee of a right to inclusion in the community,<sup>135</sup> such that any attempted justification of involuntary psychiatric interventions must contend with the CRPD-based claim that the state has not met its supportive obligations in this respect.

Predictably, this is not a position that has impressed governments otherwise inclined to defend their mental health regimes as at the cutting edge of human rights-regarding policy. Australia, for one, has registered an interpretive declaration/reservation asserting its view that the CRPD permits involuntary hospitalization and treatment in accordance with that country’s mental health laws.<sup>136</sup> In contrast, the UN Office of the High Commissioner for Human Rights (OHCHR) tersely stated, in 2009, that Article 14 of the CRPD requires that “legislation authorizing the institutionalization of persons with disabilities on the grounds of disability without their free and informed consent must be abolished.”<sup>137</sup> This pronouncement was expressly stated to include “situations where the deprivation of liberty is grounded in the combination between a mental or intellectual disability and other elements such as dangerousness, or care and treatment.”<sup>138</sup> Recently, the CRPD Committee too has stated its position that laws authorizing involuntary institutionalization or treatment on the basis of mental disability are non-compliant with the CRPD.<sup>139</sup>

These developments suggest that the abolitionist position relayed by DPOs at the CRPD negotiations has met with an unprecedented level of success on the international stage — at least, in theory. Here it is important to emphasize that the IDC arguments against coercive laws and practices were complemented by arguments that states must provide accessible alternatives in the form of voluntary supports. Yet it should be noted that, were the abolitionist position indeed to be taken seriously in processes of domestic law reform, there is potentially another, more conservative sort of reform that might be crafted in response. This would be to replace existing involuntary psychiatric hospitalization laws based in mental health status and risk with mental capacity laws, grounded in a functional standard of decision-making capacity applicable to all persons and across a range of decisions.<sup>140</sup> Such legislation might be argued to respect (formal) equality, as well as the justificatory principle of the least restrictive intervention, in taking a decision-specific, functional rather than status-based approach to legal incapacity.<sup>141</sup> And yet the approach has the potential to facilitate more and earlier invol-

untary psychiatric interventions than laws based in mental health status and risk.<sup>142</sup> This brings us to the heart of the second CRPD-related controversy I wish to explore herein, on the legitimacy of the status of legal incapacity and attendant regimes of substitute decision-making.

### *Article 12 — Equal Legal Capacity*

The second controversy concerns Article 12. Article 12(1) provides: “States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.” Article 12(2) shifts from the concept of legal personhood to that of legal capacity: “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” Article 12(3) then provides: “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” Two further subsections address legal safeguards that are to accompany “measures relating to the exercise of legal capacity.”<sup>143</sup>

Here it is important to have in mind how existing laws typically articulate legal capacity. Some laws provide for total/plenary guardianship, whereby guardians are conferred broad decision-making authority over a person’s personal or financial affairs or both.<sup>144</sup> An alternative sort of law contemplates more circumscribed forms of substitute decision-making, restricted to a particular decision or type of decision.<sup>145</sup> The standards for determining legal capacity vary among jurisdictions and among intra-jurisdictional statutory and common law regimes. Some standards are status-based; for instance, conditioning incapacity solely upon age (in the case of minors) or disability (sometimes stated in vague terms, e.g., “unsound mind” or “infirmity of the mind”).<sup>146</sup> Others are functional; that is, capacity is assessed in light of specified decision-making abilities, such as the ability to “understand” the relevant information and “appreciate” the consequences.<sup>147</sup> A further sort of standard is outcome-based, e.g., contingent upon the “reasonableness” of one’s decision(s).<sup>148</sup> Where legal capacity is displaced in one or more areas of decision-making, the law typically provides for a regime of substitute decision-making whereby an individual assumes responsibility to make decisions in the best interests of one deemed incapable, or in an approximation of that person’s capable judgment. Some jurisdictions also offer alternatives to substitute decision-making, such as co-decision-making (whereby a court appoints someone to share decision-making authority with a person who requires assistance)<sup>149</sup> or supported decision-making

(whereby one may nominate a person to assist one with decision-making).<sup>150</sup>

During the negotiations concerning Article 12,<sup>151</sup> some states delegates sought to add to the text a statement explicitly affirming the legitimacy of guardianship or substitute decision-making in appropriate cases and with appropriate safeguards. Contrastingly, the IDC took the position that there should be no condoning of guardianship in Article 12 and that the references to safeguards in 12(4) should be understood to refer to supported decision-making only,<sup>152</sup> positing that guardianship, indeed all substitute decision-making, is inconsistent with the overarching commitment of the CRPD to disabled persons’ autonomy and equality. This position was rooted in a critique of the concept of legal incapacity as irredeemably steeped in arbitrariness and social prejudice.<sup>153</sup>

More expansively stated, the IDC’s position on Article 12 was that the section not only grounds an obligation on states to provide appropriate decision-making supports to persons who encounter difficulty making decisions, but that it moreover grounds a thoroughgoing shift to a minimalist conception of legal capacity, based not in adequacy to a cognitivist standard but rather in the mere expression of (and efforts of others to discern) one’s will or preference. At times during the negotiations, the IDC appeared to deny that there could ever be circumstances in which one might be unable to exercise legal capacity (as opposed to able, with the right supports).<sup>154</sup> Ultimately, however, the position advanced was that substitute decision-making may be required in rare instances — the archetypical instance being coma or loss of consciousness — although these situations, too, demand ongoing, vigilant supports aimed at encouraging the exercise of legal capacity.<sup>155</sup>

So far, this is a skeletal position. An attack is leveled at the prevailing principles of legal capacity and substitute decision-making but it is not clear what exactly the alternatives are — not merely what should count as supports for legal capacity, but more generally, what it would mean to accept that legal capacity (across the full range of legal relationships and transactions) is implicit in the mere expression of individual preference or will. One may, however, discern even in this skeletal statement of the position an urgent instrumental rationale.<sup>156</sup> That is, at base the position reflects a concern to disrupt existing power relations, and with this, the deeply-held thesis that existing regimes of legal incapacity and substitute decision-making function to suppress or override the values, preferences, and life projects of persons with disabilities in favor of the values, preferences and life projects of others. To this may be added the strategic thesis that a legal regime that



strictly prohibits displacement of individual decision-making capacity will likely provide medical and other authorities with incentives to investigate and fashion innovative supports for decision-making — communication to a range of other conditions potentially conducive to deliberation<sup>157</sup> — there being no legally

also highly rationalist in orientation. Here the argument begins with the claim (put forward by the IDC in the course of CRPD negotiations) that persons with psychosocial disabilities have the same right as others to make “bad decisions.”<sup>160</sup> Typically, the right to make bad decisions is justified in light of the autonomy-

**Personhood (and not reasonableness or rationality) is thus posited as the source of legal capacity and as the basis on which respect for one's wishes is grounded. That said, the minimalist position on the requisites of legal capacity is not necessarily inconsistent with the thesis that supported decision-making should seek to enable autonomous (not merely willful) decisions, encompassing reflection on and reasoning in light of one's values in the context of a range of meaningful options.**

sanctioned option of force in the face of ill-considered choices.<sup>158</sup> In contrast, regimes of substitute decision-making may diminish the perceived importance of supports, and even provide incentives to remove supports in some circumstances, so as to increase the likelihood of a timely declaration of incapacity and so a timely medical (or other) intervention.

Beneath such instrumental considerations lie deeper claims about the meaning of the fundamental human rights value of individual autonomy. The WNUSP Implementation Manual for the CRPD states:

Autonomy and self-determination are dependent on having sufficient access to resources so that economic and social coercion do not lead to decision-making that does not reflect the person's own values and feelings. . . . Autonomy and self-determination are also dependent on the existence of meaningful alternatives related to the particular decision at issue.<sup>159</sup>

This is a relational conception of autonomy, centered upon the thesis that supportive social systems (including access to material resources and a range of meaningful options) are essential to the development and expression of autonomy. The IDC/WNUSP position on Article 12 may be understood to transpose the idea of the relationality of autonomy to the domain of legal capacity, as such locating capacity not in the individual alone but in the interaction between the individual and a robust system of supports.

Accompanying this relational conception of autonomy is a further challenge to dominant models of legal capacity, which tend not only to be individualistic but

based claim that our lives go better when they are led from inside — when we are given the opportunity to learn from our mistakes and moreover preserved from having to mechanically or inauthentically live out others' ideas of what is best for us.<sup>161</sup> The claim raised by those challenging existing models of legal capacity and substitute decision-making, then, is arguably at least in part that these models suspend the opportunity to lead one's life “from inside.” But the deeper claim is that these models fail to capture what it is about individual preferences, or more generally about the human personality, that should ground respect. On the approach taken by the IDC during CRPD negotiations and by sympathetic exponents of the position thereafter, what grounds this respect is not our ability to reason but our status as persons.<sup>162</sup> To clarify, the idea is not simply that this status obliges others to refrain from doing us harm; it obliges them, moreover, to respect our preferences, in short our expressions of aspiration or will, as expressions of legal capacity. Personhood (and not reasonableness or rationality) is thus posited as the source of legal capacity and as the basis on which respect for one's wishes is grounded.<sup>163</sup> That said, the minimalist position on the requisites of legal capacity is not necessarily inconsistent with the thesis that supported decision-making should seek to enable autonomous (not merely willful) decisions, encompassing reflection on and reasoning in light of one's values in the context of a range of meaningful options.

Critics will be ready with responses to the minimalist conception of legal capacity,<sup>164</sup> including examples in which it would be unconscionable to treat another's expression of preference or will as a capable choice; for

instance, cases in which the person is clearly unable (despite supports) to understand what is at stake. Might the minimalist position recognize intention or will as expressive of legal capacity only where there is evidence that the person grasps the likely consequences — particularly if these are dire? But this would probably conflict with the background practical or political commitment to protecting psychiatrized persons and others from attributions of incapacity based in a lack of concordance with others' value-laden assessments of the risks and benefits at stake. Alternatively, might legal effect be assigned to expressions of intention or will only where some further non-cognitivist criterion is satisfied; for instance, consistency with the individual's "life narrative"?<sup>165</sup> And what if any role might legal doctrines such as fraud, duress, or mistake have in nullifying the legal effect of an exercise of legal capacity conceived in minimalist terms? These and other difficult questions surround the radical yet skeletal positions on Article 12 advanced by DPOs during and after the CRPD negotiations.

Canada has registered an interpretive declaration/reservation concerning Article 12, whereby it affirms the CRPD-consistency of substitute decision-making "in appropriate circumstances and in accordance with the law" and reserves the right to maintain such regimes in the face of contrary interpretations.<sup>166</sup> Australia has registered a similar declaration.<sup>167</sup> Moreover, certain other states have maintained the conservative position they advanced in the negotiations, namely that "equal legal capacity" refers to "capacity for rights," not capacity to act or to exercise one's rights.<sup>168</sup>

These positions stand in tension with recent statements from the CRPD committee indicating endorsement of the claims advanced by the IDC. For instance, the committee's concluding observations on Spain's report state:

The Committee recommends that the State party 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. It further recommends that training be provided on this issue for all relevant public officials and other stakeholders.<sup>169</sup>

Some may take this to indicate that states should prioritize supportive decision-making, leaving substitute decision-making as a last resort — an interpretation that does not require abolishment of the latter regimes. But such interpretations are uncertain.<sup>170</sup> The CRPD Committee has held discussions concerning Article 12

and requested submissions on its implementation, in light of which one may expect a General Comment.<sup>171</sup>

The above-noted challenges to involuntary hospitalization and substitute decision-making in light of the CRPD should not be dismissed, as some have suggested, as fantastical extensions of the social model to the point of denying the phenomenon of impairment.<sup>172</sup> Rather, academics and policy makers alike must take seriously the provocative theoretical as well as practical claims informing the efforts of DPOs to shift entrenched relationships of power and coercion to relationships of support. Ultimately, the arguments canvassed herein urge states to devote imaginative as well as financial resources to enabling this shift. The question of what exactly this would entail<sup>173</sup> in law and in practice requires further inquiry — normative, conceptual, and empirical.<sup>174</sup> Such inquiries may link up with ongoing efforts to critique dominant conceptions of autonomy in philosophy and bioethics in light of theses on the social constitution of the self,<sup>175</sup> and explorations of how agency or autonomy may be exercised in the face of systemic oppression.<sup>176</sup> Moreover, they may link up with the growing interest in the specific challenges posed by mental or intellectual disability to philosophical conceptions of "personhood, agency, responsibility, equality, citizenship, the scope of justice, and human connection."<sup>177</sup> However, any such inquiries must carefully attend to the perspectives of persons with psychosocial disabilities as well as persons with intellectual disabilities, who, through their interventions in the CRPD negotiation process and now at the implementation stage, have brought to global prominence the emancipatory project of shifting mental health policy from its historical fixation on involuntariness and incapacity toward the relatively uncharted territory of supports.

