Turning the tables:
The imperative to reframe the debate towards full and effective participation and inclusion of persons with psycho-social disabilities

Excerpt from "Galway-Trieste" conversations [1]

Contents

[1] Different organizations and individuals were involved in these sustained dialogues including, TCI Asia Pacific, WNUSP, ENUSP, PANUSP, USP Kenya, INTAR, MHE, a Latin American emerging network, and others.

Introduction

In parallel of celebrating *the 10 years of the adoption of the Convention on the Rights of Persons with Disabilities* (CRPD) an informal community of individuals and organizations of persons with psycho-social disabilities and allies have taken stock of the progress and challenges globally with regards *full and effective participation and inclusion of persons with psycho-social disabilities.*

Over a period of 18 months, through continuous discussion and several key moments (*INTAR global conference, November 2016, Pune – NUI summer school, June 2017- Galway – International Conference "The right to have (whole) life", November 2017, Trieste among others*) an overall picture emerged urging both the movement of persons with psychosocial disabilities and their allies to review their strategies and define a way forward. The present document aims at providing a synthesis of some of those conversations. *Considering that this report has been written in the first quarter 2018, there is a post script at the end to include some key elements and events that have taken place since.*

The starting point was the acknowledgement that the global momentum on mental health generates great opportunities but also significant threats depending on the extent to which global, regional and national policy responses will be framed by the CRPD. There has been a sense of race against times are governments are taking actions to tackle "the mental health crisis".

Indeed, the last years has witnessed contradictory trends with among others:

- The jurisprudence of the CRPD committee and groundbreaking report of the special rapporteur on the right to health in one hand and the pursuit of negotiation of the Oviedo protocol intrinsically at odd with the CRPD in the other hand
- Greater public awareness of mental health issues but also political spin of public opinion around the link mental health and public safety in the global North
- Greater awareness about the CRPD overall but also challenge by some mental health professionals and academics that CRPD jurisprudence threatens to undermine critical rights for persons with psychosocial disabilities.
- Few countries developed legal innovation to reach compliance with CRPD while many others adopted mental health legislation that do not.
- Growing evidence of community-based support systems in resource poor settings as well as in other global contexts.

The differences between low, middle and high-income countries have also been source of debate and dialogue. In many high income and countries in transitions, the focus has been on reducing harm done by the widespread mental health system that is curtailing human rights. This is a challenging battle considering the imbalance of power between self-advocates and medical bodies as well as pressure of public opinion for social control. In lower income countries, the focus is on development of any possible system to support persons with psychosocial disabilities. While emerging groups of persons with psychosocial disabilities focus on community inclusion, the trend among policy makers often leans toward development of mental health care systems inspired by higher income countries. The lack of a shift of the paradigm is an issue everywhere.

For instance, in Asia,with the convergence of the global mental health agenda, the momentum created by CRPD, SDGs, and the Incheon strategy, states take action *sourcing their policies in the typical mental health sourcebook and international experts which are most focused on psychiatry rather than social inclusion.* This leads to adoption of mental health legislations which might not provide for better services and support for inclusion of persons with psychosocial disabilities and may curtail their rights. The situation in Japan, China and Korea with heavy institutionalization and violation of human rights gives an indication of the danger of health care focused policies in contexts with growing fiscal capacities, but prone to favor social control.

Through the debates in different fora, emerged the evidence that *majority of mental health professionals even some of the most progressive (and by extension the public authorities they advise)will not part with the legal possibility of coercion, involuntary treatment, deprivation or restriction of legal capacity as last resort*. Indeed, the debate around mental health is rarely about how to guaranty the full recognition and exercise and enjoyment of all human rights but rather about the impossible framing in a human rights' approach of some human rights' restrictions deemed inevitable. The *almost unanimous resistance from Member States to include clear mention on the prohibition of forced treatment and confinement* in the otherwise very progressive 2017 resolution of the Human Rights Council on Mental Health and Human Rights is a good indicator of this state of play.

The *prevalent medical approach prevents stakeholders to focus on the diversity of barriers faced by persons with psychosocial disabilities* and equal diversity of responses needed across sectors. In turn, the lack of social and community-based support lead to crisis situation that appear to justify the perpetuation of coercive practices among others. The special rapporteur on health reportcalls *to confront the "global burden of obstacles" that has maintained the status quo in mental health*.

In addition, the *imbalance of powers between self-advocate and medical professional/decision makers lead to negotiation whose outcomewill never be CRPD compliant***.**As long as psychiatry is given a "gate keeping" role with regards to rights of persons with psychosocial disabilities, true change won't happen.

Reflecting on the CRPD shift of paradigm, this led to efforts spearheaded by Transforming Community for Inclusion-Asia (TCI-Asia) to push to fundamentally *reframe the debate, by exploring the change required across sectors, including prohibition of coercion, to ensure support full participation and inclusion of persons with psychosocial disabilities;* rather than focusing mostly on human rights violations linked with the mental healthcare systems. *Truly implementing the shift paradigm means that support to inclusion and participation of the person in its diversity becomes the center of policy debates rather than mental health and related care system.* As long as mental health care is at the centre, the burden of proof is on persons with psychosocial disabilities that have to demonstrate that they are "capable" to exercise their rights.

