

# The Implementation of the Convention on the Rights of Persons with Disabilities: More Than Just Another Reform of Psychiatry

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## Abstract

The social model of disability—which is grounded in the lived realities of disabled people, as well as their activism, research, and theoretical work—has enabled a historic turn in the understanding of disability. This model also facilitates the transition to the rights-based approach that is at the core of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). However, the social model of disability does not straightforwardly translate to the lives of people who end up being detained and forcibly treated in psychiatric facilities. This paper examines the implications of the lack of an equivalent theoretical framework to counteract the hegemony of the biomedical model of “mental illness” and to underpin and guide the implementation of the CRPD for people with psychiatric diagnoses. Critically engaging with some recent attempts to make the CRPD provisions integral to psychiatry, we expose fundamental contradictions inherent in such projects. Our discussion seeks to extend the task of implementation of the CRPD beyond reforming psychiatry, suggesting a much broader agenda for change. We argue for the indispensability of first-person knowledge in developing and owning this agenda and point to the dangers of merely remaking former treatment objects into objects of human rights.

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## Introduction

The implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) for “persons with psychosocial disabilities” or people currently undergoing psychiatric treatment appears to be the most controversially discussed aspect of this international treaty. While the debates regarding the rights of people with physical and sensory impairments progress toward improving laws, policies, and practices, the decision-making processes regarding persons with psychiatric diagnoses continue to regress and still remain very much in the pre-CRPD era: the very possibility of equal rights being achieved in the case of this particular group is being called into question. We are well aware that the implementation process of the CRPD is generally slow and partially also retrograde, and it is certainly not our aim to compete with any other marginalized or oppressed group. But we would like to point out the levels of resistance and also sabotage of the recognition of fundamental rights and freedoms of people with psychosocial disabilities, including the explicit calls to revise the CRPD and exclude us from its provisions.<sup>1</sup> This is the climate in which the efforts to implement the CRPD for people with psychiatric diagnoses is taking place.

Even though significant progress has been achieved in some countries’ legislation (such as Peru’s abolition of guardianship on the basis of disability in 2018), and despite a few available alternatives to psychiatric treatment, so far no country in the world has effective measures in place that fully protect people deemed mad, mentally distressed, or psychiatrically disordered from detention and forced medical treatment.<sup>2</sup> Moreover, the legitimacy and sense of such potential laws and policies is being questioned and often simply declared utopian. The argumentation employed to justify such views commonly mistakes detention and forced interventions for care and the right to health. In our “Open Letter to WPA [World Psychiatric Association]”—signed by several international organizations of mental health service users, psychiatric survivors, and people with psychosocial disabilities—we extensively engaged with those views.<sup>3</sup> In this special

section, we see the opportunity to leave that kind of debate behind and take the analysis forward, beyond the question of whether psychiatrically diagnosed people should have equal human rights just like anybody else. The adoption of the CRPD gives a clear and legally binding answer to that question. However, it opens up another, more urgent and rather complex question of how this can be achieved. In this contribution, we critically examine some of the current clinician-led initiatives to adopt a human rights framework in psychiatry and more generally explore why the biomedical model of mental illness is incompatible with the human rights-based approach. Our analysis is informed by our respective experiences of being subjected to coercion and forced psychiatric treatment, by many years of activism in the Western European and international user/survivor movement, and by our research and theoretical work. Based on this background and spirited by the way in which the social model of disability arose, we advocate for the place of our distinctive, collective knowledge in the long-term project of making the CRPD provisions a reality for our people.

First, we analyze certain contradictions and structural obstacles to integrating CRPD provisions into current psychiatric systems. Second, we discuss some less explored avenues of research, theory, and practice as a means to secure and advance the rights and knowledge of people deemed mad or mentally disordered.

### *A note on language*

Writing a note on language without elucidating the concepts behind the terms we use, their origins, and their implications is almost impossible. An additional difficulty here relates to the very subject of this paper because the power to name (and consequently treat) is central to psychiatrization. Taking that power back in a collective and liberating act of re-naming and self-identification has always been at the heart of the political organizing of (former) mental patients. But our movements are diverse, and the terms we choose need to be seen in their historical, political, and other contexts. Common in the Global North are the notions of “survivors of

psychiatry,” “mental health service users,” “clients,” and “consumers,” and we agree with Mary O’Hagan’s observation that “[t]here isn’t even a word for patients that doesn’t put us in relationship to the system that dominates us.”<sup>3</sup> This is not the case with the concept of psychosocial disability, which emerged later and which is strongly connected to the CRPD. While there is no unity about this concept in the West and Global North, the notion of psychosocial disability is being embraced by movements in the Global South that seek to move away from “mental health” toward social inclusion in much broader terms.<sup>5</sup> This development in less psychiatrized parts of the world opens up new avenues for both theory and action and is highly relevant for the implementation of the CRPD. However, in this paper we focus on the recent psychiatric co-optation of the human rights discourse that we are encountering in our region, Western Europe.