#### IV. Conclusion: Building Capacities

WHO discourse on the global burden of mental disability reflects a privileging of professional knowledge to the exclusion of lived experience. However, the WHO has increasingly come to acknowledge the importance of promoting human rights as these intersect with mental health, a project that necessarily requires attention to the social context as well as subjective experience of mental disability. This shift in attention is accompanied by new global development initiatives aimed at promoting mental health by reducing poverty and discrimination. However, tensions between professional and first-person perspectives have resurfaced under the CRPD, as DPOs advance positions that "go to the very heart"<sup>178</sup> of mental health laws and policies widely accepted among

nations and indeed promulgated by the WHO as a model for all nations.

Given the depth of the challenges raised to mental health law and policy by DPOs, there is a risk that they (or their most radical claims) may be shut out of domestic and international mental health policy development efforts or pressed to the margins of those efforts.<sup>179</sup> But this would conflict with the CRPD imperative of enhancing the political participation of persons with disabilities, domestically and internationally. It would also conflict with the imperatives of global mental health policy, not only because such policies should be concordant with the CRPD, but also because the increasingly organized and politically engaged cadre of DPOs presents an important source of expertise for informing policy development. The question is how to initiate and sustain inclusive and mutually educative policy deliberations, and avoid the retrenchment of historical polarization and exclusion. A further question as CRPD implementation unfolds is how DPOs may enrich and protect their claims to representativeness, and moreover, their independence, in an environment saturated with pharmaceutical industry presence extending to deployment of disease-based advocacy groups as lobbying and marketing tools.<sup>180</sup>

There is, however, also reason to be optimistic about the prospects for inclusive efforts at mutual capacity-building regarding CRPD rights. Commitment to CRPD implementation has been demonstrated in a number of ways in recent years.<sup>181</sup> This includes efforts within and across UN agencies to identify implications of the Convention that cut across their respective mandates,<sup>182</sup> and on the part of states parties to effect CRPD-compliant reforms including the introduction of anti-discrimination laws and accommodation policies.<sup>183</sup> Moreover, DPOs have been intensely active on the implementation front — in part, the result of new funding opportunities in the wake of the CRPD.<sup>184</sup> These activities have included participation in international forums on CRPD implementation alongside governments and other representatives of civil society<sup>185</sup> and intensive efforts to forge relationships of mutual support with other DPOs and NGOs, for instance in the areas of human rights monitoring and shadow reporting.<sup>186</sup>

Continued efforts toward inclusive policy deliberations should not neglect the areas of controversy discussed herein. Reports prepared for the WHO and World Bank<sup>187</sup> have recognized the importance of promoting supported decision-making. These agencies are in a position to foster broad-based inquiry into the social supports required to assist decision-making and moreover to promote the development and expres-

sion of autonomy and active citizenship. Such efforts should include particular attention to the perspectives of persons with psychosocial disabilities and also those with intellectual disabilities<sup>188</sup> — including persons with direct experience of capacity determination or coercive interventions<sup>189</sup> — across different cultural, social, and national locations and across intersecting categories of discrimination including race, gender, and age.<sup>190</sup>

This paper might have dwelled further on the suffering that may accompany mental disability and the propensity of human rights to assist in easing such suffering. Certainly the CRPD articulates commitments supportive of such an analysis. Instead, I have focused on the function of the CRPD in opening new global conversations about what it means to promote human rights in relation to mental health, within a framework that recognizes the complexity of this aspect of human diversity. The unique role taken by DPOs in the drafting and now implementation of the CRPD reminds us of the possibility for human rights to disrupt dominant assumptions and power relations, including those that have calcified around global mental health policy. Going forward, the interaction of global mental health policy and the CRPD — by way of the many social actors brought together through these political mechanisms — will continue to pose challenges running deeper even than the challenge of improving global mental health outcomes or reducing concomitant burdens. As I have suggested herein, these challenges reach to the meaning and practical implications of the human rights values of equality, autonomy, and political participation — or the relevance of these fundamental values to our collective efforts to support individual and social well-being in and beyond the policy domain of mental health.

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1. *Convention on the Rights of Persons with Disabilities*, December 13, 2006, 46 ILM 433, UN Doc A/RES/61/106 [hereinafter cited as CRPD].
2. *Id.*, at Art. 1 (“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”)
3. This is the case particularly in the areas of legal capacity and enabling community inclusion.
4. See, e.g., F. Mégret, “The Disabilities Convention: Towards a Holistic Concept of Rights,” *International Journal of Human Rights* 12, no. 2 (2008): 261-278; J. E. Lord and R. Brown,



- "The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities," in M. Rioux, L. A. Basser, and M. Jones, eds., *Critical Perspectives on Human Rights and Disability Law* (Boston: Martinus Nijhoff, 2011): 273-307, at 277, 281 [hereinafter cited as "The Role of Reasonable Accommodation"]; J. E. Lord et al., "Global Health Governance: Lessons from the Experience of the U.N. Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance," *Journal of Law, Medicine & Ethics* 38, no. 3 (2010): 564-579, at 569 [hereinafter "Global Health Governance"]; G. Quinn, "The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability," *Texas Journal on Civil Liberties & Civil Rights* 15, no. 1 (2009): 33-52, at 42-46 [hereinafter cited as "Toward a New International Politics of Disability"].
5. The importance of this shift from object status to subject status has been often noted in discussions of Article 12 and of the CRPD more generally. See, e.g., G. Quinn, "Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD," paper presented at Conference on Disability and Legal Capacity under the CRPD, Harvard Law School, Boston, February 20, 2010, available through <[http://www.nuigalway.ie/cdlp/staff/gerard\\_quinn.html](http://www.nuigalway.ie/cdlp/staff/gerard_quinn.html)> at 3-5 (last visited March 1, 2013) [hereinafter cited as "Personhood and Legal Capacity"].
  6. The prevalence of intellectual disabilities has received less attention. The Association of Intellectual and Developmental Disabilities (AAIDD) has issued guidelines whereby diagnosis of intellectual disability requires assessment in three areas: cognitive functioning, adaptive behavior, and support needs. See R. Luckasson et al., *Mental Retardation: Definition, Classification and Systems of Support*, 10th ed. (Washington, D.C.: American Association on Intellectual and Developmental Disability, 2002). On global incidence, see P. K. Maulik et al., "Prevalence of Intellectual Disability: A Meta-Analysis of Population-Based Studies," *Research in Developmental Disabilities* 32, no. 2 (2011): 419-436. For critical analysis of the social and medical constructs of intellectual disability, see L. Carlson, *The Faces of Intellectual Disability: Philosophical Reflections* (Bloomington, IN: Indiana University Press, 2010).
  7. World Health Organization, *The Global Burden of Disease: 2004 Update* (Geneva: WHO Press, 2008) [hereinafter cited as *Global Burden of Disease*]. I note critiques of the construct of the global burden of disease, and in particular disability adjusted life years, below.
  8. See *mhGAP Mental Health Gap Action Programme: Scaling Up Care for Mental, Neurological, and Substance Use Disorders* (Geneva: WHO, 2010) [hereinafter cited as *mhGAP Mental Health Gap Action Programme*]: at 4.
  9. The *Global Burden of Disease* ranks unipolar depression as third highest contributor to the global burden of disease, at 4.3% of the total, and estimates that this condition will rise to top contributor by 2030. Moreover, it identifies "[m]ental disorders such as depression, alcohol use disorders and psychoses (e.g., bipolar disorder and schizophrenia)...among the 20 leading causes of disability." (See *supra* note 7, at 34, and also Table 9 at 35).
  10. This analysis is said to reflect, *inter alia*, the role of mental disorders in depleting "labour, capital and other factors [relevant] to production levels in a country" (D. E. Bloom et al., *The Global Economic Burden of Noncommunicable Diseases* (Geneva: World Economic Forum, 2011) [hereinafter *The Global Economic Burden of Noncommunicable Diseases*]: at 14).
  11. *Id.* "Three distinct approaches are used to compute the economic burden: (1) the standard cost of illness method; (2) macroeconomic simulation and (3) the value of a statistical life" (at 6). The third approach places an economic value on health that "reflects a population's willingness to pay to reduce the risk of disability or death associated with NCDs" (at 14). The report is prefaced by the comment: "This evaluation takes place in the context of enormous global health spending, serious concerns about already strained public finances and worries about lacklustre economic growth. The report also tries to capture the thinking of the business community about the impact of NCDs on their enterprises" (at 6).
  12. See WHO Executive Board Resolution on Mental Health, "Global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level," EB130.R8, January 20, 2012, [hereinafter cited as WHO EB Resolution (2012)], relying upon *The Global Economic Burden of Noncommunicable Diseases*, *supra* note 10 at 5. In introducing this figure, the resolution states: "Mental health conditions frequently lead individuals and families into poverty and hinder economic development at the national level." The statement indicates that these conditions are causal factors for poverty and impeded economic development (not vice versa). But see the comments below on the WHO's acknowledgement elsewhere of the "bi-directionality" of mental health and harms to human rights (including social and economic rights). See also P. E. Greenberg et al., "The Economic Burden of Anxiety Disorders in the 1990s," *Journal of Clinical Psychiatry* 60, no. 7 (1999): 427-435 (estimating the economic costs imposed by anxiety disorders in the U.S. during the 1990s, including treatments for somatic illness associated with these conditions, as 42.3 billion dollars annually).
  13. *World Report on Disability* (Geneva: WHO, 2011): at 62 [hereinafter cited as *World Report on Disability*].  
A large multicountry survey supported by WHO showed that between 35% and 50% of people with serious mental disorders in developed countries, and between 76% and 85% in developing countries, received no treatment in the year before the study. A meta-analysis of 37 epidemiological studies across 32 developed and developing countries uncovered a median treatment gap between 32% and 78% for a range of mental health conditions including schizophrenia, mood disorders, anxiety disorders, and alcohol abuse or dependence. (citations and references omitted)
  14. *Mental Health Atlas (2011)* (Geneva: WHO, 2011) at 26-29 [hereinafter cited as *Mental Health Atlas (2011)*]. The data indicate that "[g]lobally, spending on mental health is less than two US dollars per person, per year and less than 25 cents in low income countries" (at 10).
  15. *Id.*, at 10, 26.
  16. *Id.*, at 63 ("Median expenditures on medicines for mental and behavioural disorders in upper-middle and high income countries is approximately 340 times greater than median expenditures in low and lower-middle income countries").
  17. *Id.*, at 72; *World Report on Disability*, *supra* note 13, at 71, 95-96, 103-106. See *mhGAP Mental Health Gap Action Programme*, *supra* note 8, at 8. Laws, policies, and practices directed at the support of persons with intellectual disabilities are addressed in the *WHO Atlas: Global Resources for Persons with Mental Disabilities* (Geneva: WHO, 2007). And see J. Lecomte and C. Mercier, "The WHO Atlas on Global Resources for Persons with Intellectual Disabilities: A Right to Health Perspective," *Salud Publica de Mexico* 50, Supp. 2 (2008): s160-s166.
  18. These are the WHO Mental Health Gap Action Programme (mhGAP) and WHO MIND (Mental Health Improvements for Nations Development). See *mhGAP Mental Health Gap Action Programme*, *supra* note 8, and the WHO MIND report, M. Funk et al., *Mental Health and Development: Targeting People with Mental Health Conditions as a Vulnerable Group* (Geneva: WHO Press, 2010) [hereinafter cited as *Mental Health and Development*].
  19. See V. Patel, "The Movement for Global Mental Health," *British Journal of Psychiatry* 198, no. 2 (2011): 88-90, and P. Y. Collins et al., "Grand Challenges in Global Mental Health," *Nature* 475, no. 7354 (2011): 27-30 [hereinafter "Grand Challenges"]. Also see the website: <[www.globalmentalhealth.org](http://www.globalmentalhealth.org)> (last visited February 1, 2013). For a critique of "The Movement" as dismissive of alternative cultural approaches and