All the conversations and exchanges showed that there are for the movement, *common and different challenges leading to common and different priorities.* The present paper summarizes and elaborates on the discussion that have taken place around a few main topics:

- The global momentum with uncertain outcomes
- The imperative of reframing the debate towards full inclusion and participation
- Key factors to promote shift of paradigm
- Implication for the movement of persons with psychosocial disabilities

A global momentum with uncertain outcomes[2]

In recent years, we have seen formidable momentum building around mental health across the globe. Whether in UN processes or in major media outlets, mental health has come across as a major global priority. Many countries have reviewed or adopted mental health legislations and action plans, and there is plenty of debate on how to best include mental health related care and medicines in Universal Health Coverage. Nevertheless, different UN mechanisms such as the UN Committee on the Rights of Persons with Disabilities and the Office of the High Commissioner on Human Rights have pointed out the need to ensure that mental health systems embrace a human rights-based approach rooted in the CRPD in their interventions, calling to abolish all forms of coercion in mental health and the adequate provision of support to individuals.

The evolution of the UN narrative on mental health, disability and human rights

For too long discussions around the rights of persons with psychosocial disabilities within the United Nations system were reduced to the right to the highest attainable standard of physical and mental health. Even within the disability movement, persons with psychosocial disabilities were seen as persons that needed to be cured, protected and cared for. Therefore, as potential "patients" and "recipients" of mental health services, the main concern was ensuring their access to quality mental health services. Expanding and improving mental health services were deemed the best ways to respond to the needs of persons with psychosocial disabilities.

Mental health legislation was a central aspect of this narrative. The influential 2005 WHO Resource Book on Mental Health, Human Rights and Legislation, for example, considered that mental health legislation could improve rights and mental health standards for persons with psychosocial disabilities. However, despite its rights-based rhetoric, the evidence shows that mental health laws achieved the opposite, legitimizing coercion in health care by conferring clinical authority to mental health professionals to involuntarily detain and treat people.

The UN Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, represented a paradigm shift in relation to the rights of persons with psychosocial disabilities. The focus was no longer the right to health, but achieving the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. The CRPD does not question the existence of psychosocial disability, which is part of human diversity, but the existence of structures and practices that are contrary to the full enjoyment of rights. Moreover, moving away from medical and paternalistic approaches, the CRPD challenges coercion in mental health services, prohibiting any deprivation of liberty on the basis of disability and upholding a universal application of the right to free and informed consent. In doing so, the CRPD, with its binding obligations on States party, surpasses earlier 'soft law' standards, including the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles).

The CRPD is helping to create a new narrative at the United Nations on this matter. The Committee on the Rights of Persons with Disabilities (CRPD Committee) has been instrumental in this regard. The CRPD Committee has repeatedly stated that States parties should repeal provisions which allow for involuntary commitment and treatment of persons with disabilities in mental health institutions based on actual or perceived impairments. According to the CRPD Committee, involuntary commitment and treatment of persons with psychosocial disabilities contradicts the absolute ban on

[2] based on background paper for the dialogue in Galway NUI Summer school meeting, develop by Alberto Vasquez

deprivation of liberty on the basis of disability, the principle of free and informed consent in health care, the right to personal integrity, and the right to equal recognition before the law[3].

The Office of the High Commissioner for Human Rights (OHCHR) has supported the views of the CRPD Committee, calling for a human rights-based approach to mental health. In response to the Human Rights Council Resolution 32/18, the OHCHR has issued a comprehensive report on mental health and human rights, which recommends a number of policy shifts to put an end to involuntary treatment and institutionalization, and to create a legal and policy environment that is conducive to the realization of the human rights of persons with psychosocial disabilities.[4] The report stresses that persons with psychosocial disabilities – as well as other groups deemed as having a "mental health condition"– are still disproportionately exposed to human rights violations in the context of mental health services.

More recently, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Pūras, has issued a **groundbreaking report calling for a paradigm shift on mental health services "based on the recurrence of human rights violations in these settings".**[5] Notably, the report questions the "biomedical model" of psychiatry for contributing to the overexpansion of diagnostic categories and over-medicalization of people. This reductionist paradigm is seen as one of the causes of the exclusion, neglect, coercion and abuse of people with intellectual, cognitive and psychosocial disabilities, persons with autism and "those who deviate from prevailing cultural, social and political norms"[6]. The report also questions the "**biased use of evidence in mental health" to promote psychotropic medications and other biomedical psychiatric interventions**, as well as the existence of legal "exceptions" to normalize coercion in mental health practice. Pūras warns against further medicalization of global mental health, and calls to confront the **"global burden of obstacles"** that has maintained the *status quo* in mental health.

Complementarily, the UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, while urging States to **"do away with non-consensual psychiatric treatment**"[7], has focused her work on promoting access to support to enable persons with disabilities to fully participate in their communities[8]. Devandas reminded States that proving support to persons with disabilities is a human rights obligation, but also an essential condition to ensure that no one is left behind in the implementation of the 2030 Agenda for Sustainable Development. Devandas stressed **that persons with psychosocial disabilities can benefit significantly from community support services, *inter alia*, by supporting people experiencing severe emotional distress and preventing coercion in mental health services.** She has recommended that States and international stakeholders develop and implement support arrangements and services for persons with disabilities, including those with psychosocial disabilities, and to supportresearch and technical assistance for the provision of such services. The Special Rapporteur has also announced that she is working on a study on legal capacity and another on deprivation of liberty.

Other special procedures and agencies are progressively adapting their standards to the CRPD. The Working Group on Arbitrary Detention (WGAD), for example, has **upheld the absolute ban on deprivation of liberty based on disability in its Basic Principles and Guidelines** on Remedies and

[3] Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities - The right to liberty and security of persons with disabilities (Adopted at the CRPD 14th Session (17 August-4 September 2015)
[4] A/HRC/34/32.
[5] A/HRC/35/21.
[6] A/HRC/35/21, para. 8.
[7] http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16583
[8] A/HRC/34/58.