Given the variety of ways in which people choose (or refuse) to identify themselves, we know that the terms we are familiar with will not resonate with everybody. Aspiring to a world in which madness and distress will be understood as part of humanity rather than attributed to certain groups of people only, we deliberately try to move away from defining and labeling. In our struggle to find the right words, we opt for descriptions, such as “people with psychiatric diagnoses,” “people with psychiatric experience,” and “people deemed mad or mentally disordered.” But with the term “our people,” we wish to express connection and solidarity with anyone who has undergone or is undergoing forced psychiatric treatment. We use these words while fully aware of our many differences and multiple layers of discrimination that psychiatric experience intersects with due to racist, capitalist, and other hegemonic structures in our lives. The expression is not intended to assimilate or neutralize our unequal exposure to these structures and this oppression.

### Can there be such a thing as “human” psychiatry?

The CRPD embodies no less than a demand for a

fundamental reconsideration of psychiatric treatment as a conventional societal response to human crisis. At the heart of that demand is the recognition of the legal capacity of people whose right to make their own decisions has been traditionally denied on the grounds of psychiatric diagnoses. It is clear that such a fundamental revision cannot occur via legislation only and that changes envisioned by the CRPD require decisive and synchronized action on many levels. The implementation of the CRPD touches on the history of psychiatry as a discipline and challenges its designated social role. Part of the psychiatric establishment across the globe lobbies for the maintenance of that role and acts as a gatekeeper and opponent to the changes that the CRPD demands. At the same time, there is a growing number of calls and initiatives from less prominent professional representatives to revise psychiatric practice and bring it into harmony with the provisions of the CRPD. Leaving aside the presumably good will of this new edition of “progressive” psychiatry and various services providing housing, sheltered work, or even guardianship for the “mentally ill,” we maintain that the task of implementing the CRPD cannot be carried out solely by these professions. The CRPD does not demand a different psychiatry but rather an entirely different approach to madness and distress. The attempts we see being made by psychiatry to take a lead and appropriate the agenda for change run the risk of turning the whole long-term objective into just another psychiatric reform. We have already witnessed the mainstreaming of recovery and “upscaling” of mutual support practiced in our communities via peer specialist workforces within psychiatric services.<sup>6</sup> These developments demonstrate what can happen to progressive and emancipatory concepts once they enter the psychiatric terrain—which is based on very different premises. Detached from their origins, depoliticized, and employed as mere techniques, these novelties have ultimately renewed and strengthened existing mental health systems rather than bringing any substantial changes to their coercive or potentially coercive nature. We therefore wish to highlight the dangers involved in psychiatry adopting a human rights agenda and

becoming the lead “implementer” of the CRPD. Such a scenario would fortify the role of psychiatry that the CRPD seeks to challenge. The belief that CRPD provisions can simply be “adopted” in clinical practice lays the pathway to another *déjà vu*, as described by long-term survivor activist Matthias Seibt: “Everything has to improve. But nothing is allowed to change.”<sup>7</sup>

As an example, by taking a closer look at the “Berlin Manifesto for a Human Psychiatry,” recently initiated by a critical psychiatrist, we can see how psychiatry cannot just be remade into a human rights-based enterprise.<sup>8</sup> The first principle laid down in this document, signed by many organizations and individuals, including a number of service users, states:

*A humane psychiatry in accordance with the UN-CRPD guarantees the right of users/consumers/survivors to decide for themselves which type of psychiatric and psychosocial support services they want to use and how to do so. In crisis situations, if and when it is more difficult to determine the person's own preferences, intensive individual support must be offered. Supported decision-making also helps to avoid coercive measures.*

Leaving aside the expectation that persons experiencing a psychosocial crisis would know about and be able to avail of “types of support,” we first need to point out the extremely limited and clearly defined spectrum of available “choices” out there. These “choices” are almost all biomedically framed. The right to *choose to refuse* any or all of them is not mentioned. Moreover, the call for coercive measures to be “avoided” rather than abolished obviously takes coercion for granted. The manifesto further outlines principles of transparency, participation, economic security, and inclusion in individual social networks as if psychiatry were not operating as part of the system of social control with a clear assignment and role to fulfill within that system. These kinds of contradictions are inherent in any attempt to change psychiatry within its own realm.