- as overly focused on pharmaceutical interventions, see G. Gombos, "Global Movement for Mental Health: A Well-Paved Road to Hell?" September 3, 2008, available at <<http://gabor-in-india.blogspot.ca/2008/09/global-movement-for-mental-health-well.html>> (last visited February 1, 2013). Mr. Gombos was elected to a two-year term on the UN Committee on the Rights of Persons with Disabilities in September 2010 (commencing January 1, 2011).
20. See World Health Organization, *mhGAP Intervention Guide for Mental, Neurological and Substance Abuse Disorders in Non-Specialized Health Settings* (Geneva: WHO, 2010) [hereinafter cited as *mhGAP Intervention Guide*].
  21. See *id.*, at 10-30 and *mhGAP Mental Health Gap Action Programme*, *supra* note 8, at 11-12. See also *Early Psychosis Declaration: An International Consensus Statement about Early Intervention and Recovery for Young People with Early Psychosis* (jointly issued by the World Health Organization and International Early Psychosis Association), available at <<http://www.iris-initiative.org.uk/silo/files/early-psychosis-declaration.pdf>> (last visited February 1, 2013). And see Grand Challenges, *supra* note 19, at 28-29.
  22. See, e.g., *mhGAP Mental Health Gap Action Programme*, *supra* note 8, at 11-21.
  23. World Health Organization, *Breaking the Vicious Cycle between Mental Ill-Health and Poverty* (Geneva, World Health Organization, 2007) (Infosheet), available at <[http://www.who.int/mental\\_health/policy/development/1\\_Breakingviciouscycle\\_Infosheet.pdf](http://www.who.int/mental_health/policy/development/1_Breakingviciouscycle_Infosheet.pdf)> (last visited February 1, 2013); UN-DESA-WHO, *Mental Health and Development: Integrating Mental Health into All Development Efforts Including MDGs* (UN-DESA-WHO Policy Analysis, September 16, 2010), available at <[http://www.who.int/mental\\_health/policy/mhtargeting/mh\\_policyanalysis\\_who\\_undesa.pdf](http://www.who.int/mental_health/policy/mhtargeting/mh_policyanalysis_who_undesa.pdf)> (last visited February 1, 2013).
  24. See *Global Burden of Disease*, *supra* note 7, at 34.
  25. See *World Report on Disability* *supra* note 13, at 267; *What Is Disability? UN Convention on the Rights of Persons with Disability, Eligibility Criteria and the International Classification of Functioning Disability and Health* (proceedings from a conference in Rome, Italy, April 2010), *BMC Public Health* 11, Supp. 4 (2011); D. Mont, *Measuring Disability Prevalence* (Disability & Development Team, HDNSP -The World Bank, 2007) available at <<http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf>> (last visited February 1, 2013).
  26. The point is made by Peter Cohen in connection with prevalence estimation of problem drug use: P. D. Cohen, "The Relationship between Drug Use Prevalence Estimation and Policy Interests," in *Estimating the Prevalence of Problem Drug Use in Europe* (Luxembourg: Council of Europe, 1997): at 27.
  27. "Some people reject [the descriptor 'disability'] because they do not accept that anything about their mental health problem makes them less able than others. Others reject the disability label because their mental health problem is a fluctuating and not a permanent state." (K. Harrison, "Disability and Mental Health Law," in Jeremy Cooper, ed., *Law, Rights and Disability* [London: Jessica Kingsley Publishers, 2000]: 193-215, at 193).
  28. A positive interpretive framework is encouraged by the organization Intervoice (The International Community for Hearing Voices): "Our research shows that to hear voices is not the consequence of a diseased brain, but more akin to a variation in human behaviour, like being left-handed. It is not so much the voices that are the problem, but the difficulties that some people have in coping with them." See <<http://www.intervoiceonline.org>> (last visited February 1, 2013).
  29. On the thesis that cultural context may affect both symptomology and prognosis, see C. Tranulis, E. Corin, and L. J. Kirmayer, "Insight and Psychosis: Comparing the Perspectives of Patient, Entourage and Clinician," *International Journal of Social Psychiatry* 54, no. 3 (2008): 225-241, at 229. On the socio-cultural embeddedness of mental health problems, specifically as this relates to the mental health of indigenous peoples, see A. Cohen, *The Mental Health of Indigenous Peoples: An International Overview* (Geneva: Dept. of Mental Health, WHO, 1999): at 11-15. While warning against an extreme cultural relativism that would deny the possibility of any cross-cultural evaluation of health or mental health, Cohen adopts from Kleinman the idea of culture-specific "idioms of distress" (A. Kleinman, *Rethinking Psychiatry: Cultural Category to Personal Experience* [New York: The Free Press, 1988]), to argue that "when assessing the mental health of indigenous peoples, it is necessary to remember that the distinctness of their cultures and how they express distress and conceptualize well-being may challenge many universalist notions in psychiatry." (Cohen, *id.*, at 15).
  30. Allan Frances, who was Chair of the task force that produced the DSM-IV, uses the phrase "the ever-shrinking domain of the normal" to describe the rapid expansion of diagnoses proposed for the DSM-V; A. Frances, "It's Not Too Late to Save 'Normal': Psychiatry's Latest DSM Goes Too Far in Creating Mental Disorders," *Los Angeles Times*, March 1, 2010, available at <<http://articles.latimes.com/2010/mar/01/opinion/la-oe-frances1-2010mar01>> (last visited February 1, 2013).
  31. See E. Watters, "The Americanization of Mental Illness," *New York Times*, January 8, 2010, and E. Watters, *Crazy Like Us: The Globalization of the American Psyche* (New York: Free Press, 2010).
  32. The mode of calculation of Disability Adjusted Life Years, and a critique from a public health perspective, is articulated by Scott D. Grosse et al. as follows: "DALYs are composed of two components: (1) years of life lost due to premature death and (2) years lived with disability (YLD) associated with nonfatal injuries and disease...YLD is calculated as the discounted present value of years lived in a condition multiplied by a disability or severity weight for that condition assigned on a scale from 0 (representing perfect health) to 1 (representing death). Weights closer to 1 imply that a year spent in that condition is perceived as being more equivalent to death than to a state of health." The authors raise the following critique: "Because YLD is based on perceived desirability rather than measures of activity limitations, we do not believe the DALY meaningfully measures disability." S. D. Grosse et al., "Disability and Disability-Adjusted Life Years: Not the Same," *Public Health Reports* 124, no. 2 (2009): 197-202, at 197.
  33. *Id.*
  34. Note however that the language of human rights law also constructs as "burdens" the accommodations required to enable the participation of disabled persons. See R. Kayess and P. French, "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities," *Human Rights Law Review* 8, no. 1 (2008): 1-34, at 15 [hereinafter cited as "Out of Darkness into Light?"].
  35. The efficacy of anti-depressive medications has been widely disputed. See I. Kirsch et al., "Initial Severity and Antidepressant Benefits: A Meta-Analysis of Data Submitted to the Food and Drug Administration," *PLoS Medicine* 5, no. 2 (2008): e45 260-268; K. A. Fountoulakis and H. J. Moller, "Efficacy of Antidepressants: A Re-Analysis and Re-Interpretation of the Kirsch Data," *International Journal of Neuropsychopharmacology* 14, no. 3 (2011): 405-412.
- Judging the efficacy of anti-psychotics is complex, and the leading studies typically give little if any close attention to subjective experience. Some studies of antipsychotic treatment of first-episode psychosis show up to 90% efficacy rates by 12 months, judged in terms of symptom reduction (J. A. Lieberman et al., "Time Course and Biologic Correlates of Treatment Response in First Episode Schizophrenia," *Archives of General Psychiatry* 50, no. 5 (1993): 369-376). However, rates of discontinuation of medication – whether due to intolerability of effects or inefficacy in satisfactorily altering symptoms or other reasons – are as high as 50% (S. M. Cotton et al., "Gender Differences in Premorbid, Entry, Treatment, and Outcome Characteristics in a Treated Epidemiological Sample of 661

- Patients with First Episode Psychosis*, *Schizophrenia Research* 114, no. 1-3 [2009]: 17-24; N. A. Crossley et al., "Efficacy of Atypical v. Typical Antipsychotics in the Treatment of Early Psychosis: Meta-Analysis," *British Journal of Psychiatry* 196, no. 6 [2010]: 434-439, at 434. Moreover, antipsychotics have fewer symptom reducing effects among persons with chronic conditions, and discontinuation rates are even higher among this population (J. A. Lieberman et al., "Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia," *New England Journal of Medicine* 353, no. 12 (2005): 1209-1223). On the lack of clear advances in efficacy among new generation (atypical) antipsychotics, see M. McDonagh et al., *Drug Class Review: Atypical Antipsychotic Drugs: Final Update 3 Report* (Portland, OR: Oregon Health & Science University, 2010) (original report January 2005; Update 1 April 2006; Update 2 May 2008; Update 3 July 2010), available at <<http://derp.ohsu.edu/about/final-document-display.cfm>> (last visited February 1, 2013) [hereinafter cited as *Drug Class Review*].
- On the side effects of psychiatric medications more generally, see J. K. Aronson, *Meyler's Side Effects of Psychiatric Drugs* (Amsterdam: Elsevier, 2009) [hereinafter cited as *Meyler's Side Effects*]. On widespread under-reporting of inefficacy data from clinical trials, see S. Nassir Ghaemi et al., "Publication Bias and the Pharmaceutical Industry: The Case of Lamotrigine in Bipolar Disorder," *Medscape Journal of Medicine* 10, no. 9 (2008): 211; N. McGauran et al., "Reporting Bias in Medical Research: A Narrative Review," *Trials* 11 (2010): 37.
36. See Crossley et al., *id.*; Lieberman et al., *id.*
  37. See *Drug Class Review*, *supra* note 35; *Meyler's Side Effects*, *supra* note 35.
  38. On the tendency for medico-legal reliance on the concept of "insight" despite the scientific inspecificity of this term, see K. Diesfeld, "Insights on 'Insight': The Impact of Extra-Legal Factors on Decisions to Discharge Detained Patients," in K. Diesfeld and I. Freckelton, eds., *Involuntary Detention and Therapeutic Jurisprudence: International Perspectives on Civil Commitment* (Aldershot: Ashgate, 2003). Valuable background to the concept is provided in I.S. Markova, *Insight in Psychiatry* (Cambridge, NY: Cambridge University Press, 2005).
  39. On recriminatory societal attitudes toward persons who discontinue psychiatric (in particular, anti-psychotic) medications, and sensitive discussion of the bases on which discontinuance may be chosen, see the *Report of the Fatality Inquiry into the Death of Howard Hyde*, (Report, pursuant to the *Fatality Investigations Act*, prepared by Nova Scotia Provincial Court Judge Anne S. Derrick [Halifax, NS: November 30, 2010]): at 304-307.
  40. I return to this point at the end of this section, on turning to the socio-economic determinants of mental health.
  41. World Health Assembly Res. 54.21, May 22, 2001. A brief summary statement of this classificatory framework and a link to it may be accessed at <<http://www.who.int/classifications/icf/en/>> (last visited February 1, 2013). An ICF browser may be accessed at <<http://apps.who.int/classifications/icfbrowser/>> (last visited February 1, 2013).
  42. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed., text revision (Arlington, VA: American Psychiatric Association, 2000).
  43. World Health Organization, *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines* (Geneva: World Health Organization, 1992).
  44. See R. Hurst, "The International Disability Rights Movement and the ICF," *Disability and Rehabilitation* 25, nos. 11-12 (2003): 572-576; J. Bickenbach, "Monitoring the United Nations Convention on the Rights of Persons with Disabilities: Data and the International Classification of Functioning, Disability and Health," *BMC Public Health* 11, Supp. 4 (2011): S8. See also Lord et al., "Global Health Governance," *supra* note 4, at 574. For a positive evaluation of the ICF's application to cross-cultural analysis of mental disability, see K. Vroman and S. Arthanat, "ICF and Mental Functions: Applied to Cross Cultural Case Studies of Schizophrenia," in J. H. Stone and M. Blouin, eds., *International Encyclopedia of Rehabilitation*, available at <<http://cirrie.buffalo.edu/encyclopedia/>> (last visited February 1, 2013).
  45. A. S. Alvarez, "The Application of the International Classification of Functioning, Disability and Health in Psychiatry: Possible Reasons for Lack of Implementation," *American Journal of Physical Medicine & Rehabilitation* 91, no. 13, Supp. 1 (2012): S69-S73; see also E. Helander (Former Chief Medical Officer Rehabilitation Programme, WHO), "A Critical Review of the 'International Classification of Functioning, Disability and Health (ICF)' (Presentation at a conference in Bucharest, Romania, 2003), available at <<http://www.einarhelander.com/critical-review-ICF.pdf>> (last visited February 1, 2013).
  46. C. Baylies, "Disability and the Notion of Human Development: Questions of rights and capabilities," *Disability & Society* 17, no. 7 (2002): 725-739, at 728-30. ("In practice, although a social context to disability has been conceded, the actual classification remains grounded in western scientific concepts and formulations") (at 729). However, Baylies considers the ICF "an important exercise in moving towards a broader agenda of rights and participation" (at 730). Also see H. Hemmingsson and H. Jonsson, "The Issue Is: An Occupational Perspective on the Concept of Participation in the International Classification of Functioning, Disability and Health - Some Critical Remarks," *American Journal of Occupational Therapy* 59 (2005): 569-576 (the ICF insufficiently reflects the individual's subjective perception of autonomy and participation). For a call for increased concordance as between the ICF and the disease-modeled ICD, see S. Baron and M. Linden, "The Role of the 'International Classification of Functioning, Disability and Health' in the Description and Classification of Mental Disorders," *European Archives of Psychiatry and Clinical Neuroscience* 258, Supp. 5 (2008): 81-85. An alternative model for monitoring human rights as they relate to disability, developed by Disability Rights Promotion International, explicitly aims to empower persons with disabilities through the data-gathering process; see P. C. Pinto, "Monitoring Human Rights: A Holistic Approach," in M. H. Rioux et al., eds., *Critical Perspectives on Human Rights and Disability Law* (Boston: Martinus Nijhoff Publishers, 2010): at 451-478.
  47. Kayess and French, *supra* note 34 ("Out of Darkness into Light?") discuss the rejection of the ICF as a data-gathering tool by the International Disability Caucus [IDC], a group of disabled persons' organizations that played an important role in negotiations. "The IDC vehemently opposed reference to the ICF on the basis that it reflected a medical model of disability. From the IDC's point of view, the ICF was part of the human rights problem faced by persons with disability that the CRPD was to overcome through its exposition of the social model of disability" (at 25).
  48. For an applied critique of the use of ICF-based analysis to shape social policy, see S. d'Allesio, *Inclusive Education in Italy: A Critical Analysis of the Policy of Integrazione Scolastica* (Studies in Inclusive Education, Vol 10) (Rotterdam: Sense Publishers, 2011): at Chapter 6: "Deconstructing Integrazione Scolastica," at 107-127.
  49. See D. Jolly, "A Tale of Two Models," on the website of the UK-based Disabled People Against the Cuts, available at <<http://www.dpac.uk.net/2012/04/a-tale-of-two-models-disabled-people-vs-unum-atos-government-and-disability-charities-debbie-jolly/>> (last visited February 1, 2013). Jolly observes that the ICF originates in "a theory that seeks to broaden the perspective on illness, by taking into account not only the biological, but also psychological and social factors which may have an influence on sickness, and consequently on the course that healing takes." However, the approach has been strategically deployed by public and private actors to disentitle disability claimants from social benefits, on the thesis that subjective attitudes rather than unsurmountable obstacles (internal or external) are to blame for their unemployment.