Procedures on the Right of Anyone Deprived of His or Her Liberty by Arrest or Detention to Bring Proceedings Before Court.[9]

Similarly, the World Health Organization (WHO) has launched the WHO Quality Rights initiative, which aims to promote access to good quality mental health and related services and respect for the rights of persons with disabilities, including those with psychosocial disabilities. As part of the **QualityRights Initiative, the WHO has developed a comprehensive package of training and guidance modules based on the CRPD** and other international human rights standards.[10] The WHO has also withdrawn from its webpage the 'Resource Book on Mental Health, Human Rights and Legislation', arguing that "it was drafted prior to the coming into force of the UN Convention on the Rights of Persons with Disabilities and is therefore not compliant with the latest human rights norms and standards"[11].

Building on the Special Rapporteurs' report mentioned earlier, the 2017 landmark Human Rights Council resolution on Mental Health and Human Rights acknowledges that the **Convention on the Rights of Persons with Disabilities laid the foundation for a paradigm shift in mental health**. It created the momentum for de-institutionalization and the identification of a model of care based on respect for human rights which, addresses the global burden of obstacles in mental health, provides effective mental health and community-based services and respects the enjoyment of legal capacity on equal basis with others. In addition, the resolution calls upon all UN members states to abandon all practices that fail to respect the rights, will and preferences of all persons, on an equal basis, and that lead to power imbalances, stigma and discrimination in mental health settings. The resolution also urges **States to develop community-based, people-centered services and supports that do not lead to over-medicalization and inappropriate treatments, that fail to respect autonomy**, will and preferences of all persons. Yet, the Resolution **fails to include clear mention on the prohibition of forced treatment and confinement, due to almost unanimous resistance from Member States**.

While all these developments are extremely positive, **some treaty bodies and special procedures are still showing resistance to the new legal framework**. This is the case of the Human Rights Committee (CCPR), the Subcommittee on Prevention of Torture (SPT), and the former Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan Méndez. According to them, the existence of a disability cannot "in itself" justify a deprivation of liberty, but involuntary commitment and treatment would be lawful if it is necessary and proportionate, for the purpose of protecting the individual from serious harm or preventing injury to others[12]. Moreover, the need to transform psychiatry and mental health services has not been addressed at all.

The Global Mental Health Agenda

Mental health has become a recurrent theme of the global development and health agenda. The 2030 Agenda for Sustainable Development – an ambitious set of goals and targets that all 191 UN Member States have committed to achieve by 2030 – affirms that universal health coverage and access to quality health care are necessary to promote mental health and well-being.[13] Prevention and treatment of non-communicable diseases, and promotion of mental health and wellbeing, is one of its specific goals.[14] The Human Rights Council – the principal human rights political body of the UN – also adopted on 1 July 2016 a resolution on mental health and human rights, aiming to

[9] A/HRC/30/37.
[10] http://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/
[11] *See* http://www.who.int/mental_health/policy/legislation/en/
[12] CCPR/C/GC/35, para. 19.
[13] A/RES/70/1, para. 26.
[14] Goal 3.4.

promote the realization of the human rights and fundamental freedoms of "persons with mental health conditions or psychosocial disabilities, including persons using mental health and community services".[15] The Third Committee of the UN General Assembly discussed early this year, the adoption of a resolution to promote mental health and well-being in the framework of the 2030 Agenda. Most of these developments were substantiated on the increasing medical literature around the "global burden of disease attributable to mental, neurological and substance use disorders**".**[16]

The Movement for Global Mental Health has led the global advocacy towards positioning access to mental health care as a global priority. This network of individuals and organizations—mostly health care providers, activists, policymakers and researchers—aim to expand mental health care worldwide. In its initial call for action, published in 2007 in the first Lancet series on global mental health, the Movement called the global health community, governments, donors, multilateral agencies, and other mental health stakeholders, such as professional bodies and consumer groups, to scale up the coverage of services for mental disorders in all countries, but especially in low-income and middle-income countries.[17]

The Movement has gradually become a very influential stakeholder shaping global discussions around mental health.[18] The Movement has been very effective in convening the support of different leaders on the fields of health and development, including Amartya Sen, former UN Secretary General Ban Ki-moon, former WHO Director-General Margaret Chan, the World Psychiatric Association, and other influential mental health professionals.

Moreover, **the Movement had a significant impact in the development of two key WHO policies: the 2008 Mental Health Gap Action Programme (mhGAP) and the Comprehensive Mental Health Action Plan 2013–2020.** The former proposes to "scale up services for mental, neurological and substance use disorders for countries, especially with low- and middle-income"; while the latter aims to "promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders". Both documents share a biomedical approach to mental health and a priority focus on expanding mental health services. Moreover, the Mental Health Action Plan further calls for the adoption of mental health legislation to "codify the key principles, values and objectives of policy for mental health". The World Bank has recently endorsed these efforts building the case for investing in mental health services.[19]

There is a strong convergence between the global mental health movement and trends in development with push for greater use of public private partnerships and innovative financing, with the involvement of pharmaceutical companies.

While the Movement and its allies claim to be both "rights-based" and "evidence-based", many authors have pointed out the shortfalls and contradictions of its proposal, including its allegiance to

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[15] A/HRC/RES/32/18.