From the establishment of psychiatric treatment in the form of institutions in the 18th century to the present day, which is characterized by the

introduction of community treatment orders, what remains unchanged is this discipline’s mandate to maintain social order. In distinction to other forms of incarceration such as prison, the target of psychiatric forced treatment is people who have not committed crimes but are seen as potentially dangerous to themselves and to others. So far, all initiatives to bring psychiatric practice into harmony with the CRPD operate on that same unchanged ground. So the obvious question is how psychiatry can safeguard the human rights of its targeted subjects while its task remains precisely to control and preventively deprive them from exercising those rights.

Two other German psychiatrists engage specifically with these questions; they envision a future in which psychiatry no longer has the function of social control and offer a revised concept of mental health services that would then provide “support only.”<sup>9</sup> We appreciate the efforts of these authors to explore the concrete implications of such a fundamental revision of psychiatry’s social contract for the day-to-day practice of services, and, most of all, we value their determination to work in non-coercive ways.<sup>10</sup> However, we need to problematize the rather naive view that the abilities and skills to provide pure “support” can spontaneously emerge in psychiatric services by virtue of abolishing forced treatment, as the authors suggest:

*The task for health care professionals is to change to support only, based at the same time on the extent of the disability and on the will and the preferences of the person concerned.*<sup>11</sup>

There is no doubt that the elimination of coercion opens up new prospects for interpersonal interaction of every kind, but “respect for will and preferences” is much more a necessary precondition for any such interaction rather than its sole content. This principle marks the beginning and provides ground to any helping relationship but cannot by itself sufficiently define support. Furthermore, we have serious reservations that mental health services based on a biomedical approach can simply switch to providing comprehensive and ample re-

sponses to the range of human crises. Despite their struggle to use a different language, these authors remain faithful to psychiatric diagnoses as a framework to understand psychosocial crises, which they basically approach as impairment:

*Depending on the extent of the disability, this may be informal support and counselling in minor impairments or wide-ranging and intensive support in severe impairments.*<sup>12</sup>

As previously mentioned, our analysis is not meant to underestimate or devalue the attempts of psychiatrists to rethink their practice and work according to human rights standards. What we want to point out are the contradictions built into the aim of implementing the CRPD via its translation into clinical practice. In our view, the CRPD came about not as a demand to change psychiatry but rather as a clear call to change policies, practices, and mind sets that create psychiatry. As Theresia Degener, former chair of the CRPD Committee puts it, “Like any other human rights treaty, the CRPD is a visionary law designed to transform society into a more just society.”<sup>13</sup> However, contrary to the social model of disability, there is no equivalent theoretical framework to underpin and guide such transformation of responses to madness and distress. When we say equivalent, we do not necessarily mean the content of the social model; above all, we refer to its knowledge base grounded in experiences of disabled people themselves. This does not mean that the social model of disability operates as a magic bullet able to make people with physical and sensory impairments be heard and taken seriously, let alone instantly secure their full human rights. But at least it exists as a powerful tool, as a commonly known, easy-to-understand reference point to be employed in that struggle. In her comprehensive analysis of multilayered effects of ableism, the UN Special Rapporteur on the rights of persons with disabilities observes how

*[t]he claims of persons with disabilities to have their rights recognized are often dismissed and the underlying power imbalance invalidates their lived experiences. Their narratives are considered to be*

*subjective and ill-suited to informing objective decision-making and thus are not given the space to be genuinely weighed or to challenge ableism.*<sup>14</sup>

In the case of psychiatrized people, the situation is somewhat different, and that is not only because we are traditionally feared as irrational and dangerous. The fact that our collective first-person knowledge has not yet amounted to our own model or theory but remains subject to expert interpretations makes us continue to seek better explanations of our own lives and leaves us without a self-articulated framework to understand and communicate our social realities beyond our individual stories. We will come back later to the far-reaching implications of this kind of blank space.

Before going further, we need to raise one more issue. At the time of writing this paper, the “Berlin Manifesto for a Human Psychiatry” tallied over 7,500 signatures.<sup>15</sup> What concerns us is the popularity that such initiatives quickly gain and their ability to obscure the issues at stake and mobilize people toward investing in another, improved version of the same. The distrust in a human version of psychiatry, shared by many survivors of forced treatment, is not just a matter of gaining back trust in services, as some psychiatrists suggest.<sup>16</sup> The oxymoron that the very project of humanizing psychiatry constitutes is well articulated in Frank Blankenship’s comment on this manifesto:

*If it weren’t for inhumane psychiatry there would be no need for humane psychiatry. Problem. When inhumane psychiatry has marginalized and disenfranchised, one might say, subhumanized and decitizenized, a segment of the population, humane psychiatry is going to bring it back into the fold again? Let me say that I have serious doubts about the matter. Once inhumane psychiatry targeted a population, humane psychiatry is still targeting them but in a different way.*<sup>17</sup>

This paper gives us the opportunity to explain why survivor advocates like ourselves cannot join alliances with critical psychiatrists, nor subscribe to this type of shared agenda for change. Our further concern is the nature of such alliances and their

impact on our movement, as described by UK survivor-activist Peter Campbell:

*One aspect of the problem is that we have lost control of agendas through working with other groups who are more powerful than us, are more organised and have more urgent agendas than ours. There are underlying difficulties in being involved in work that is wrapped up in the seductive notions of common concerns or partnerships when we are the conspicuously less powerful partner, when others are always issuing the invitations and we are always the new arrivals at the party.<sup>18</sup>*

Campbell's analysis from almost 20 years ago regarding user/survivor action on biomedical psychiatry is still very current:

*There are dangers in gathering around a flag that someone else has planted, just because it flies quite proudly and has colours similar to ours. But if we have doubts, the answer is not to stand colour-less but to raise our own flag with our own true colours and fight on alongside. The current initiative on biomedical psychiatry deserves a survivor-response and in the course of it, perhaps a second flag.<sup>19</sup>*

In the remainder of this paper, we explore what stands in the way of raising this second flag and also suggest some colors for it.

### Who creates and owns the agenda for change?

There are no easily implementable answers to the CRPD's demand for a radically different way of treating madness and distress in our societies. At the same time, many small-scale answers can be found in the variety of ways people treat one another and one another's crises outside of organized "mental health care" systems. Sustainable and self-organized, community-based practices are especially present in places where colonial Western psychiatry has not (yet) achieved its profitable mission of filling "treatment gaps."<sup>20</sup> Many of us who have been through madness and extreme states of mind have found ways to understand and integrate these experiences and live free of psychiatry and pharmacological interventions to our full poten-

tials. The problem with collective knowledge gained through those first-hand experiences is that it is not recognized and explored in its own terms, as a distinctive rather than just an auxiliary epistemic source. Australian scholar Fleur Beaupert terms this phenomenon a "medico-legal incapacitation of expressions, opinions and epistemologies of users and survivors" and highlights the connections between mental health legislation and the suppression of knowledge of people deemed mad or psychiatrically disordered.<sup>21</sup> So when addressing our general absence from places where decisions about our lives are being made, it is important not to just focus on the symbolic violence of our epistemic exclusion but to also consider how its roots lie in the *material* violence legalized by mental health acts around the world. Those acts not only constrain our thinking abilities by virtue of forced drugging but also physically limit our freedom of movement and communication through forced detention. This means that we are continuously and systematically being denied the very possibilities of joining forces and constituting ourselves as a stakeholder capable of developing positions and having a say in policies that directly affect us. Beaupert argues that

*[t]he medico-legal discourse of mental health laws, by consecrating this symbolic violence, operates to manipulate and nullify individual ways of knowing and being, and to radically diminish opportunities for the epistemologies of users and survivors to exert influence on societal systems and structures. Constructions of people with psychosocial disability as lacking capacity and "insight" are central to these processes of dehumanisation.<sup>22</sup>*

This situation creates a chronically vacant space, leads to token representation, and makes it easy for other stakeholders to speak for us and often also to make our cause their own. Our capacity to think and act for ourselves is being recognized at the most on an individual level, but it always proves extremely hard to constitute and especially to preserve our autonomous grassroots organizations and pursue our own priorities for action. Paradoxically, with the CRPD now legally corroborating the long-standing claims of our movement and making the human rights of psychiatrically treated people part

of official agendas, it seems to have become even more difficult to justify the need for us to organize ourselves separately to defend our rights and articulate our own interests. It almost seems as if our goals were apparently achieved with the adoption of the CRPD and the task of implementation is now back in the hands of more “competent” and more powerful players. In their analysis of how structures of “social responsibility” are being created, survivor-authors Anne Wilson and Peter Beresford point to the mechanisms of exclusion inherent in the making of those structures:

*By speaking for or acting on behalf of those deemed mentally ill, they (“the socially responsible”) also contribute to, and perpetuate notions of the “dependency,” “passivity” and “incompetence” of people with a mental illness diagnosis; irrespective of whether or not this is their intention.<sup>23</sup>*

Even when distant and apparently opposed to each other, what both psychiatric and human rights discourse have in common is the clear dominance of expert knowledge. However different from each other, both approaches rest on an assumption of “an active ‘we’ who are the solution and a passive ‘them’ who are the problem.”<sup>24</sup> Beresford describes this deep-rooted, unquestioned division as common to lay approaches as well:

*People still frequently talk and write about “the mentally ill” as though they were a distant separate group of people very different from the rest of “us.” Discussion is still often framed in terms of what can “we” do about “them.”<sup>25</sup>*

The substantial involvement of people with disabilities themselves, including people with psychosocial disabilities and survivor-activists, in the making and monitoring of the CRPD has clearly disrupted the traditional making of policy and legislation and demonstrated how things can be done differently. Implementing the CRPD cannot be owned narrowly and requires doing away with these deeply seated divisions. We understand the implementation process as a widely shared undertaking that is about what we can all do for us all. The task of turning the CRPD into reality for people deemed mad brings

us to no less than a profound a question as how to approach madness in a radically different way. Central to that different way is the shift from treating madness and distress toward treating circumstances and conditions that create madness and distress. In the next section, we share some thoughts on what is needed in order to enable this shift.

### From treating madness toward intervening in a mad world

As mentioned earlier, one crucial distinction between the implementation of the CRPD for people with physical and sensory impairments, on one side, and people with psychiatric diagnoses, on the other, is the fact that the latter lacks an equivalent to the social model of disability. This model, grounded in political activism, research, and theory work by disabled people themselves marked a historic turn in understanding disability.<sup>26</sup> The CRPD exemplifies one of its far-reaching impacts. We do agree with Degener’s view that unlike the social model, the human rights model is “a tool to implement the CRPD.”<sup>27</sup> But when she states that “most states parties to the CRPD are far from comprehending this new model of disability and are still stuck with the medical model of disability,” it should be added that in the case of understanding madness and distress, there is no established model at all to counter the biomedical model of “mental illness” and facilitate a move toward a human rights model.<sup>28</sup> This is where the divergence from the situation of people with physical and sensory impairments becomes the most visible: while the social model of disability has enabled a shift from the medical focus toward an understanding of societal conditions that create disablement, there is no comparable model or theory to overpower the individualizing and pathologizing biomedical concept of “mental illness.”

Despite its indisputable achievements, the social model of disability is subject to ongoing criticism, including from the Mad movement in the Global North.<sup>29</sup> We do agree that this model is not easily applicable to experiences of psychiatrization because of the contested nature of the underly-

ing “impairment” in “mental illness” and, even more importantly, because people deemed mad experience not only discrimination but also “criminalization by civil commitment.”<sup>30</sup> However, we do not perceive the lack of attention to these issues as weaknesses of the social model of disability. That model never claimed to be an “all-encompassing framework” to capture all our diverse experiences.<sup>31</sup> Rather than engaging in criticism that treats this model as a field for academic battle and intellectual exercise, we approach it as unique example of theory building that is grounded in collective first-person knowledge and also developed from “within.” The lack of such a model of madness has tangible implications and cannot go unnoticed. In our view, this absence is one of the main obstacles to realizing the provisions of the CRPD for our people. Even though the overall approach, the language of the CRPD, and the related documents issued by the Committee on the Rights of Persons with Disabilities pose significant challenges and disrupt the biomedical model, this legal treaty itself cannot substitute for the obvious lack of an alternative model to guide the implementation process and replace current practices. The biomedical model that depoliticizes, silences, and ultimately controls rather than listens and helpfully responds to the madness and distress of our lives cannot straightforwardly transform itself into an approach based on human rights. Nothing less than the whole new paradigm to understanding psychosocial crisis would be missing this way.

There are surely many different paths to safeguard the human rights of people deemed mad, and it is not our intention to discourage any of them. However, we need to make it clear that the biomedical model overshadows and powerfully inhibits these much-needed changes. Even though this framework has not been able to offer any sound explanation for the “impairment” that it purports to treat, it remains the ruling explanatory model that is allowed to continue despite an entire body of evidence that contests not only its effectiveness but also its very premises. With the rise of global initiatives in psychiatry and the conquering of new markets for psychiatric drug treatment, the medical

model is even being coated in a human rights-based approach: in places where people deemed mad or possessed by evil spirits are being exposed to high degrees of physical violence both in their communities and in traditional healing centers, psychiatric treatment presents itself as a more humane alternative.<sup>32</sup> What effectively upholds this model is neither its scientific nor ethical value, but the whole machinery behind it, made up of the pharmaceutical industry and other interests involved. These are forces that stand in the way of implementing the CRPD for people with psychiatric diagnoses. We have as yet no answer as to how we could confront those forces beyond the act of at least naming them. Exposing the powerful corporate interests behind the medical model is something that still happens too rarely in the debates on the implementation of the CRPD. Such an unequal division of power makes any reasoned argument with the proponents of the biomedical model an endless endeavor ending with the same outcome and forces us to seek alternative modes of action, as wisely suggested by Buckminster Fuller: “You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete.”<sup>33</sup>