50. On the historical loss and then tentative rediscovery of human rights at the WHO (in particular, of a human right to the social determinants of health), see B. Meier, "Global Health Governance and the Contentious Politics of Human Rights: Mainstreaming the Right to Health for Public Health Advancement," *Stanford Journal of International Law* 46, no. 1 (2010): 1-50.
51. See *Mental Health and Development*, *supra* note 18.
52. *Id.*, at 8-26, 28-31. See also United Nations Economic and Social Council, *Mainstreaming Disability in the Development Agenda* (Report for the Commission for Social Development, 46th Session 6-15 February 2008, ref E/CN.5/2008/6, 23 November 2007), available at <[www.undp.org/mdg/basics.shtml](http://www.undp.org/mdg/basics.shtml)> (last visited March 4, 2013); L. O. Gostin, "Human Rights of Persons With Mental Disabilities: The European Convention of Human Rights," *International Journal of Law and Psychiatry* 23, no. 2 (2000): 125-159, at 127-28 [hereinafter "Human Rights of Persons With Mental Disabilities"]; V. Patel and A. Kleinman, "Poverty and common mental disorders in developing countries," *Bulletin of the World Health Organization* 81 (2003): 609-615; see *World Report on Disability*, *supra* note 13, at 10.
53. See *Mental Health and Development*, *supra* note 18, at xv, xxv, 10; *World Report on Disability*, *supra* note 13, at 59.
54. See *Mental Health and Development*, *supra* note 18, at 28-31.
55. See K. Pickett and G. Wilkinson, "Inequality: An Underacknowledged Source of Mental Illness and Distress," *British Journal of Psychiatry* 197, no. 6 (2010): 426-428. See also WHO Fact Sheet, "Gender and Women's Mental Health" available at <[http://www.who.int/mental\\_health/prevention/genderwomen/en/](http://www.who.int/mental_health/prevention/genderwomen/en/)> (last visited February 1, 2013); C. Garcia-Moreno et al., "Prevalence of Intimate Partner Violence: Findings from the WHO Multi-Country Study on Women's Health and Domestic Violence," *The Lancet* 368, no. 9543 (2006): 1260-1269; V. Patel et al., "Gender Disadvantage and Reproductive Health Risk Factors for Common Mental Disorders in Women: A Community Survey in India," *Archives of General Psychiatry* 63, no. 4 (2006): 404-413; C. Kuehner, "Gender Differences in Unipolar Depression: An Update of Epidemiological Findings and Possible Explanations," *Acta Psychiatrica Scandinavica* 108, no. 3 (2003): 163-174; M. Prince et al., "No Health without Mental Health," *The Lancet* 370, no. 9590 (2007): 859-877. The complexity of the interaction of race and mental health status is addressed in D. Williams and T. Earl, "Commentary: Race and Mental Health - More Questions Than Answers," *International Journal of Epidemiology* 36, no. 4 (2007): 758-760. The authors affirm that, as with gender, socio-economic determinants rather than biological or genetic factors account for differences in prevalence.
56. The holistic conception of mental health orienting contemporary WHO mental health policy is stated as follows: "Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. In this positive sense, mental health is the foundation for individual well-being and the effective functioning of a community." ("Mental Health: A State of Well-Being," WHO 2011, available at <[http://www.who.int/features/factfiles/mental\\_health/en/index.html](http://www.who.int/features/factfiles/mental_health/en/index.html)> [last visited February 1, 2013]).
57. *WHO Resource book on mental health, human rights and legislation* (Geneva: World Health Organization, 2005).
58. *The Mental Health Atlas (2011)*, *supra* note 14 at 22, indicates that dedicated mental health legislation is in place in just 38.5% of low income nations, as compared with 77.1% of high income nations. It is important to note, however, that the dedicated mental health laws in place in some nations may themselves be in conflict with human rights norms. Moreover, questions may be raised about the adequacy of institutional practice to existing laws whether in high-, middle- or low-income nations. See P. Bartlett, "Thinking about the Rest of the World: Mental Health and Rights Outside the 'First World,'" in B. McSherry and P. Weller, eds., *Rethinking Rights-Based Mental Health Laws* (Oxford: Hart, 2010): 397-418, at 410 [hereinafter "Thinking About the Rest of the World"] (procedural protections in central European nations "are often in form only"). For a critique of the legality of institutional practices in Canada, see M. Bay (former Chair of Ontario's Consent and Capacity Board), "Making the Law Match the Reality: Making the Reality Match the Law," *Journal of Ethics in Mental Health* 1, no. 1 (2006): 1-5.
59. See P. Bartlett, "Thinking about the Rest of the World," *id.*, at 403-408; P. Bartlett and V. Hamzic, *Reforming Mental Disability Law in Africa: Practical Tips and Suggestions* (Nottingham: University of Nottingham Human Rights Law Centre, 2010). [hereinafter *Reforming Mental Disability Law in Africa*].
60. This is discussed below with reference to legal controversies arising under the CRPD. For pre-CRPD critique of the WHO Resource Book, see The World Network of Users and Survivors of Psychiatry [WNUSP], "Comments on the Draft WHO Manual on Mental Health Legislation (July 12, 2001)," in M. Perlin et al., *International Human Rights and Comparative Mental Disability Law* (Durham, NC: Carolina Academic Press, 2006): at 891-894 [hereinafter cited as *International Human Rights and Comparative Mental Disability Law*].
61. From UPIAS, *Fundamental Principles of Disability*; Reprinted in edited form in M. Oliver, *Understanding Disability: From Theory to Practice* (Basingstoke, Hampshire, UK: Palgrave Macmillan, 1996): at 33 [hereinafter cited as *Understanding Disability: From Theory to Practice*]. Oliver provides background to and elaboration upon the Fundamental Principles at 19-29. Also see V. Finkelstein, "The Social Model Repossessed," Manchester Coalition of Disabled People - December 1, 2001, available at <<http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/soc%20mod%20repossessed.pdf>> (last visited February 1, 2013) [hereinafter "The Social Model Repossessed"]. Finkelstein distinguishes the historical materialist critique launched by the UPIAS from a "legalistic" or human rights-based approach, which he characterizes as vindicating an individualized model of impairment, along with individuated rights to health or well-being, and ignoring the central role of capitalist market systems in the production and reproduction of disability. Careful attention to a variety of "social models" is provided in H. A. Kaiser, "Canadian Mental Health Law: The Slow Process of Redirecting the Ship of State," *Health Law Journal* 17 (2009): 139-194, at 155, fn. 73 [hereinafter "Redirecting the Ship of State"].
62. See *Understanding Disability: From Theory to Practice*, *supra* note 61, at 32; M. H. Rioux and F. Valentine, "Does Theory Matter? Exploring the Nexus between Disability, Human Rights, and Public Policy," in D. Pothier and R. Devlin, eds., *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2006): 47-69, at 50-51 (distinguishing "biomedical" from "functional" approaches, both of which are grounded in the idea of individual pathology (or incapacity) and position "disability as a field of professional expertise") [hereinafter *Critical Disability Theory*]. For description of the medical model as it applies in the mental health context specifically, see H. A. Kaiser, *id.*, at 153-54 ("the physician becomes the authority figure and decision maker, wielding the wide discretionary powers provided by legislation, to ensure that ill individuals, once several preconditions are present, can be forcibly assessed, hospitalized, and treated.")
63. But see A. M. Samaha, "What Good Is the Social Model of Disability?" *University of Chicago Law Review* 74, no. 4 (2007): 1251-1308, at 1308 ("a causal account of disadvantage, however insightful, is no substitute for norms.") Samaha argues that the social model may potentially inform a set of alternative political and policy approaches, including utilitarianism and libertarianism, in addition to one or another form of egalitarianism.
64. On the historical materialist critique, see "The Social Model Repossessed," *supra* note 61. On the postmodern or poststructuralist critique, see S. Tremain, "On the Government of Dis-