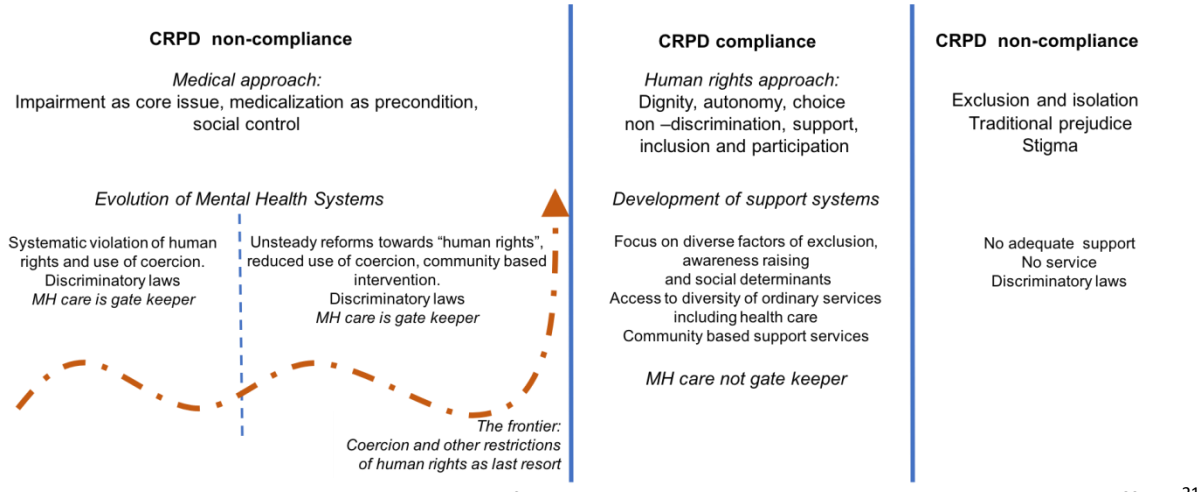
[16] See, for example,Whiteford, Harvey A et al., *Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010*, The Lancet , Volume 382 , Issue 9904 , 1575 - 1586; Patel, Vikram et al., *Addressing the burden of mental, neurological, and substance use disorders: key messages from Disease Control Priorities*, *3rd edition,* The Lancet , Volume 387 , Issue 10028 , 1672 – 1685.

[17] http://www.globalmentalhealth.org/about/aims/call-action

[18] http://www.globalmentalhealth.org/about/history

[19] Seth Mnookin, *Out of the shadows: making mental health a global development priority*, World Bank Group and WHO (2016): http://documents.worldbank.org/curated/en/270131468187759113/pdf/105052-WP-PUBLIC-wb-background-paper.pdf

a biomedical model of psychiatry and its proximity with the pharmaceutical industry.[20] As Dainius Pūras has noted, there is growing evidence that psychotropic drugs are not as effective as previously thought, that they produce harmful side effects and, in the case of antidepressants, specifically for



mild and moderate depression, the benefit experienced can be attributed to a placebo effect.[21] Furthermore, as previously discussed, the expansion of mental health services, strongly dominated by psychiatrists who believe access to treatment is the central issue, also raises concerns about the extent of human rights abuses, and specifically the use of coercion.

The imperative to reframe the debate towards full inclusion and participation

Exchanges that took place in Galway and Trieste among other places, have shown that there is a widespread acknowledgement of human rights violations in mental health institutions and the growing recognition of the importance of community-based solutions, the importance of recovery and inclusion. However, the medical profession and governments are unlikely to part with the legal possibility of coercion, involuntary treatment, deprivation or restriction of legal capacity as last resort to prevent the individual from serious harm or preventing injury to others. As a result, the recovery approach may be co-opted by mental health systems that do practice coercion.

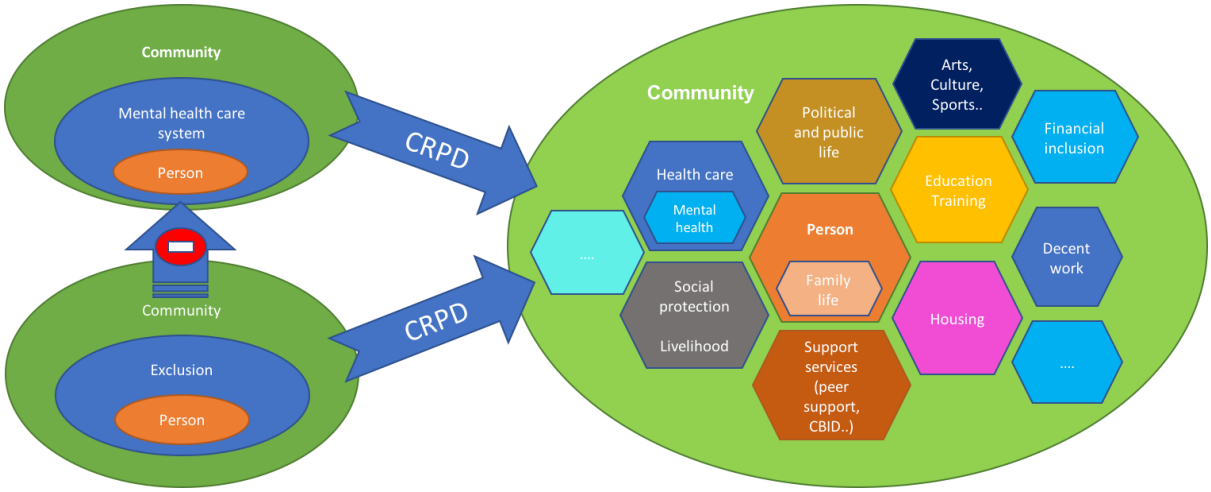
As mentioned, the almost unanimous resistance from Member States to include clear mention on the prohibition of forced treatment and confinement in the otherwise very progressive 2017 resolution of the Human Rights Council on mental health and human rights is a good indicator of the state of play.