In our view, the creation of such a model of madness and distress, grounded in our own experiences and knowledge gained through those experiences, is a central task for user/survivor communities and movements of people with psychosocial disabilities in the post-CRPD era. This does not mean that we are unaware of alternative approaches and theories developed by different authors and schools. Many of those come close to our lives and offer viable explanations of human crises. But in all these third-person approaches, we remain the objects of interest, the ones to be explained and ultimately othered through the very process of knowledge production, with its clearly assigned roles. People going through madness and distress have been extensively studied. What we need are no new spectacular discoveries about our lives but rather a complete epistemic shift in knowledge making: the time has come for *us* to pose the questions and invert the microscope.<sup>34</sup>



In his extensive work with first-person narratives of physical illnesses, Canadian sociologist Arthur Frank argues for a shift “from needing more knowledge to needing values that allow us to take a stand with respect to what we know.”<sup>35</sup> But even though the CRPD offers a clear value framework and demands that we take a stand, the post-CRPD era is characterized by a bloom of inquiries into the personal impact of coercive measures as if there were new discoveries to make on this topic.<sup>36</sup> The explanations of the incidence of coercive measures focus primarily on insufficient staffing levels in psychiatric services.<sup>37</sup> This new wave of investigations, predominantly conducted within the fields of mental health and psychiatric research, is usually directed toward minimizing the occurrence of certain coercive practices such as restraint and seclusion. These practices are certainly the most tangible expressions of psychiatric violence, but they are in fact all being employed in order to provide standard “health care,” which equals the administration of psychiatric drugs. That (forced) medicalization of social realities remains a main feature of current mental “health” provision is rarely being problematized. Broadening the definition of what constitutes human crises and figuring out ways to de-medicalize our lives and mobilize largely unexplored community potential to provide different responses do not seem to be urgent topics of interest. Organizing true and sustainable support systems for people undergoing psychosocial crises could greatly benefit from practices that are already in place but continue to be marginalized and ignored. Many survivor groups and communities of people with psychosocial disabilities have their own knowledge-making traditions that approach a breakdown as a potential breakthrough and know how to “carry each other” in times of crises.<sup>38</sup> Activists in the Global South are developing new knowledge through their community inclusion programs.<sup>39</sup> They are using the CRPD as a framework to build a new paradigm through their practical work on the ground. People deemed mad have also been documenting their knowledge for centuries, but we are not collectively owning

and advancing that knowledge. Learning from us, from our sources, and from our movements cannot occur if we are approached as “one-dimensional objects of a knowing gaze.”<sup>40</sup>

The social model of disability as a model grounded in the lived realities of disabled people has demonstrated an enormous emancipatory potential. An equivalent achievement by psychiatrized people could finally relocate madness and distress from their conventional placement within our bodies and minds and back into the structures in our lives where these phenomena emerge from. And most importantly, such change of focus would enable us to *jointly* start targeting and improving those structures instead of letting ourselves be targeted and intervened on. Such a comprehensive shift is quite different from the simple recognition of the social determinants of mental health. Beresford, who has done considerable research and theoretical work toward developing a social model of madness and distress, reminds us of this important distinction:

*There is no question that there has been an awareness of social issues in some mental health disciplines and professions for some time. But this has tended to focus on social issues as factors in the creation of mental health problems. It has tended still to take mental illness or disorder as a given—to accept the idea—rather than attempting to reconceptualise mental health within a social framework.<sup>41</sup>*

If our societies aim to one day achieve a fundamentally different understanding of madness and distress and above all fully transform conventional approaches that seek to isolate and medicate these human experiences, first-person knowledge cannot just be inserted as an additional or optional resource, as is now the case. The time has come for collective and diverse survivor knowledge to become a central resource, and this hour is long overdue. If treated with due respect and with very different methodologies than the present ones, our own accumulated knowledge holds the key emancipatory potential to facilitate the paradigm shift that is urgently needed to implement the CRPD. As

envisioned by Canadian survivor Irit Shimrat, this could lead us to “a society brave and moral enough to eschew the whole paradigm of mental health and illness, replacing it with a creation of real community, and real help.”<sup>32</sup>

## Concluding remarks

It was a year ago that we drafted an “Open Letter to WPA” in reaction to the debate on the CRPD published in its official journal.<sup>43</sup> We ended that letter with an explicit call for psychiatrists willing to take a *new* departure to speak up. The year that followed has seen a few initiatives that are far from the impression that the WPA establishment left in its journal. However, taking a closer look at those initiatives has made us understand that it takes much more than a decision and a will to “break from the old, controlling paradigm.”<sup>44</sup> With due respect for all the efforts to move in this direction, we hope to have demonstrated why the implementation of the CRPD is not just a matter of another reform of psychiatry. We also hope to spur many more opportunities for extensive and *diverse* first-person knowledge to take the lead on the way to CRPD provisions becoming a reality for people currently undergoing psychiatric treatment.