- ability: Foucault, Power, and the Subject of Impairment," in L. Davis, ed., *The Disability Studies Reader*, 2nd ed. (New York: Routledge, 2006): 185-196. Also see generally, "Out of Darkness into Light?" *supra* note 34, at 5-8, 21-22.
65. See Bradley Lewis, "A Mad Fight: Psychiatry and Disability Activism," in *The Disability Studies Reader*, *id.*, at 339-352.
  66. See J. Chamberlin, *On Our Own: Patient Controlled Alternatives to the Mental Health System* (New York: Hawthorn, 1978); J. Chamberlin, "The Ex-Patients Movement: Where We've Been and Where We're Going," *Journal of Mind and Behaviour* 11, nos. 3 & 4 (1990): 323-336 [hereinafter cited as "The Ex-Patients' Movement"]; J. Chamberlin, "Citizenship Rights and Psychiatric Disability," *Psychiatric Rehabilitation Journal* 21, no. 4 (1998): 405-408. Also see J. Cook and J. Jonikas, "Self-Determination among Mental Health Consumers/Survivors: Using Lessons from the Past to Guide the Future," *Journal of Disability Policy Studies* 13, no. 2 (2002): 87-95.
  67. See, e.g., *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (Washington, D.C.: National Council on Disability, 2000).
  68. See, e.g., T. Szasz, *Ideology and Insanity: Essays on the Psychiatric Dehumanization of Man* (Syracuse, NY: Syracuse University Press, 1991 [1971]).
  69. See, e.g., B. Burstow and D. Weitz, eds., *Shrink Resistant: The Struggle Against Psychiatry in Canada* (Vancouver: New Star Books, 1988). Also see S. Estroff, "Subject/Subjectivities in Dispute: The Politics and Poetics of First Person Narratives of Schizophrenia," in R. Barrett and J. Jenkins, eds., *The Edge of Experience: Schizophrenia, Culture, and Subjectivity* (Cambridge: Cambridge University Press, 2004): 282-302.
  70. See J. Chamberlain, "The Ex-Patients' Movement," *supra* note 66; "Self Advocate Net: Our History," available at <<http://selfadvocates.sharevision.ca/History.aspx>> (last visited February 1, 2013).
  71. The Mental Disability Advocacy Centre [MDAC] and Mental Disability Rights International [MDRI] are two examples of active non-governmental investigative and advocacy bodies. See, e.g., MDAC, *Cage Beds: Inhuman and Degrading Treatment or Punishment in Four EU Accession Countries* (2003), available at <[http://mdac.info/sites/mdac.info/files/English\\_Cage\\_Beds.pdf](http://mdac.info/sites/mdac.info/files/English_Cage_Beds.pdf)> (last visited March 1, 2013); MDRI, *Human Rights & Mental Health: Uruguay* (1995), available at <<http://www.mdri.org/PDFs/reports/uruguay%20report%20spanish%20and%20english.pdf>> (last visited February 1, 2013); MDRI, *Human Rights & Mental Health: Hungary* (1997), available at <<http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/Hungary.pdf>> (last visited March 1, 2013). Also see J. E. Lord, "Shared Understanding or Consensus-Masked Disagreement? The Anti-Torture Framework in the Convention on the Rights of Persons with Disabilities," *Loyola of Los Angeles International & Comparative Law Review* 33, no. 1 (2010): 27-81, at 29-32 [hereinafter "The Anti-Torture Framework"].
  72. The precedent instruments (and key decisions thereunder) are described and subject to critical analysis in L. O. Gostin, "Human Rights of Persons with Mental Disabilities," *supra* note 52, at 128-131; L. O. Gostin and L. Gable, "The Human Rights of Persons with Mental Disabilities: A Global Perspective on the Application of Human Rights Principles to Mental Health," *Maryland Law Review* 63, no. 1 (2004): 20-121 [hereinafter cited as "The Human Rights of Persons with Mental Disabilities: A Global Perspective"]; *International Human Rights and Comparative Mental Disability Law*, *supra* note 60, at 927-934, 938-939; M. Perlin, *International Human Rights and Mental Disability Law: When the Silenced Are Heard* (Oxford: Oxford University Press, 2012): at 21-33, 46 [hereinafter *When the Silenced Are Heard*]. See also "Global Health Governance," *supra* note 4, at 566-567; Kaiser, "Redirecting the Ship of State," *supra* note 61, at 159-160; A. Dhir, "Human Rights Treaty Drafting through the Lens of Mental Disability," *Stanford Journal of International Law* 41, no. 2 (2005): 181-216, at 184-189 [hereinafter cited as "Human Rights Treaty Drafting"].
  73. See the sources cited and discussed in *When the Silenced Are Heard*, *id.*, at 21-27.
  74. See "Human Rights Treaty Drafting," *supra* note 72, at 186; E. Rosenthal and C. J. Sundram, "International Human Rights in Mental Health Legislation," *New York Law School Journal of International and Comparative Law* 21, no. 3 (2002): 469-536, at 474 [hereinafter cited as "International Human Rights in Mental Health Legislation"].
  75. For examples of institutional abuses, see the MDAC and MDRI reports cited in *supra* note 71; O. Lewis, "Mental Disability Law in Central and Eastern Europe: Paper, Practice, Promise," *Journal of Mental Health Law* 8 (December 2002): 293-303; *Reforming Mental Disability Law in Africa: Practical Tips and Suggestions*, *supra* note 59; E. Sailas and K. Wahlbeck, "Restraint and Seclusion in Psychiatric Inpatient Wards," *Current Opinion in Psychiatry* 18, no. 5 (2005): 555-559; *When the Silenced Are Heard*, *supra* note 72, at 89-95, and from the same volume, Chapter 6, "The Use of Mental Disability Law to Suppress Political Dissent," at 59-80; the Bulgarian Helsinki Committee, *Submission to the Human Rights Committee Regarding the Consideration of the Third Periodic Report of Bulgaria 102nd session (11 -29 July 2011), Geneva*, at 22-24 [hereinafter *Bulgarian Helsinki Committee Submission 2011*], available at <[http://www2.ohchr.org/english/bodies/hrc/docs/ngo/BHC\\_Bulgaria\\_HRC102.pdf](http://www2.ohchr.org/english/bodies/hrc/docs/ngo/BHC_Bulgaria_HRC102.pdf)> (last visited February 1, 2013).
  76. See *When the Silenced Are Heard*, *supra* note 72, at 93-95.
  77. See P. Bartlett, "Thinking about the Rest of the World," *supra* note 58, at 410 (discussing imposition of "plenary guardianship almost as a matter of routine" in cases of involuntary psychiatric hospitalization in much of central Europe); and see the *Bulgarian Helsinki Committee Submission 2011*, *supra* note 75, at 17-18.
  78. See, e.g., "Global Health Governance," *supra* note 4, at 566-567; "International Human Rights in Mental Health Legislation," *supra* note 74, at 476-477. On the "hardening" of soft law into customary international law or domestic legal regimes, see *When the Silenced Are Heard*, *supra* note 72, at 29-30.
  79. See "International Human Rights in Mental Health Legislation," *supra* note 74, at 475; "Human Rights Treaty Drafting," *supra* note 72, at 186-189. On controversy among interpretations of the MI Principles as rights-promoting or rights-eroding, see "Out of Darkness into Light?" *supra* note 34, at 15. At 16, Kayess and French note criticism of the *United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities* for reflecting a medical model of disability rather than one based in acknowledgement of human diversity (GA Res. 48/96, 20 December 1993, A/RES/48/96, Supp No. 49, Annex at 202&11, available at <<http://www.un.org/documents/ga/res/48/a48r096.htm>> [last visited February 1, 2013]).
  80. On the European Convention on Human Rights as it applies to persons with mental disabilities, see "Human Rights of Persons with Mental Disabilities," *supra* note 52, at 136-149; and P. Bartlett et al., *Mental Disability and the European Convention on Human Rights* (Leiden: Martinus Nijhoff, 2007). Criticism of Article 5(1)(e) (which contemplates deprivation of liberty on the basis of "unsound mind" subject to certain safeguards) is noted by Amnesty International Ireland, "Annex 1 - Is the Existence of a Separate Mental Health Act Inherently Discriminatory? - Discussion" in *Mental Health Act 2011: A Review* (March 22, 2011), available at <<http://www.amnesty.ie/sites/default/files/MENTAL%20HEALTH%20ACT%20REVIEW.pdf>> (last visited February 1, 2013) [hereinafter *Mental Health Act 2011: A Review*]. For a critical appraisal critique of developments under the *African Charter on Human and Peoples' Rights* (in particular the decision in *Purohit and Moore v. The Gambia*, Communication No. 241/2000 (2003), AHRLR 96), see *Reforming Mental Disability Law in Africa*, *supra* note 59, at 4 and 8-9; and "The Role of Reasonable



- Accommodation," *supra* note 4, at 293-297. For discussion of some important advances under the Inter-American Convention on Human Rights, see *International Human Rights and Comparative Mental Disability Law*, *supra* note 60, at 932-933; "The Human Rights of Persons with Mental Disabilities: A Global Perspective," *supra* note 72, at 516-518.
81. See *When the Silenced Are Heard*, *supra* note 72, at 46-56.
  82. See "Human Rights Treaty Drafting," *supra* note 72, at 189; "Toward a New International Politics of Disability," *supra* note 4, at 37-39.
  83. For discussion of systemic effects of litigation brought under the *Inter-American Convention of Human Rights* in Paraguay and in Brazil, see *When the Silenced are Heard*, *supra* note 72, at 53-54. The Paraguay settlement discussed by Perlin is also noted in the *World Report on Disability*, *supra* note 13, at 144 (Box 5.3). Also of note is the recent decision of the European Court of Human Rights in the case *Stanev v. Bulgaria*, (Grand Chamber judgment, Strasbourg, January 17, 2012), finding violations of Arts. 3 & 5 of the ECHR and so confirming the entitlement of residents of Bulgarian social care homes to certain procedural safeguards. For critical discussion of the decision from an intervener in the case, Interights, see <<http://www.interights.org/stanev/index.html>> (last visited February 1, 2013).
  84. See the sources cited at notes 71-80, above. International legal recognition of the rights of persons with disabilities, in particular the right to non-discrimination, carries the potential to spur domestic legal reforms as well as the potential to inform and strengthen the application of these rights in legal regimes in which they are already acknowledged. On advances in and limitations of anti-discrimination approaches to disability in Canada, see D. Pothier, "Appendix: Legal Developments in the Supreme Court of Canada Regarding Disability," in *Critical Disability Theory*, *supra* note 62, at 305-317. ("Although decisions in the Supreme Court of Canada in the last two decades have involved significant advances for persons with disabilities, there is much to be done to achieve substantive equality" [at 316]). For analysis of the U.S. *Americans with Disabilities Act*, emphasizing the implications for workers with mental disabilities, see S. Stefan, "You'd Have to be Crazy to Work Here: Worker Stress, the Abusive Workplace, and Title I of the ADA," *Loyola of Los Angeles Law Review* 31, no. 3 (1998): 795-846; S. Stefan, *Unequal Rights: Discrimination against People with Mental Disabilities and the Americans with Disabilities Act* (Washington, D.C.: American Psychological Association Press, 2001). See also G. Quinn and E. Flynn, "Transatlantic Borrowings: The Past and Future of EU Non-Discrimination Law and Policy on the Ground of Disability," *American Journal of Comparative Law* 60, no. 1 (2012): 23-48; *International Human Rights and Comparative Mental Disability Law*, *supra* note 60, at 924-926; and T. Degener, "Disability Discrimination Law: A Global Comparative Approach," in A. Lawson and C. Gooding, eds., *Disability Rights in Europe: From Theory to Practice* (Oxford: Hart, 2005): at 87-106.
  85. See, e.g., A. Dhanda, "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?" *Syracuse Journal of International Law & Commerce* 34, no. 2 (2007): 429-462 [hereinafter cited as "Legal Capacity in the Disability Rights Convention"]; T. Melish, "The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. Should Ratify," *Human Rights Brief* 14, no. 2 (2007): 37-47, at 43-47; "Global Health Governance," *supra* note 4, at 567-569; S. Tromel, "A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities," in G. Quinn and L. Waddington, eds., *European Yearbook of Disability Law*, vol. I (Portland: Intersentia, 2009): at 115 [hereinafter cited as "A Personal Perspective"]; "Out of Darkness into Light?" *supra* note 34, at 17-32.
  86. The decision of August 1, 2002 stated: "That representatives from non-governmental organizations accredited to the Ad Hoc Committee may participate in the work of the Ad Hoc Committee by:
    - i. Attending any public meeting of the Ad Hoc Committee;
    - ii. Making statements, given the availability of time, in accordance with current United Nations practice;
    - iii. When time is limited, selecting from among themselves spokespersons, on a balanced and transparent basis, taking into account equitable geographical representation and the diversity of non-governmental organizations;
    - iv. Receiving copies of the official documents, as well as making written or other presentations. Written presentations shall not be issued as official documents except in accordance with Economic and Social Council resolution 1996/31 of 25 July 1996. Furthermore, non-governmental organizations may make their material available to delegations in accessible areas designated by the Secretariat.
 See Part IV of the Report of the First Session of the Ad Hoc Committee" (A/57/357).
  87. The decision of the ad hoc committee is found at item 15 of the Report of the Second Session of the Ad Hoc Committee (New York, June 16-27, 2003), available at <[http://www.un.org/esa/socdev/enable/rights/a\\_58\\_118\\_e.htm](http://www.un.org/esa/socdev/enable/rights/a_58_118_e.htm)> (last visited February 1, 2013).
  88. The list of selected DPOs is available at <<http://www.un.org/esa/socdev/enable/rights/ahcwg.htm#membership>> (last visited February 1, 2013). Thanks to Frank Hall-Bentick for communications on the composition of the working group.
  89. A 2003 WNUSP submission to the ad hoc committee stated that it then had over 70 organizational members based in 30 countries, in addition to individual memberships. WNUSP is further described as having grown "out of users' and survivors' demands for recognition and representation." The terms "user" and "survivor" are explained as follows: "A user or survivor of psychiatry is self-defined as a person who has experienced madness and/or mental health problems and/or has used or survived psychiatry/mental health services. We say 'survive' in recognition that the experience of confinement and imposition of forced treatments is harmful and life-threatening," available at <<http://www.un.org/esa/socdev/enable/rights/contrib-wnusp.htm>> (last visited February 1, 2013).
  90. M. V. Reina, "How the International Disability Caucus worked during negotiations for a UN Human Rights Convention on Disability," February 6, 2008, available at <<http://globalag.igc.org/agingwatch/events/CSD/2008/maria.htm>> (last visited February 1, 2013). See also "Global Health Governance," *supra* note 4, at 567. Lord relates that the unprecedented inclusion of DPO delegates occurred in part because "the gallery space was inaccessible for people using wheel-chairs, and a move to an alternative conference room was not viable because of equally inaccessible gallery space. As a result, disability activists were forced onto the floor of the committee itself, allowing these activists the unintended advantage of heightened access to government delegates and participation in the negotiations."
  91. See the record of opening comments at the 5th session of the Ad Hoc Committee, on January 27, 2005:
 