It is clear that with regards to persons with psychosocial disabilities unlike for some others the shift of paradigm away from the medical approach did not take place. The starting point is not "what needs to be done to ensure that persons with psychosocial disabilities enjoy their right to live independently and being included in the community" but rather what can be done to the person so that she/he fit in its environment. There is to a certain extent a negation of social determinants of health and of the impact of social barriers on exclusion. The issue of compliance with behavioral norms is central and is transfer from community social control to medical control, back to

[20] See China Mills, Decolonizing Global Mental Health: The Psychiatrization of the Majority World (Routledge, 2014); David Ingleby, *How 'evidence-based' is the Movement for Global Mental Health?*, Disability and the Global South, 2014, Vol.1, No. 2, 203-226.
[21] A/HRC/35/216, para. 19.

community control. The medical system becomes the gate keeper to recognition, exercise and enjoyment of many rights (medical expertise in relation to legal capacity, civil commitment, ability to stand trial…).

The debates are dominated by the situation of crises rather than far more widespread issues of isolation, withdrawal, victimization… Too little attention is paid to the barriers in society, the driving factors behind psychosocial and mental health issues such as violence, poverty, economic stress, the lack of community support to concerned individuals and their families. It is fair to acknowledge that the shift of paradigm implies more complexity and co-ordination across sectors and that medicalization is in many ways a policy shortcut, leading to poor outcomes at significant economic costs.

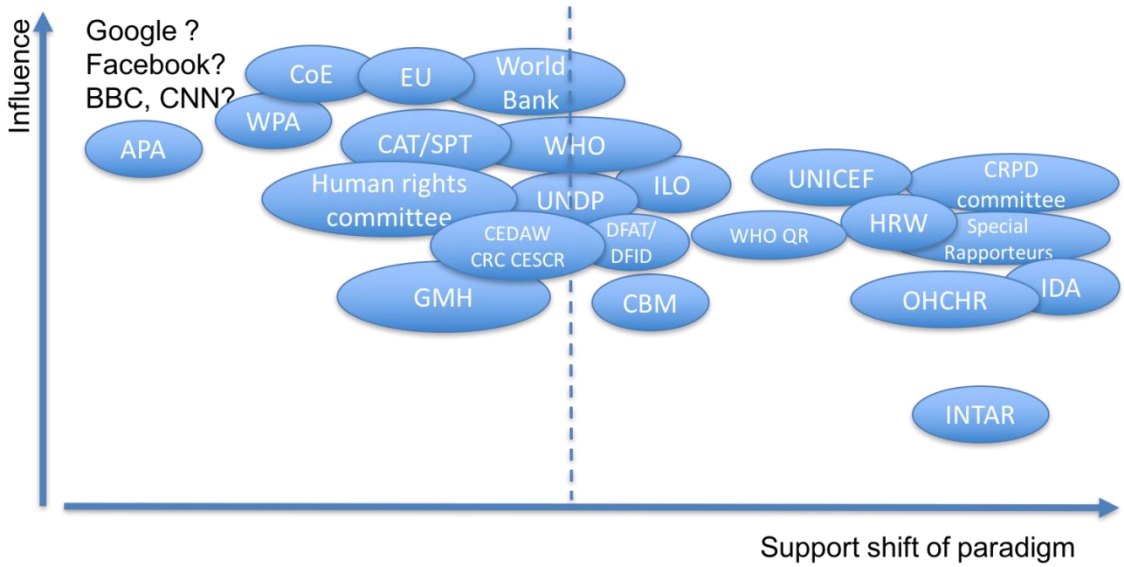


Importantly, the shift of paradigm demands a holistic approach away from the biomedical model but does not imply that health and mental health care are unimportant. They are essential but no more than, and not as precondition to, access to social protection, education, housing, employment, safety and adequate standard of living.

As mentioned, the diversity of situation between countries with or without developed mental health systems, often related to the lower or higher country income status contributed to complicate advocacy. Along the lines of the debate on inclusive education, the emerging consensus is that whatever the starting point, the destination is the same: development of contextually relevant, CRPD compliant support systems for full participation and inclusion.

Mapping key international organizations

In the Trieste workshop, the group mapped different international organizations based on their perceived level of influence and perceived support to the shift of paradigm.



Some of the key factors to promote the shift of paradigm

As mentioned, during the several meetings held to lead to this report, avenues to promote shift of paradigm have been discussed. Several have been considered which mutually reinforce each other:

- Strengthening and disseminating evidence
- Strengthening and consolidating a progressive normative framework
- Shifting public opinion
- Reaching out to a broader range of stakeholder

3.1 Strengthening and disseminating evidence on CRPD compliant social innovations and community-based interventions

Around the world there is a growing number of good practices in CRPD compliant service delivery as demonstrated in the 2016 INTAR conference in Pune, but there is a lack of systematization in national policy leading to poor scaling up/out.

Many effective approaches and services are not known yet outside of the core groups dealing with those issues. There is a lack of documentation and dissemination of those practices in authoritative academic and mainstream influential media.

An important element is to reframe the work done as viable option on their own rather than complementary alternative to a main mental health system.

Some key elements identified were the need for:

- Documenting and systematizing good practices, including in the global south
- Documenting and systematizing what does not work – challenging the evidence of traditional models and interventions
- Developing and disseminating relevant and strategic research questions that could inspire and frame academia's work
- Complementing by testimony of people (evidence is not always enough)
- Building widely accessible repository of practices and literature reviews

In terms of transforming research and evidence for advocacy, several elements were also identified:

- Close alliances between academia, NGOs and DPOs
- Strategic definition of messages based on available evidence
- More collaboration and sharing -but taking into account the politics of knowledge creation and sharing

There was an emphasis on importance of building coalition and alliances with universities, there was also caution in ensuring that academicians do not set the agenda and frame the knowledge on their own acknowledging that there is today a big gap between academia and DPOs.

Above and beyond, all those **evidence needs to contribute to a new "source book" with policy options.** This implies an in-depth work of sorting and organizing existing practices.

