HANDOVER DIALOGUES

UN Special Rapporteur on the Right to Health

Notes from Dialogue

Global mental health and human rights: history and the need for change

Panellists:
China Mills, Senior Lecturer, City University of London
Julian Eaton, Mental Health Director, CBM Global Disability and Inclusion
Bhargavi Davar, Director, Transforming Communities for Inclusion, TCI
Alberto Vásquez Encalada, president of the Sociedad y Discapacidad – SODIS

Special Rapporteurs: Tlaleng Mofokeng (current) and Dainius Pūras (former)

Moderator:
Alexandre Cote, UNICEF Disability and social protection policy specialist

Organising partners: Transforming Communities for Inclusion (TCI), Human Rights Monitoring Institute, and the Human Rights Center at the University of Essex.

Introduction

Alexandre Cote spoke of the impact of the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, especially the shift from thinking of disability as a medical issue. For many people, this has resulted in greater inclusion and in recognition of environmental and social barriers that can exclude people with disabilities. However, this is not yet fully embraced in the field of mental health and persons with psychosocial disabilities.

Bhargavi Davar described TCI as a movement about the inclusion of persons with psychosocial disabilities, and not a 'mental health activist movement'. She emphasized this as a key difference, because typically, mental health activists are locked in a biomedical model, advocating for better services, better access to medications, and so on. While this can be important, and TCI acknowledges this need for psychosocial support, they seek something much more. In particular, their work is about inclusion of people who have different identities, neuro-diverse identities, or psychosocial disabilities. TCI advocates that the entry point for inclusion is not through 'mental health services' but through disability inclusion

within development. Different policies are needed to allow their inclusion in various generic and specific services and in the community at large: This has led to the "What We Need" campaign, where persons with psychosocial disabilities have expressed the need for work, housing, education, family, supportive communities, etc.

Alberto Vasquez spoke of the change that the CRPD brought about in international normative framework by explicitly including people with psychosocial disabilities, acknowledging their human rights and the discrimination they have historically experienced. This has helped move away from the very strong medical framing of psychosocial disabilities and question the power of the mental health system with its denial of legal capacity, institutionalization, and coercive practices. The CRPD reinforces the fundamental principle of the universality of human rights, and legitimises support paradigms to help people with disabilities claim their rights to make decision on equal basis with others. General Comment 1 on legal capacity challenges the legitimacy of detaining and treating people against their will. The CRPD Committee has called for an absolute ban on all forms of involuntary commitment to mental health facilities, as have the reports on the right to mental health by Dainius Pūras. But despite these important advances, there is still an 'impasse', as Dainius Pūras refers to it, in which support for medical models and coercion are considered necessary.

He referred to the conflicts between different mental health frameworks. The CRPD can be used by service providers to advocate for more mental health services, and the right to mental health framework has been used to advocate for mental health legislation. But both can result in rights failings, with, for example, about 120 countries that have standalone mental health laws that legitimize coercive practices, many of which have only been adopted recently. He said that although the rights of people with psychosocial disabilities have been included in mainstream disability frameworks and policies, there is clearly a contradiction in approaches, with mental health legislation on one side and disability legislation on the other.

There has been progress in some countries such as Peru or Costa Rica that adopted legislation that focuses on supported rather than substituted decision making paving the way towards CRPD compliance.

China Mills expanded further on this difficulty of the appeal to human rights being made by conflicting interests. She said global mental health can be hard to navigate because the push to scale up mental health services in low - and middle - income countries, as well as the critique of scaling up, often appeal to human rights. The Movement for Global Mental Health rightly pushes the right to health, but it can narrowly frame this as a right to treatment which for many has been harmful. Similar difficulties arise when global mental health is framed as a crisis, because while that has been a very successful way of getting political support for mental health, the concept of crisis or emergency is often used within psychiatry to justify coercive treatments.

In explaining her research over the past decade, she referred to tensions between global and local discourses, between complexity and pragmatism, and messiness versus simplicity (the latter never being helpful). She has observed that calls for evidence-based research implicitly favours pharmaceutical interventions, because they are better suited to randomized research design, even where psychosocial interventions are being recommended. All these different tensions or conflicts end up allowing pharmaceutical treatments in global mental health to dominate, because it often is the easiest course of action.

One of the risks of looking only through a service lens at global mental health is that it can miss ways of supporting people that already exist but which are not spoken about as mental health interventions. Another current global mental health issue is the framing of untreated mental disorder as an economic burden. Such a focus on the impact on economies overlooks how the economy damages mental health. It is an easy slide from saying mental illness is a burden to saying people with mental illness are a burden, and generally only

valuing people's lives through their market value. Rather, we need to understand burdens of disablement and sanism as systems of discrimination and oppression. This has been captured in the work of the mandate that argues the failure to realize the right to mental health doesn't rest with individuals, but in structural and political global burdens of obstacles.

Issues of power are central to any discussion of global mental health: who has the power to label, diagnose, or prescribe, and who has the power to set the agenda for a global movement?