The Coordinator reminded the delegates about the last three days' process. Expertise from disability organizations has been lacking, and as a result the discussion of Article 9 [the draft Article on equal legal capacity] was unbalanced. He suggested that, from time to time, disability organizations be invited to speak. He will propose that the Chairman set up a plenary meeting this afternoon because NGOs are allowed to speak at plenaries. This should be a short session led by Ambassador Luis Gallegos after which the Committee would resume informal sessions. Available at <<http://www.un.org/esa/socdev/enable/rights/ahc5sum27jan.htm>> (last visited February 1, 2013). Following this, a process was adopted whereby state and regional representatives typically held the floor in the mornings and DPOs were given the chance to make comments in formal plenary sessions in the afternoons.
  92. See "List of NGO Representatives Registered for the Sixth Session," available at <<http://www.un.org/esa/socdev/enable/>>

- rights/ahc6ngorepslist.htm> (last visited February 1, 2013). See also “Global Health Governance,” *supra* note 4, at 568: “[G]roups falling outside the membership of the international disability rights community – such as mainstream human rights organizations, public health organizations and health care professional associations – were secondary and relatively inactive participants in the process, although by the end of the negotiations...more than 800 representatives of DPOs and NGOs were registered to participate in the Ad Hoc Committee process.”
93. There were 59 participating organizations listed in a document submitted by the IDC on the right to equal legal capacity, submitted during the seventh session of the Ad Hoc Committee: *available at* <<http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7idechairamend1.doc>> (last visited February 1, 2013).
  94. Support Coalition International was described in an article written in the late 1990s as “a non-profit alliance of over 70 grassroots groups in eleven countries, advocating for human rights and alternatives in the ‘mental health’ system.” J. Foner, “Support Coalition International: Advocating for Human Rights and Alternatives in the ‘Mental Health’ System,” *available at* <[http://www.power2u.org/articles/empower/support\\_coal.html](http://www.power2u.org/articles/empower/support_coal.html)> (last visited February 1, 2013). In 2005, the organization changed its name to MindFreedom International, recently described as “a nonprofit organization that unites 100 sponsor and affiliate grassroots groups with thousands of individual members to win human rights and alternatives for people labeled with psychiatric disabilities.” See <<http://www.mindfreedom.org/about-us>> (last visited January 1, 2013).
  95. The mission statement of the CACL states that it is “a family-based association assisting people with intellectual disabilities and their families to lead the way in advancing inclusion in their own lives and in their communities.” It adds: “We do this in Canada and around the world by sharing information, fostering leadership for inclusion, engaging community leaders and policy makers, seeding innovation and supporting research. We are dedicated to attaining full participation in community life, ending exclusion and discrimination on the basis of intellectual disability, promoting respect for diversity and advancing human rights to ensure equality for all Canadians,” *available at* <<http://www.cacl.ca/about-us>> (last visited February 1, 2013).
  96. This organization is described as “a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. For over forty years Inclusion International has been committed to the promotion of these human rights and our organization now represents over 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific,” *available at* <<http://www.inclusion-international.org/about-us/who-we-are/>> (last visited February 1, 2013).
  97. “Report by John McCarthy – MindFreedom delegate in the United Nations,” *available at* <<http://www.mindfreedom.org/kb/mental-health-global/john-mccarthy-un>> (last visited February 1, 2013).
  98. On contestation regarding the definition of disability, see “A Personal Perspective,” *supra* note 85, at 117-121; “Out of Darkness into Light,” *supra* note 34, at 23.
  99. See CRPD, *supra* note 2, Preamble, sub-Article (e). See also Article 1 (Purpose).
  100. These tensions are examined by Kayess and French in “Out of Darkness into Light,” *supra* note 34, at 21-25.
  101. The full set of overarching principles of the CRPD, as stated in Article 3, are:
    - (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
    - (b) Non-discrimination;
    - (c) Full and effective participation and inclusion in society;
    - (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
    - (e) Equality of opportunity;
    - (f) Accessibility;
    - (g) Equality between men and women;
    - (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.”
  102. For further examination of the substantive rights included in the CRPD, see “Out of Darkness into Light,” *supra* note 34, at 22-33; “Toward a New International Politics of Disability” *supra* note 4, at 41-46; “The Role of Reasonable Accommodation” *supra* note 4, at 273-281; and “Redirecting the Ship of State” *supra* note 61, at 161-164.
  103. Kayess and French note that such elaborations in the CRPD text often “transform formerly essentially non-interference based rights (or ‘negative’ rights) into positive state obligations.” See “Out of Darkness into Light,” *supra* note 34, at 33.
  104. This point is brought out carefully, with a particular focus on substantive equality and the attendant duty of reasonable accommodation, in “The Role of Reasonable Accommodation,” *supra* note 4, at 274-275, 277, 281: “The CRPD serves to re-conceptualize and unite civil and political rights and economic, social and cultural rights in the realization of equality for persons with disabilities by requiring reasonable accommodation through positive measures in all areas of life” (at 281).
  105. For analysis of the CRPD provisions relating to monitoring, see J. E. Lord and M. Stein, “Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Potential and Future Opportunities,” *Human Rights Quarterly* 32, no. 3 (2010): 689-728. Also see “Global Health Governance” *supra* note 4, at 569-571; and O. Lewis, “The Expressive, Educational and Proactive Roles of Human Rights: An Analysis of the United Nations Convention on the Rights of Persons with Disabilities,” in B. McSherry and P. Weller, *Rethinking Rights-Based Mental Health Laws* (Oxford: Hart, 2010): 97-128, at 113-126. [Hereinafter cited as “The Expressive, Educational and Proactive Roles of Human Rights”].
  106. On the constitution of the committee, see Articles 34(1)-(3).
  107. Kayess and French note that “under the Optional Protocol all CRPD rights are potentially justiciable, not just its civil and political rights”: see “Out of Darkness into Light,” *supra* note 34, at 33. However, as Janet Lord and Rebecca Brown point out, “In many countries, many or all economic, social and cultural rights are not recognized or enforceable by law, leaving people with little hope of any remedy.” (See “The Role of Reasonable Accommodation,” *supra* note 4, at 305.)
  108. The implications of this obligation are examined by Oliver Lewis in “The Expressive, Educational and Proactive Roles of Human Rights,” *supra* note 105, at 115.
  109. Oliver Lewis elucidates the importance of this aspect of the convention, describing it as an “audacious constitutional masterstroke,” *id.*, at 124.
  110. For developments on this front, see *Survey of National Human Rights Institutions on Article 33.2 of the Convention on the Rights of Persons with Disabilities* (Prepared for the International Coordinating Committee of National Institutions for the Promotion and Protection of Human Rights by the Canadian Human Rights Commission, August 2011), *available at* <<http://www.nuigalway.ie/cdlp/documents/publications/ICC%20SurveyReport33.2.pdf>> (last visited February 4, 2013).
  111. See Lewis’s discussion of these tripartite functions: “The Expressive, Educational and Proactive Roles of Human Rights,” *supra* note 105, at 117-121.
  112. This was suggested by Uganda near the end of the negotiations, at the Seventh Session of the Ad Hoc Committee (January 27, 2006), to which the Chair responded that “a consultation provision had been included but was moved to Article 4(3) on General Obligations,” *available at* <<http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7idechairamend1.doc>> (last visited February 1, 2013).

- www.un.org/esa/socdev/enable/rights/ahc7sum27jan.htm > (last visited February 4, 2013).
113. The CRPD also specifies a forum for such cooperation: the Conference of States Parties, to be held at least every two years, at which states parties are to discuss matters relating to CRPD implementation (Art 41(1)). Lewis indicates that these conferences have so far been inclusive of NGOs (*supra* note 105 at 123-24). See <<http://www.internationaldisabilityalliance.org/en/conference-of-states-parties>> (last visited February 4, 2013).
  114. Various human rights scholars have commented upon the “expressive” (also “communicative”, “educative” and “proactive”) function of human rights. Oliver Lewis is my direct precedent in explicitly applying this approach in an analysis of the CRPD. See “The Expressive, Educational and Proactive Roles of Human Rights,” *supra* note 105, at 98-100, 105. Lewis in turn draws on S. Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (Oxford: Oxford University Press, 2008): see esp. 32-33; W. van der Burg, “The Expressive and Communicative Functions of Law, Especially with Regard to Moral Issues,” *Law and Philosophy* 20, no. 1 (2001): 31-59 [hereinafter cited as “The Expressive and Communicative Functions of Law”]; and A. Geisinger and M. A. Stein, “A Theory of Expressive International Law,” *Vanderbilt Law Review* 60, no. 1 (2007): 77-131.
  115. The CRPD had been ratified by 127 nations at the time of final approval of this article. See <<http://www.un.org/disabilities/countries.asp?navid=17&pid=166>> (last visited March 1, 2013).
  116. See the sources listed at *supra* note 114.
  117. “The Expressive and Communicative Functions of Law,” *supra* note 114, at 33.
  118. “The Expressive, Educational and Proactive Roles of Human Rights,” *supra* note 105, at 105, citing “The Expressive and Communicative Functions of Law,” *supra* note 114, at 41.
  119. “The Expressive and Communicative Functions of Law,” *id.*
  120. “The Expressive, Educational and Proactive Roles of Human Rights,” *supra* note 105, at 98.
  121. Tina Minkowitz argues that involuntary psychiatric interventions breach not only Article 17, but also Articles 12 (equal legal capacity), 15 (the right to be free from torture and cruel, inhuman or degrading treatment or punishment), and 25 (the right to health care provided “on the basis of free and informed consent”): “The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions,” *Syracuse Journal of International Law & Commerce* 34, no. 2 (2007): 405-428. See also T. Minkowitz, “Abolishing Mental Health Laws to Comply with the CRPD,” in B. McSherry and P. Weller, eds., *Rethinking Rights-Based Mental Health Laws* (Oxford: Hart, 2010): 397-418, at 151-177 [hereinafter cited as “Abolishing Mental Health Laws to Comply with the CRPD”]. On the scope of Article 15, see also “The Anti-Torture Framework,” *supra* note 71.
  122. See the notes from the Fifth Session of the Ad Hoc Committee (January 26, 2005 – afternoon), available at <<http://www.un.org/esa/socdev/enable/rights/ahc5sum26jan.htm>> (last visited February 4, 2013).
  123. See the comments from the representatives of Japan and Uganda in the notes from January 26, 2005, *id.*
  124. See the comments from the representatives of Mexico and Thailand in the notes from January 26, 2005, *id.*
  125. See the comments from representatives of the IDC in the notes of discussions at the Fifth Session of the Ad Hoc Committee from Jan 27 2005, available at <<http://www.un.org/esa/socdev/enable/rights/ahc5sum27jan.htm>> (last visited February 4, 2013): “It was said yesterday that disability itself is not a justification for deprivation of liberty, but together with something else disability can be a basis of deprivation of liberty. Any adjective and addition to this paragraph such as ‘solely’ or ‘exclusively’ based on disability is a threat to human rights.”
  126. See “Abolishing Mental Health Laws to Comply with the CRPD,” *supra* note 121, at 412-413; “Out of Darkness into Light?” *supra* note 34, at 30.
  127. However, the importance of this Article should not be diminished. Kayess and French note that this is “the first time the concept of ‘integrity of the person’ has been included as a standalone Article in a core United Nations human rights treaty.” See *supra* note 34, at 29. See also the discussion of Article 17 in B. McSherry, “Protecting the Integrity of the Person: Developing Limitations on Involuntary Treatment,” in B. McSherry, ed., *International Trends in Mental Health Laws* (Annandale: Federation Press, 2008): Special edition Volume 26, no. 2 of *Law in Context*: at 111-124.
  128. See the negotiation notes from the Seventh Session of the Ad Hoc Committee (19 January 2006), available at <<http://www.un.org/esa/socdev/enable/rights/ahc7sum19jan.htm>> (last visited February 4, 2013).
  129. Janet Lord states: “Accordingly, Article 17 provides no guidance whatsoever on the regulation of forced treatment that is practiced often with sweeping abandon and with little or no due process protection in many parts of the world.” (See “The Anti-Torture Framework,” *supra* note 71, at 55.) The point is also made by Kayess and French, *supra* note 34, at 30: “The IDC and WNUSP sought the ultimate goal of the CRPD ‘outlawing’ all forms of compulsory assistance, but, when this proved impossible to achieve, they adopted the alternative lobbying stance that there ought to be no reference to compulsory treatment in the CRPD as this would provide it with legitimacy. Ultimately, this was the outcome of the Ad Hoc Committee’s deliberations, although this appeared to be more to avoid conflict with the IDC and WNUSP, than because of any underlying commitment to the principle on which this opposition was based. The result is that one of the most critical areas of human rights violation for persons with disability – the use of coercive State power for the purpose of ‘treatment’ – remains without any specific regulation.”
  130. Terry Carney makes the point that “neither silence nor ambiguous drafting displaces *prior explicit* language in previous international instruments”: “Guardianship, ‘Social’ Citizenship and Theorizing Substitute Decision-Making Law,” in I. Doron and A. Sodon, eds., *Beyond Elder Law: New Directions in Law and Aging* (Berlin: Springer-Verlag, 2012):1-17, at 5, footnote 6 (hereinafter cited as “Guardianship, ‘Social’ Citizenship and Theorizing Substitute Decision-Making Law”). There remains room for debate on how explicit contemplation of involuntary hospitalization or substitute decision-making in, for instance, a regional instrument such as the ECHR or in soft law at the international level stacks up against arguments based in purposive interpretation of the CRPD.
  131. See “Abolishing Mental Health Laws to Comply with the CRPD,” *supra* note 121, esp. at 167-168.
  132. See S. Morse, “A Preference for Liberty: The Case Against Involuntary Commitment of the Mentally Disordered,” *California Law Review* 70, no. 1 (1982): 54-106 [hereinafter cited as “A Preference for Liberty”]; and Morse’s modified position (still in favor of abolishing involuntary civil commitment) in “Rationality and Responsibility,” *Southern California Law Review* 74 (2000): 251-268, at 266-267.
  133. See “A Preference for Liberty,” *id.*, at 93-98. On the lack of correlation of most mental disorders (including schizophrenia) with increased risk of violent behavior, absent other factors such as substance abuse, see J. Monahan et al., *Rethinking Risk Assessment: The MacArthur Study of Mental Disorder and Violence* (New York: Oxford University Press, 2001).
  134. See Kaiser, “Redirecting the Ship of State,” *supra* note 61, at 154 (“People subject to mental health law are too readily depicted as being incapable of making decisions and dangerous to themselves or others owing to their supposed individual pathologies”). WNUSP argued (successfully) for specific mention of informed consent as an aspect of the right to health. See the report of WNUSP commentary at the 6th session, August 8, 2005, available at <<http://www.un.org/esa/>