3.2 Strengthening and consolidating a progressive normative framework

As mentioned, there are discrepancies in the development of the normative framework with resistance to CRPD shift of paradigm in some institutions: Subcommittee for Prevention of Torture, CAT and Human Rights Committee brings significant challenges as they do not even recognize the problem of discrepancies.

While the CRPD Committee has achieved a lot, it does not have the same weight and direct normative power compared to the HRC, for instance. In addition, change in the CRPD committee can weaken its stance. It is important to remain vigilant to committee related elections and work to ensure that it upheld and deepen its jurisprudence.

At regional level, the negotiation of the Oviedo protocol within the Council of Europe raises significant concerns and illustrates the post CRPD conservative backlash.

There are still challenges on the best way forward. There is a need to try to engage in constructive dialogue with open Committee members, especially Subcommittee for Prevention of Torture, CAT and Human Rights Committee and other law makers to engage to present the issues and the evidence. In parallel, it is important to continue to raise issues related to persons with psychosocial disabilities, through increased participation in review processes.

3.3 Shifting public opinion

Once again there is a contrasted picture. On the one hand, there is growing public awareness and discussion about mental health, which is breaking down stigma - including public figures who are sharing their experience. Personal stories of persons with psychosocial disabilities can have an impact on raising awareness and changing attitudes.

On the other hand, there is still a powerful and negative association with mental health with violence, mass shootings which politicians tend to spin for short term electoral gains. The mental health framing of the gun control debates in the US or the aftermath of catastrophe like the 2015 suicide/crash of the German wings pilot in France are symptomatic of such trends.

In western, risk averse societies, a subtle and uncomfortable parallel in public opinion seems to have emerged, in the recent years, between risks related to persons with psychosocial disabilities and terrorism. The same use of the fear factors by politicians and media, the same anxiety of unpredictability and of the enemy within, as well as the same acceptance of violation of human rights of some for the protection of most.

In parallel, in global south notably in some African countries, superstition and belief such as those linking mental health issues to witchcraft can also lead to very harmful practices.

There is also however little awareness of public opinion of the cost and poor outcomes of typical mental health policies or rather there is often a "voluntary ignorance" of the situation of people with psychosocial disabilities.

Shifting public opinion will require communication and media tactic that the movement has not yet been able to afford. Experience of MAD in America in debunking false evidence and making accessible existing knowledge for change is a good source of inspiration. However, it does not reach a broader audience.

There was exchange on the fact that the movement need to move in a pro-active mode, rather than reactive mode, with needs to gather evidence and data, create material for public opinion and media, influencing middle class public opinion and combine direct lobbying, with awareness of families, religious leaders, and training of judges.

3.4 Reaching out to stakeholders

From all the exchanges, it appeared very strongly that in most regions, there is a need for a broader canvas than "mental health recovery", and "inclusion" seems to be that canvas, for example, by tackling work, livelihood and housing. This implies engaging with the cross-disability movement, the women's rights movement, the human rights movement, etc. which would be more empowering than focusing all energy only on dialogue/battle with mental health professionals. In Indonesia, for example, to address judicial concerns within the constitutional court, help was successfully sought from diverse groups.

3.4.1 The cross-disability movement

The CRPD created opportunity for collaboration and engagement with cross disability movement. At the global level, there has been great progress with support from disability movement especially from IDA. At the national level, it varies greatly as there are countries where there is:

- solid alliance with strong support by the cross-disability movement to the agenda of persons with psychosocial disabilities
- the cross-disability movement does not support actively but does not oppose advocacy of persons with psychosocial disabilities
- some countries where some members of the disability movement oppose based on prejudice and medical approach

It was agreed that engagement with the cross-disability movement is critical to create a new center of gravity of state action to support persons with psychosocial disabilities, more in line with CRPD and less centered on mental health intervention.

3.4.2 Intersectionality

There is obviously many intersectionality related issues connection mental health with disabilities, discrimination against women, Sexual Orientation and Gender Identity (SOGI) and race or ethnicity.

Once again CRPD provides a useful framework, but there are some persistent issues. The CRPD committee is the body that has the most intersectional approach to stigma and discrimination – this is necessary when looking at LGBTQITA+ for instance. However, same sex desire still seen as mental

illness in many countries, despite international standards. There is a lack of resource material regarding LGBTQITA+, disabilities and mental health – both conceptual and practical at country level.

There is a lack of investment in capacity building of DPOs and HR activists around knowledge of CRPD and intersections with Convention on Elimination of Racial Discrimination and other Treaty. For instance, alternatives evidenced as effective elsewhere (e.g. Open Dialogue) remains inaccessible and insensitive to the needs of communities marginalized along racial and ethnic lines. Shadow reports process are often non-consultative with marginalized communities and oblivious of some multiple discriminations.

This implies a need for further outreach to the diversity of gender equality movement and other social movements; as well as linking with marginalized constituencies within persons with psychosocial disabilities, such as indigenous peoples.

3.4.3 Human rights organizations

Considering the positive work of Human Rights Watch globally and interaction with human rights groups at country level, further engagement seems to be a relevant investment. Such group can bring light and credibility in denunciation of human rights violation and generate adhesion within their supporters. It can create a greater awareness of the true cost and little outcomes of mental health policies.

Some issues were raised on the "control" over the message and the leadership of advocacy. Many would be well intentioned and call for improvement of psychiatric institutions, rather than closing them, contributing to pseudo reform. Moreover, it is unlikely that they would embrace a broad inclusive agenda, but rather focus on civil and political rights violations.

At the national level, it was highlighted the need to engage with National Human Rights Institutions and ombudsman offices as they can open space for participation and new avenue for advocacy.