## References

1. P. S. Appelbaum, “Saving the UN Convention on the Rights of Persons with Disabilities – from itself,” *World Psychiatry: Official Journal of the World Psychiatric Association* 18/1 (2019), pp. 1–2.
2. For a thorough analysis of this development, see T. Minkowitz, *Peruvian legal capacity reform: Celebration and analysis* (2018). Available at <https://www.madinamerica.com/2018/10/peruvian-legal-capacity-reform-celebration-and-analysis>; see also International Network Toward Alternatives and Recovery. Available at <http://intar.org>.
3. European Network of (Ex-) Users and Survivors of Psychiatry, *Open letter to WPA* (2019). Available at <http://enusp.org/wp-content/uploads/2019/03/Open-Letter-to-WPA-1.pdf>.
4. M. O’Hagan, *Madness made me* (Wellington: Open Box, 2014), p. 160.
5. P. Beresford, M. Nettle, and R. Perring, *Towards a social model of madness and distress? Exploring what service users say* (York: Joseph Rowntree Foundation, 2010); J. Russo and D. Shulkes, “What we talk about when we talk about disability: Making sense of debates in the European user/survivor movement,” in H. Spandler, J. Anderson, and B. Sapey (eds), *Madness, distress and the politics of disablement* (Bristol: Policy Press, 2015) pp. 27–41; P. Beresford, R. Perring, M. Nettle, and J. Wallcraft, *From mental illness to a social model of madness and distress* (London: Shaping Our Lives, 2016); see Pan African Network of People with Psychosocial Disabilities. Available at <https://www.facebook.com/pg/PANPPD/about/>; Transforming Communities for Inclusion – Asia Pacific. Available at <http://www.tci-asia.org/>; Latin American Network of Psychosocial Diversity. Available at <http://www.rompiendolaetiqueta.com/declaration>.
6. M. Morrow, “Recovery: Progressive paradigm or neoliberal smokescreen,” in B. A. Lefrançois, G. Reaume, and R. J. Menzies (eds), *Mad matters: A critical reader in Canadian mad studies* (Toronto: Canadian Scholars’ Press, 2013), pp. 323–333; B. McWade, “Recovery-as-policy as a form of neoliberal state-making,” *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice* 5/3 (2016), pp. 62–81; D. Penney and L. Prescott, “The cooptation of survivor knowledge: The danger of substituted values and voice,” in J. Russo and A. Sweeney (eds), *Searching for a rose garden: Challenging psychiatry, fostering mad studies* (Monmouth: PCCS Books, 2016), pp. 35–45; D. Penney and P. Stastny, *Peer specialists in the mental health workforce: A critical reassessment* (2019). Available at <https://www.madinamerica.com/2019/10/peer-specialists-mental-health-workforce>.
7. M. Seibt, “Selbsthilfe Psychiatrie-Erfahrener – ein Ladenhüter,” *BPE Rundbrief* 1 (2018), p. 5.
8. *Berlin manifesto for a humane psychiatry* (2019). Available at <http://berliner-manifest.de/english>.
9. M. Zinkler and S. von Peter, “End coercion in mental health services: Toward a system based on support only,” *Laws* 8/3 (2019).
10. M. Zinkler, “Germany without coercive treatment in psychiatry: A 15 month real world experience,” *Laws* 5/15 (2016); M. Zinkler and J. M. Kousse mou, “Menschenrechte in der Psychiatrie – Wege und Hindernisse zu einem umfassenden Gewaltverzicht,” *Recht und Psychiatrie* 32/3 (2014), pp. 142–147; M. Zinkler and J. M. Kousse mou, “Kann auf Zwangsmedikation in der klinischen Praxis verzichtet werden? – Pro,” *Psychiatrische Praxis* 43/4 (2016), pp. 187–188.
11. Zinkler and von Peter (2019, see note 9), p. 3.
12. Ibid.
13. T. Degener, “A human rights model of disability,” in P. Blanck and E. Flynn (eds), *Routledge handbook of disability law and human rights* (New York: Routledge 2014), pp. 31–50.
14. C. Devandas-Aguilar, *Rights of persons with disabilities: Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc. A/HRC/43/41 (2020), para. 15.
15. See the petition at <https://www.change.org/p/>

gesellschaft-politik-in-deutschland-manifest-einer-menschenw%C3%BCrdigen-psychiatrie.