- socdev/enable/rights/ahc6sum8aug.htm> (last visited February 4, 2013).
135. "Abolishing Mental Health Laws to Comply with the CRPD" *supra* note 121 at 168. Also see the WNUSP submissions on then-Article 15 (now Article 19), arguing that persons with disabilities should not be subject to involuntary hospitalization but, rather, should be offered supports to enable community inclusion. WNUSP makes the further point that access to community services should not be contingent upon acceptance of medication or other constraints upon fundamental liberties. (Sixth Session of the Ad Hoc Committee, August 1, 2005, available at <<http://www.un.org/esa/socdev/enable/rights/ahc6sum1Aug.htm>> [last visited March 4, 2013].)
  136. The main focus of the declaration is Article 17 (physical and psychological integrity): "Australia recognizes that every person with disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Australia further declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards." This is one of a set of reservations, including one (noted below) on the right to equal legal capacity.
  137. *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities*, UN Doc. A/HRC/10/48 (January 26, 2009) [hereinafter cited as the OHCHR Thematic Report 2009]: at para. 48.
  138. *Id.* The Special Rapporteur on Torture has also indicated that involuntary treatment and confinement are contrary to Articles 14 and 15 of the CRPD. (*Interim Report of the Special Rapporteur on Torture and other Cruel, Inhuman and Degrading Treatment or Punishment*, July 28, 2008, UN Doc A/63/175, at para. 44).
  139. See Committee on the Rights of Persons with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities (Tunisia)*, CRPD/C/TUN/CO/1, 5th sess. (May 13, 2011) para. 25 (recommending that Tunisia "repeal legislative provisions which allow for the deprivation of liberty on the basis of disability, including a psychosocial or intellectual disability"). And see Committee on the Rights of Persons with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities (Spain)*, CRPD/C/ESP/CO/1, 6th sess. (October 19, 2011), para. 36 (stating that Spain must "repeal provisions that authorize involuntary internment linked to an apparent or diagnosed disability; and adopt measures to ensure that health-care services, including all mental-health-care services, are based on the informed consent of the person concerned").
  140. See J. Dawson and G. Szmukler, "Fusion of Mental Health and Incapacity Legislation," *British Journal of Psychiatry* 188 (2006): 505-509.
  141. *Id.*
  142. *Id.*, at 505: "This [...] might permit earlier intervention, in both physical and mental illness, because intervention would be authorised as soon as the patient lacked capacity to determine treatment, whether or not there was an imminent threat of harm. That approach is likely to find support with many patients' families."
  143. Under Article 12(4), states parties must ensure "that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards," specifically requiring "that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body." Additionally, "The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests."
  - Article 12(5) provides: "Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property."
  144. See for instance my home jurisdiction's guardianship statute, Nova Scotia's *Incompetent Persons Act*, RSNS 1989, c 218.
  145. See for instance Ontario's *Health Care Consent Act, 1996*, SO 1996, c 2, Sch A, and *Substitute Decisions Act, 1992*, SO 1992, c 30.
  146. For discussion of this and the other types of existing legal capacity standards, see "Legal Capacity in the Disability Rights Convention," *supra* note 85, at 431-433.
  147. Again see Ontario's *Health Care Consent Act*, *supra* note 145, at s. 4(1). These (and other) common legal criteria informed the design of the influential clinical model of Appelbaum and Grisso, the MacCAT-T (consisting of four parameters: the ability to understand relevant information; the ability to reason about options; the ability to appreciate one's situation and the consequences of the choice; and the ability to express a choice.) See P. T. Grisso et al., "The MacCAT-T: A Clinical Tool to Assess Patients' Capacities to Make Treatment Decisions," *Psychiatric Services* 48, no. 11 (1997): 1415-1419.
  148. See "Legal Capacity in the Disability Rights Convention," *supra* note 85, at 431-433 (discussing this and the other conventional standards for assigning legal [in]capacity). This standard might also describe an illicit capacity assessment practice (i.e., substituting an outcome-based standard in practice where a functional standard is formally required).
  149. See Saskatchewan's *The Adult Guardianship and Co-decision-making Act*, SS 2000, c A-5.3, ss. 14(1)(a), 15, 16(1), 17(1)&(2).
  150. See British Columbia's *Representation Agreement Act*, RSBC 1996, c 405. Under this statute, a person may appoint someone to help one make decisions, or to make decisions on one's behalf (s. 7). Capacity to make a representation agreement is adjudged on a different, more flexible standard than other forms of legal capacity (s. 8). However, this is not a comprehensive alternative to traditional forms of legal incapacity and substitute decision-making; B.C. also features more traditional guardianship and substitute decision-making laws. Moreover, under s.11, a representative cannot refuse involuntary psychiatric hospitalization and treatment authorized under the province's *Mental Health Act*, RSBC 1996, c 288.
  151. The negotiations concerning Article 12 are explored in detail by Amita Dhanda in "Legal Capacity in the Disability Rights Convention," *supra* note 85.
  152. See "Abolishing Mental Health Laws," *supra* note 121, at 160.
  153. See the daily summary from January 27, 2005 (Fifth Session of the Ad Hoc Committee): "The International Disability Caucus (IDC) emphasized the need to address the legal capacity issue in the context of history. PWD [Persons with disabilities] have, over centuries, been perceived as lacking capacity. The notion of disqualification persists in existing legal norms across jurisdictions and is a result of social prejudices," available at <<http://www.un.org/esa/socdev/enable/rights/ahc5sum27jan.htm>> (last visited February 4, 2013).
  154. The daily summary from January 18, 2006 (7th session of the Ad Hoc Committee) reflects an exchange between the discussion facilitator and an IDC representative, in which the facilitator asks if guardianship has any place in the model endorsed by IDC. The response is recorded as: "The IDC goal is to not legitimize guardianship. The point is that a need for 100% support will become 99% and then 98% if we are talking about supported decision making and this would not be possible in a guardianship situation," available at <<http://www.un.org/esa/socdev/enable/rights/ahc6sum18jan.htm>> (last visited February 4, 2013).



- www.un.org/esa/socdev/enable/rights/ahc7sum17jan.htm> (last visited February 4, 2013).
155. The IDC's "Explanatory Note on Legal Capacity and Forced Interventions," available at <www.un.org/esa/socdev/enable/rights/ahc8contingos.htm> [last visited February 4, 2013]) states: "The support model acknowledges that there are times when other people make decisions for us, such as when a person is unconscious. Support continues to be provided to encourage the person to begin exercising legal capacity, while urgent needs are taken care of." See also T. Minkowitz, "Abolishing Mental Health Laws," *supra* note 121, at 157-58.
  156. See "Legal Capacity in the Disability Rights Convention," *supra* note 85, at 444-446.
  157. Exploration of the conditions that may support decision-making are proliferating in the wake of the CRPD. See, e.g., M. Bach and L. Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, report prepared for the Law Commission of Ontario, October 2010, at 72-82 [hereinafter cited as *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*]; S. McDaid and S. Delaney, "A Social Approach to Decision-Making Capacity: Exploratory Research with People with Experience of Mental Health Treatment," *Disability & Society* 26, no. 6 (2011): 729-742 [hereinafter cited as "A Social Approach to Decision-Making Capacity"]; T. Minkowitz, "Abolishing Mental Health Laws to Comply with the CRPD," *supra* note 121, at 160-166; S. Wildeman, "Insight Revisited: Relationality and Psychiatric Treatment Decision-Making Capacity," in J. Downie and J. Llewellyn, eds., *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver: UBC Press, 2011): 255, at 268-277.
  158. Of course, one practical alternative (contrary to the values of the CRPD) would be to rely on coercive institutional responses making non-compliance so awful that compliance is effectively compelled.
  159. WNUSP Implementation Manual for the United Nations Convention on the Rights of Persons with Disabilities (Feb 2008), available at <http://www.wnusp.net/documents/WNUSP\_CRPD\_Manual.pdf> [last visited March 1, 2013]. Similarly, the IDC is reported to have stated in the negotiations: "Seeking support in exercising legal capacity does not diminish or negate one's independence and capacity. Human interdependence is a fact that should be recognized as a legal principle." (Daily summary from January 27, 2005 [Fifth Session of the Ad Hoc Committee], available at <http://www.un.org/esa/socdev/enable/rights/ahc5sum27jan.htm> [last visited February 4, 2013]).
  160. The daily summary of discussions from the Fifth Session of the Ad Hoc Committee (Feb 3, 2005) reflects the following statement from an IDC representative: "Non-disabled people take for granted their right to make bad decisions. PWD [persons with disabilities] deserve the same right," available at <http://www.un.org/esa/socdev/enable/rights/ahc5sum3feb.htm> (last visited February 4, 2013). See also *Koch (Re)*, (1997) 33 OR (3d) 485 (Gen. Div.) at 521, cited in *Starson v. Swayze*, 2003 SCC 32, [2003] 1 S.C.R. 722 at para. 76.
  161. This is the "endorsement constraint" propounded by Ronald Dworkin: the idea that "our lives do not go better when led from the outside," even if this means we will make mistakes. See R. Dworkin, *Sovereign Virtue: The Theory and Practice of Equality* (Cambridge, MA: Harvard University Press, 2000): at 216-18, and W. Kymlicka, *Liberalism, Community and Culture*, (Oxford: Clarendon, 1989): at 12-13.
  162. Gerard Quinn states that "at the bottom of the debate" about legal capacity are "conceptions – sometimes competing conceptions – of personhood." See G. Quinn, "Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD," paper presented at Conference on Disability and Legal Capacity under the CRPD, Harvard Law School, Boston, February 20, 2010, at 5-6, available at <www.inclusionireland.ie/documents/HarvardLegalCapacityqcdraft2.doc> (last visited February 4, 2013).
  163. Michael Bach and Lana Kerzner (*A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, *supra* note 157) ground their approach to legal capacity in part in the capacities of support-persons to interpret expressions of will in light of a broader understanding of a person's "life narrative" (at 60-61).
  164. Allen Buchanan and Dan W. Brock argue that the ability to "express a choice" does not qualify as a standard of decision-making capacity at all. A. E. Buchanan and D. W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1989): at 49. But this would appear to be precisely the point of the radical model: to explode the concept of legal capacity and start fresh from the idea of mutual supports.
  165. See Bach and Kerzner, in *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, *supra* note 157, construct a highly nuanced model of legal capacity. They propose three types of decision-making status – independent, supported, and facilitated – reflecting distinct functional abilities and supports. The standard applicable to independent decision-making is similar to existing functional standards, despite a different theoretical frame. In contrast, supported decision-making status is attracted where one is able to express one's intention, with supports (intention being a clearer indication of preference than will), or alternatively, to express one's will or to have support persons discern one's will in light of their familiarity with one's wider "life narrative." Facilitated decision-making status (which requires recourse to a form of substitute decision-making) is reserved for situations in which no one can discern a person's contemporaneous will or intent, although the support person must remain vigilant for expressions of will.
  166. Declaration (registered upon Canada's accession to the Convention, March 11, 2010, available at <http://treaties.un.org/Pages/ViewDetails.aspx?mtdsg\_no=IV-15&chapter=4&lang=en> (last visited March 1, 2013)).
  167. "Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards" (registered upon Australia's accession to the Convention, July 17, 2008). Available at <http://treaties.un.org/Pages/ViewDetails.aspx?mtdsg\_no=IV-15&chapter=4&lang=en> (last visited March 1, 2013).
  168. Declarations on point were made by Egypt and the Syrian Arab Republic. Iran declared that it does not consider itself bound by any of the terms of the Convention inconsistent with its existing rules. Declarations are available at <http://treaties.un.org/Pages/ViewDetails.aspx?mtdsg\_no=IV-15&chapter=4&lang=en> (last visited March 1, 2013). For discussion of the asserted distinction between "capacity for rights" and "capacity to act," see *Background Conference Document Prepared by the Office of the United Nations High Commissioner for Human Rights: Legal Capacity*, available at <www.un.org/esa/socdev/enable/rights/ahc6documents.htm> (last visited February 4, 2013); "Abolishing Mental Health Laws to Comply with the CRPD," *supra* note 121, at 159-160; "Legal Capacity in the Disability Rights Convention," *supra* note 85, at 442-445, 453-455.
  169. Committee on the Rights of Persons with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities: Spain* (Sixth session, 19-23 September 2011), at para. 34. See also Committee on the Rights of Persons with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities: Tunisia* (Fifth session, April 11-15, 2011), at para. 23; Committee on the Rights of