3.4.4 Development processes and organizations

As the mental health momentum expand development organizations are getting involved such as WB, ILO or OECD and others think tank such as ODI, often in relation to Universal Health Coverage. On the other hand, there is an interest of disability section of development organizations, to work with most marginalized groups, including persons with psychosocial disabilities. The issue is that often those organizations adopt the Progressive, yet non-CRPD compliant, approach of mental health.

Those organizations are critical as they command significant resources and have strong influence. It is therefore critical to engage. They might not be too sensitive to human rights discourse, but more to social and economic inclusion. They would be also users of policy guidelines developed based on innovative, tested, and effective CRPD compliant practices.

It is also important to engage with the disability movement on the SDG processes at the national, regional and global levels.

3.4.5 Mental health professionals

The discussions reflected a mixed picture both at national and global level. There are MH professional opening up to CRPD approach and inclusion, in some case leading innovative approaches. But there are also MH professional who stick to traditional psychiatry, impose their

views and occupy the policy space, blocking/crowding out self-advocates and innovators. There are also **actors rebranding usual MH practices with CRPD/recovery/inclusion language without much change in reality.**Those are particularly harmful as they lead to false reforms which prevent actual shift of paradigm by neutralizing opposition. Finally, there are MH professional who want to adopt the CRPD shift of paradigm to a "certain extent" (which ultimately is not shift of paradigm) as they cannot part with the idea that involuntary treatment in last resort is necessary, considering that full CRPD can deprive some people of their right to health.

There is also some difference between higher and lower income countries. The key issue is to find adequate entry point. From a global north / European perspective, it is very challenging because the "recovery" agenda have often been co-opted or hijacked. There is hesitation on the merit of engagement. In global south, it seems like there is not much need not talk to psychiatrists much because either they are not there or it may be very disempowering due to imbalance of power so far. However, there is also the importance to engage before the MH systems expand and gain even more power.Therefore, it's still important to speak to psychiatrists in general, to GMH, and not just to the progressive psychiatrists.

It was acknowledged that some advocacy approach alienates MH professionals who feel directly threatened and in return do not engage. The issue is that there are few platforms or forums where different actors in MH and psychosocial disability meet in constructive way. **The WHO "Quality Rights" training package provides an opportunity to build a progressive platform for dialogu**e.

It was also noted that while such engagement is important, it should mobilize most energy, as it is critical to engage with other actors in the human rights, intersectionality, development and disability streams.

Reflections on the movement of persons with psychosocial disabilities

Since the adoption of the CRPD, (which was in itself a great success with provision related to equal recognition before the law, liberty and security and person integrity, health…), the sum of activism has contributed to:

- Emergence of a global progressive normative framework.
- Greater CRPD understanding within the movement, more rights and inclusion perspective.
- New people and organizations from human rights or disability sector have been willing to engage.
- Strong leadership in some countries.
- Greater engagement with the cross-disability movement with regards to CRPD monitoring, legal harmonization.
- Engagement with UN processes has provided capacity building opportunities.

However, it was acknowledged that, paradoxically, the global movement of persons with psychosocial disabilities did not succeed to build on the CRPD momentum to consolidate and develop.

As mentioned earlier, there was also an acknowledgement of the need to develop a broader canvas, without weakening the initial agenda, to engage with disability, development, gender equality stakeholders and tackle issues such as social protection, housing, livelihood, access to services.

Many questions were open: Do we contest the extreme? Do we address GMH? Do we directly and right now, address places of power? Do we start at the end of "recovery"? Or, do we focus on Inclusion? In Norway, for example, there is little space to talk about "Inclusion". We need to address questions of "torture" over there, through court cases, lawyers, CAT, SPT, etc. addressing our issues on mental health and coercion within the scope of torture standards.

From the year-long conversations, emerged the agreement that **to be able to reframe the global momentum there is a need for a regeneration of the movement of persons with psychosocial disabilities, that would reflect common challenges, but also the diversity of contexts and priorities.**

The following section will tackle the discussion about the state of play of the movement and the way forward.

4.1 State of play of the movement

Intrinsic barriers faced by the constituency and the need for capacity development

There are different reasons for this evolution that are in many ways similar to the difficulties of any social movement. One of the key is the fact that the global movement of users and survivors of psychiatry, unlike other global disability groups such as blind people or deaf people has strong well-resourced national organizations only in very few countries, and is rather a network of individuals and groups.

The challenges face by the constituency include great marginalization and stigma, risk of increased discrimination when engaging publicly as self-advocate, legal issues with building the organization, still strong influence of medical professionals, lack of support that would enable more people to take part. There are issues around identities which undermine a consistent messaging and convergence: persons with psychosocial disabilities, people with mental health issues, mental health users, ex-patient, users and survivors of psychiatry… Those issues have rendered challenging the development of strong grass root national movements which in turn as limited the sustainable structuration of a global movement.

There was an emphasis on the fragility of the movement as in many countries where there is actually no real movement. In some countries, existing groups are co-opted in the frame of existing policies and services (users' organizations that are framed by service providers for instance) and they are not politicized in the sense of seeking change in power structure.

There was an overall agreement that much more need to be made in terms of capacity building. There was consensus that peer support is always important and appear as one way of both building movement while providing much needed support. In parallel, there is a need for moreCRPD training which would also seek link CRPD to local legislation as well as invest in practical approaches that demystify the medical model which many people have internalized.

Those training needs to be differentiated with a tailored way to approach group with CRPD:

- At grass root level: focus should be on key principles and provisions not the whole CRPD. Need an approach that resonate with grass roots.
- Training should also include national policy provision and help tackle key issues of daily life such as the real life how do we fight for housing, jobs, services that are needed? It should help creation of peer support groups among others.
- At national level, there is need to go deeper and provide skills related to legal harmonization and budget advocacy, how to use human rights institutions…

As for training, the importance of grass root was highlighted with movement that should ensure representation from the village level to the national level. There is a need to look at how other movements mobilize people and conduct outreach.