16. Zinkler and von Peter (see note 9).
17. See Comments section at <https://www.madinamerica.com/2019/10/berlin-manifesto-humane-psychiatriy-released/>.
18. P. Campbell, *System survivors: Is there anything we can do?* (2001). Available at <http://www.critpsynet.freeuk.com/PeterCampbell.htm>.
19. Ibid.
20. See, for example, the Seher Community Mental Health and Inclusion Program in Pune, India, at <http://bapustrust.com/seher-inclusion-program/>.
21. F. Beaupert, "Freedom of opinion and expression: From the perspective of psychosocial disability and madness," *Laws* 7/1 (2018).
22. Ibid., p. 26 (emphasis in original).
23. A. Wilson and P. Beresford, "Surviving an abusive system," in H. Payne and B. Littlechild (eds), *Ethical practice and the abuse of power in social responsibility: Leave no stone unturned* (London: Jessica Kingsley, 1999), pp. 145–174.
24. P. Beresford, *A straight-talking introduction to being a mental health service user* (Ross-on-Wye: PCCS Books, 2010), p. 30.
25. Ibid., pp. 29–30.
26. M. Oliver, *The politics of disablement* (Basingstoke: Macmillan, 1990).
27. Degener (see note 13).
28. Ibid.
29. E. M. Nabbali, "A 'mad' critique of the social model of disability," *International Journal of Diversity in Organizations, Communities and Nations* 9/4 (2009), pp. 1–12.
30. Beresford et al. (2010, see note 5); Russo and Shulkes (see note 5); Beresford et al. (2016, see note 5); Nabbali (see note 29), p. 4.
31. M. Oliver, "The social model of disability: Thirty years on," *Disability and Society* 28/7 (2013), pp. 1024–1026.
32. Mental Disability Advocacy Center and Mental Health Uganda, "*They don't consider me as a person*": *Mental health and human rights in Ugandan communities* (2014). Available at [http://www.mdac.org/sites/mdac.info/files/mental\\_health\\_human\\_rights\\_in\\_ugandan\\_communities.pdf](http://www.mdac.org/sites/mdac.info/files/mental_health_human_rights_in_ugandan_communities.pdf).
33. S. Sieden (ed), *A fuller view: Buckminster Fuller's vision of hope and abundance for all* (Studio City: Divine Arts Media, 2011), p. 358.
34. L. Costa, *Mad studies: What it is and why you should care* (2014). Available at <https://madstudies2014.wordpress.com/2014/10/15/mad-studies-what-it-is-and-why-you-should-care-2/>.
35. A. W. Frank, "The standpoint of storyteller," *Qualitative Health Research* 10/3 (2000), p. 363.
36. P. Cusak, S. McAndrew, J. Duxbury, et al., "An integrative review exploring the physical and psychological harm inherent in using restraint in mental health inpatient settings," *International Journal of Mental Health Nursing* 27/3 (2018), pp. 1162–1176.
37. M. McKeown, G. Thomson, A. Scholes, et al., "Catching your tail and firefighting: The impact of staffing levels on restraint minimization efforts," *Journal of Psychiatric Mental Health Nursing* 26/5–6 (2019), pp. 131–141.
38. R. A. Maglajlic, "Co-creating the ways we carry each other: Reflections on being an ally and a double agent," in J. Russo and A. Sweeney (eds), *Searching for a rose garden, challenging psychiatry, fostering mad studies* (Monmouth: PCCS Books, 2016), pp. 210–217.
39. See the community work of Bapu Trust at <http://bapustrust.com/vision-and-mission>.
40. A. W. Frank, "Not whether but how: Considerations on the ethics of telling patients' stories," *Hastings Center Report* 49/6 (2019), p. 13.
41. Beresford (2010, see note 24).
42. I. Shimrat, "The tragic farce of 'community mental health care,'" in B. A. Lefrançois, G. Reaume, and R. J. Menzies (eds), *Mad matters: A critical reader in Canadian mad studies* (Toronto: Canadian Scholars' Press, 2013), pp. 144–157.
43. European Network of (Ex-) Users and Survivors of Psychiatry (2019, see note 3).
44. P. Bartlett, "Will and preferences in the overall CRPD project," *World Psychiatry: Official Journal of the World Psychiatric Association* 18/1 (2019), pp. 48–50.