Persons with Disabilities, *Consideration of reports submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities: Peru* (Seventh session, April 16–20, 2012), at para. 25.

170. The Special Rapporteur on Torture has stated: “States must adopt legislation that recognizes the legal capacity of persons with disabilities and must ensure that, where required, they are provided with the support needed to make informed decisions.” (*Interim Report of the Special Rapporteur on Torture and other Cruel, Inhuman and Degrading Treatment or Punishment*, July 28, 2008, UN Doc A/63/175, at para. 73.) Also see the Parliamentary Assembly of the Council of Europe, Resolution 1642 (2009) on access to rights for people with disabilities and their full and active participation in society, January 6, 2009, para. 7.
171. “The Committee held days of general discussion on article 12 (Equal recognition before the law) of the Convention in 2009 and on article 9 (Accessibility) of the Convention in 2010 to support the formulation by the Committee of general comments on these issues. The days of general discussion were attended by representatives of States parties, civil society and others.” (“Status of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto (Report of the Secretary-General,” July 7, 2011, Doc A/66/121, available at <[www.un.org/disabilities/default.asp?id=712](http://www.un.org/disabilities/default.asp?id=712)> (last visited February 4, 2013) [hereinafter cited as “Status of the Convention”]. And see Ron MacAllum, Chair, Committee on the Rights of Persons with Disabilities, “Call for Papers on the Practical and Theoretical Measures for the Implementation of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities” (papers to be submitted by July 17, 2011), available at <[www2.ohchr.org/SPdocs/CRPD/Call\\_for\\_papers\\_art12.doc](http://www2.ohchr.org/SPdocs/CRPD/Call_for_papers_art12.doc)> (last visited March 1, 2013).
172. Kayess and French argue that uncritical assertions of the social model lie behind the IDC positions on decision-making capacity: “Ultimately, the CRPD has been most influenced by an uncritical, populist, understanding of the social model of disability. At times this understanding approaches a radical social constructionist view of disability, in which impairment has no underlying reality. While the central tenet of the social model – disability as social oppression – has not been superseded, it has been heavily nuanced and qualified by the last decade of critical disability studies, which has re-emphasised the realities of impairment as a dimension of the ontological and phenomenological experience of disability. If there is truly to be a shift to a coherent new disability rights paradigm in international law, it will be important that CRPD interpretation and implementation efforts penetrate beyond populist social model ideas to a more sophisticated understanding of impairment and disability in its social context.” See *supra* note 34, at 34.
173. Some jurisdictions’ supported decision-making mechanisms have attracted significant attention (for instance, B.C.’s regime under the *Representation Agreement Act*, *supra* note 150 (not a comprehensive alternative to guardianship laws, but rather a mechanism for individual appointment of a support person), and Sweden’s regime of the “god-man”; see the *World Report on Disability*, *supra* note 13, at 138 (Box 5.1) (a form of ombudsperson assigned to offer persons with psychosocial disabilities a variety of supports). The arguments of the IDC for absolute displacement of guardianship or substitute decision-making went beyond any existing model. See “Abolishing Mental Health Laws to Comply with the CRPD,” *supra* note 121, at 160–166, esp. 161.
174. Terry Carney observes, on the subject of evaluating options for reforming guardianship laws on the model of supported decision-making: “these are ultimately *research* questions which need to be settled in light of *evidence* about what is and is not helpful in the lived lives of people with impaired functional capacity, and with due regard to the hard lessons of past policies which demonstrate that policies often have unintended (and sometimes surprisingly disappointing) outcomes compared to those expected.” (“Guardianship, ‘Social’ Citizenship and Theorizing Substitute Decision-Making Law,” *supra* note 130, at 14.) My point is that such research should also attend to the perspectives of those likely to be subject to, or vulnerable to, the laws under scrutiny.
175. See, e.g., C. Mackenzie and N. Stoljar, eds., *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford: Oxford University Press, 2000) [hereinafter *Relational Autonomy*]; J. Downie and J. Llewellyn, eds., *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver: UBC Press, 2011). See also Susan Stefan’s groundbreaking analysis of the power dimensions of incompetency determinations, “Silencing the Different Voice: Competence, Feminist Theory, and Law,” *University of Miami Law Review* 47, no. 3 (1993): 763–815.
176. See, e.g., C. McLeod and S. Sherwin, “Relational Autonomy, Self-Trust, and Health Care for Patients who are Oppressed,” in *Relational Autonomy*, *id.*, at 259–279.
177. I take this list of “philosophy’s most cherished conceptions” from L. Carlson and E. F. Kittay, “Introduction: Rethinking Philosophical Assumptions in Light of Cognitive Disability,” in L. Carlson and E. F. Kittay, *Cognitive Disability and Its Challenge to Moral Philosophy* (Oxford: Wiley-Blackwell, 2010): 1–26.
178. See *Mental Health Act 2011: A Review*, *supra* note 80, at 246.
179. See also Janet Lord’s discussion of the democratic deficit in global health governance (at and beyond the WHO), and the prospects of the CRPD’s redressing this in some measure, in “Global Health Governance,” *supra* note 4, at 575–576.
180. See S. M. Rothman et al., “Health Advocacy Organizations and the Pharmaceutical Industry: An Analysis of Disclosure Practices,” *American Journal of Public Health* 101, no. 4 (2011): 602–609.
181. An account of recent implementation activities is given in the report “Status of the Convention,” *supra* note 171.
182. See *id.* at paras. 23–24 for discussion of the activities of the Inter-Agency Support Group for the Convention on the Rights of Persons with Disabilities, and paras. 22–63 for a broader discussion of inter-agency activity as well as cooperation with states and civil society groups aimed at CRPD implementation. The document notes in particular that the WHO / World Bank *World Report on Disability*, *supra* note 13, “has been developed with the full participation of persons with disabilities and their organizations, and will help raise awareness of the rights of persons with disabilities” (para. 54).
183. See “Status of the Convention” *supra* note 171, at paras. 15–20.
184. Examples include the UN Partnership on the Rights of Persons with Disabilities (UNPRPD) (sponsored by the WHO and five other UN agencies): see UN Development Programme, Press Release: “New United Nations Fund to Boost Action on Disability Rights,” December 8, 2011, available at <<http://www.bing.com/search?q=UN%20Development%20Programme%2c%20Press%20Release:%20e2%80%9cNew%20United%20Nations%20Fund%20to%20Boost%20Action%20on%20Disability%20Rights%e2%80%9d%20&FORM=LEMBLB&PC=MALC&QS=n>> (last visited February 4, 2013); the Disability Rights Fund <[www.disabilityrightsfund.org/](http://www.disabilityrightsfund.org/)> and Australia’s AusAID <[www.ausaid.gov.au/](http://www.ausaid.gov.au/)> (both last visited February 4, 2013).
185. See “Status of the Convention,” *supra* note 171, at paras. 64–70. Also see “Multi-stakeholder partnerships,” at paras. 71–75.
186. The cooperative capacity-building efforts of the Mental Disability Advocacy Centre are described at <<http://mdac.info/en/what-we-do/capacity-building>> (last visited February 4, 2013). Another striking example is Disabled Persons International’s engagement in consultations with persons with disabilities and their representative organizations in Tunisia, in March 2011, in order to prepare a shadow report in the face of that nation’s significant political instability during that

period. Ultimately DPI prepared two shadow reports: *available at* <<http://www.internationaldisabilityalliance.org/en/crpd-reports-0>> (last visited February 4, 2013). On the role of the UN agency UNFPA (the United Nations Population Fund) in facilitating capacity-building among DPOs in Syria in December 2010, see “Status of the Convention,” *supra* note 171, at para. 62. Further UN efforts to build capacity among DPOs are described in the same document at paras. 55-63.

187. *World Report on Disability*, *supra* note 13, at 138 (Box 5.1); K. Guernsey et al., *Convention on the Rights of Persons with Disabilities: Its Implementation and Relevance for the World Bank*, Social Protection Discussion Paper No 0712 (The World Bank, June 2007), *available at* <<http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/Disability-DP/0712.pdf>> (last visited February 4, 2013). The latter report states (at 12-13):

Whilst Article 12 does not explicitly prohibit guardianship laws, it is anticipated that many States Parties will move away from traditional guardianship approaches, and/or utilize such procedures only in rare circumstances where an individual is in need of extensive or ‘one hundred percent support.’ It is therefore reasonable to expect that a number of client countries will need assistance in engaging in legislative reform initiatives to effect these changes, as well as assistance in developing programmes and policies to implement the obligation to provide supports to those requiring assistance to exercise their legal capacity.

188. A rich example of such work is Shari McDaid and Sarah Delaney’s “A Social Approach to Decision-Making Capacity,”

*supra* note 157. In “Abolishing Mental Health Laws to Comply with the CRPD,” *supra* note 121, at 160-166, Tina Minkowitz discusses ongoing research into innovative supportive policies and practices, including an Indian study focused on traditional healing centres and the exploratory work of the U.K.-initiated Hearing Voices network, Intervoice (The International Community for Hearing Voices, *available at* <[www.intervoiceonline.org/](http://www.intervoiceonline.org/)> [last visited February 4, 2013]). Also see the results of a broad-based consultation of persons with psychosocial disabilities concerning their opinions about and experiences of violation of CRPD rights, in N. Drew et al., “Human Rights Violations of People with Mental and Psychosocial Disabilities: An Unresolved Global Crisis,” *The Lancet* 378, no. 9803 (2011): 1664-1675. The article describes the WHO’s QualityRights Project, which involves standardized assessment of human rights compliance in mental health facilities and social care homes.

189. See V. Topp et al., *Lacking Insight – Involuntary Patient Experience of the Victorian Mental Health Review Board* (The Mental Health Legal Centre Inc., October 2008), *available at* <[www.communitylaw.org.au/mhlc/cb\\_pages/li\\_contents.php](http://www.communitylaw.org.au/mhlc/cb_pages/li_contents.php)> (last visited February 4, 2013).
190. The challenges raised by this imperative to the CRPD’s status-based framework of rights and obligations are discussed in B. Ribet, “Emergent Disability and the Limits of Equality: A Critical Reading of the UN Convention on the Rights of Persons with Disabilities,” *Yale Human Rights and Development Law Journal* 14, no. 1 (2011): 155-203, at 191-193.