There was also emphasis on securing resources so that that key experts, trainers and mobilisers are getting paid for what they do within the movement but also for organizations outside the movement. If people secure income there would be also more available for advocacy and outreach, coaching mentoring. Investing also in provision of fellowship for emerging leaders could provide room for much needed time investment in movement building and advocacy.

Common and different challenges, common and different priorities

As mentioned earlier, the movement initially developed in higher income countries as a reaction to systematic violation of human rights and oppression by psychiatry and mental health systems which led to the development of users and survivors of psychiatry groups. This identity framed the focus and approach to CRPD negotiations with an advocacy focused on recognition of legal capacity, prohibition of coercion, involuntary treatment and confinement, in complement of the work with the caucus on the overall CRPD.

Groups in the global south face traditional stigma, exclusion in the community, poverty and lack of any support services, rather than widespread oppression from mental health systems, that do not exist nationally, but may have impact on the urban middle class. While at first, those groups were supportive of the "user survivor" agenda which helped them emerge and get a direction, many found out that while relevant and important, it was not matching priority and issues of the vast majority of their constituency. This led for a stronger focus on Article 19, community inclusion and livelihood, while of course preserving attention to issues of legal capacity and coercion. It also led to greater work with disability and development organizations and movements.

On the other hand, in European countries, exchange revealed a sense that there is little space to talk about "Inclusion" due to the omnipresent gate keeping role of mental health systems and related legal framework. Activists have the urgency to address of mental health, institutionalized and “legal” coercion questions, through court cases, lawyers, within the scope of torture standards through CAT, SPT, etc.

Such concern with the grip of the MH systems are also vivid in USA, Korea or other high-income countries such as Australia, much less in most low and middle income countries.

This inevitable emergence of diverse priorities linked to diverse contexts brought an additional level of complexity which rendered the steering mostly from the global level even more challenging. However, there was an emerging consensus a dual approach which would combine **reframing towards inclusion combined with sustained call for prohibition of coercion.**

The importance of the national and regional dynamic

As in other social movement, it is impossible even with substantial resources to support structuration of grass root movement from the global level. The emergence and development of TCI-Asia in recent years or the work of ENUSP in Europe among others has shown the importance of the regional level for supporting structuration and emergence of self-advocates organizations. In most countries, self-advocates are isolated and face great challenges in developing organizations. Membership in a regional organization provides a closer support and more culturally, economically and logistically relevant support.

During the Trieste workshop, the group tried to map and estimate the number of actual and potential activists in each region by level of commitment and advocacy/service related knowledge and skills. A diverse picture emerged. Some regions had less members, and some had more; some regions had grassroots participation while fewer in active, leadership role. Some were trained for advocacy, others were not; etc. Some regions had higher members in some countries, in others there was more even distribution, even though there weren't many leaders at the regional level. However, a striking feature of this activity was that, there were traces of a 'movement' in all the regions, stronger or weaker; nonetheless they were there. There were possibilities of building national, regional movements in all regions. It was also acknowledged that fundraising and operationalization work is easier at regional level than at global level.

Taking stock of the current situation, there was a sense that strengthening regions, which in turn can support and facilitate peer support between countries is critical. The regional platforms focus on capacity building of national groups, development of culturally and regionally relevant advocacy and approaches.

It was acknowledged that there are some strong regional and national voices, but there is little global coherence, while there is an urgency to tackle global momentum and issues. Questions emerged on:

- How can diverse groups collaborate together, and speak with a unified voice, acknowledging common challenges, but also diversity of issues and identity
- How do we take decisions together, and act together to have a global impact?

There was an emerging consensus that to tackle the global issues which impact regions and countries alike, it might be more viable, effective and respectful of diversity for some regional organisations to work as independent partners coming together on issues with synergized voices at a global level on a coalition rather than attempting to have a one global structure encompassing all.

4.2 The way forward

At international level, there was agreement to work on several blocks some of which have been addressed in Part 3 above.

1. Continue and consolidate works towards Human rights mechanisms:

    a. Treaty bodies
    b. UPR
    c. Special procedures
    d. OHCHR

2. Invest in framing inclusion of persons with psychosocial disabilities and the mental health momentum in SDGs
    a. Linked to HLPF, and strong linkage with SDGs discussion.
    b. Engage with UNDP, UNICEF, WB, etc.
    c. Invest in reaching out to the gender equality and women empowerment movement, SOGI focused organizations, development and human rights NGOs

3. Developing models, piloting social innovation, mapping, classifying, assess possible good practices. This could lead to sort of creation of quality label / accreditation and help create some benchmarks that would influence development processes.

4. Identify and develop a publicly available roaster of experts with and without lived experience that are supportive of the shift of paradigm and that we trust so that countries and development agencies would be guided in their search for technical assistance

Post script

Since the work on this report, important events of publications have taken place confirming the exchange summarized in this report.

- The call from the journal of world psychiatry association to ignore some CRPD standards or even amend the CRPD to which ENUSP responded with support from other groups.
- The Lancet commission on mental health and the ministerial global mental summit illustrate well the fact that, while GMH movement increasingly acknowledges social determinants and inclusion, it cannot abide by CRPD standards. The GMH movement even challenges the standards and validate interventions that originate and/or delivered by the mental health professions and system.
- The emergence of a Latin America network of persons with psycho social disabilities.
- The emergence of a new Pan African network of persons with psycho social disabilities.
- The evolution of TCI Asia to TCI Asia-Pacific and its Bali declaration
- The Campaign #WhatWENeed in response to the global MH summit and the mental health week.
- The Report of the Special Rapporteur (Disabilities) on "Deprivation of Liberty"

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