Julian Eaton in discussing his work in international environments confirmed advances made as a result of the CRPD in mental health. But he questioned how those advances translate in people's lives, and in different countries. He welcomed the change in discourse around mental health over the past 20 years, in ways that has moved its acceptability within families, and within the media. And this is also a challenge to the traditional biomedical approach because talking about mental health, whether at work or in the pub, democratizes the topic and starts a shift in how societies think about these issues. COVID has spurred this on. And importantly, these discussions have focused on basic needs, equity, relationships, isolation, access to support, and not much at all about needing medication to sort out the problems. These are positive changes, aligning at country levels with the changes advocated for by CRPD. He also observed that until recently the human rights discussion in the context of mental health tended to have a narrow focus on human rights abuses or failings. It has only been lately in mental health that human rights has come to include social determinants, health systems, and interpretation of the CRPD.

He cautioned, as had other panel members, the flip side of human rights, when they are misused to support practices that in effect are counter to human rights. For example, when there is talk about working in the community, but the risk is the invasion of people's private lives and spaces which used to be outside of the medical gaze. However, meaningful participation is an antidote to approaches that could otherwise curtail human rights. He observed that the Global Mental Health Action Plan explicitly has human rights and participation as a central pillar. Another dilemma is that governments tend to focus on services, rather than determinants, because services are what they spend money on, and populations often demand more services, possibly to seek control of people who are more diverse and different.

The CRPD has been challenging for governments, especially because of its mechanisms for reporting. The psychosocial components have often been seen as separate from other disability issues, with some governments claiming they can't fulfil these rights.

There has been a range of responses amongst professional groups, with some, like the World Psychiatric Association finally committing to improve its policies on coercion, but at country levels, many professionals and their associations resist these changes. However, the WHO QualityRights work is having an impact in many countries now.

Dainius Pūras in response to these presentations commented that having recently moved his focus of work from the global to the regional, has found the latter is more complex. As a Special Rapporteur the role is to reflect international law and norms and advise states and societies on what they should do. But acting in the region, it is not easy to bring about the changes that a former rapporteur may have sought. He acknowledged this does not mean a country or region should maintain the status quo. He has observed the pressure on states to keep the status quo, with for example, international funding going into new or improved residential care institutions or psychiatric hospitals. He turned the lens around by seeing mental health as an outcome of human rights, in addition to it being a right of its own, explaining that the protection and promotion of universal human rights principles, and addressing inequities, violence, and discrimination is crucial to the mental health of everyone. Democracy and equality, and eliminating poverty, are necessary for

exercising the realization of the right to health and mental health.

His work now focuses on Central Eastern Europe and Central Asia building networks to support rights-based initiatives in mental health. Although it is extremely hard to bring about change from large psychiatric facilities which reinforce hopelessness and discrimination, he believes there is progress. This comes from organizations of users, but also, reform minded professionals and UN bodies and experts, and importantly, the Human Rights Council with the mental health resolutions in 2016, 2017, and especially, 2020.

Tlaleng Mofokeng agreed with the panellists about the value of Dainius Puras's work in mental health and determinants. She acknowledged that COVID-19 is adding extraordinary stress to health workers, and also to children, who are unable to process the changes of the past year in the rational way adults can. She spoke of the complexities around biomedical models of mental health care, knowing that pharmaceuticals can be efficacious but they do not address the root causes of mental stress. Many of these causes go back generations, with slavery, colonialism, and apartheid all contributing, leaving direct trauma to be carried through generations. These are still the bases of systems of oppression in today's world. She supports the move away from the 'war on drugs' because she sees it as a war on people: people in the intersections of mental stress, drug use, race, gender, incarceration, and imprisonment. Across all these social issues, there are harsh realities that people have to navigate every day, and providing medications does not resolve these hardships. Our work, she said, must be guided by principles of human rights, affirming and respecting people's autonomy and bodily integrity.

Comments and responses from participants

Alex Cote, moderator, asked the panellists to comment on the issues raised by Tlaleng Mofokeng on mental health and work, and the intergenerational trauma and discrimination

Julian Eaton stated his concern that workplace mental health issues lend themselves to simplification, and quick solutions that don't address deeper issues. Some argue that improving the mental health of workers is a good investment because it improves profitability, but this reduces people to being units of the economy and nothing more. Real solutions probably involve better wages, or being entitled to flexibility in work conditions. It's important that people talk about these issues, and that solutions become emancipatory rather than reinforcing old patterns of powerlessness and discrimination.

Participant Michelle Karen: A popular solution presently is mindfulness and putting the focus on something being wrong with the person rather than with the challenges of the workplace and often toxic environments.

Participant Leah Harris: Dr Vikki Reynolds has created some liberatory work on understanding "burnout" from a social justice perspective. https://vikkireynoldsdotca.files.wordpress.com/2017/12/reynolds2011resistingburnoutwithjustice-doingdulwich.pdf

China Mills described the UK situation where since about 2008 the government has been forcing disabled welfare claimants back into work at any cost. Welfare conditionality and sanctions, and intrusive work capability assessments, have contributed to increased rates of antidepressant prescribing with links to suicides in the UK. She said that prioritising work and the return to work in government policy can be deeply damaging; it positions people who do not, or cannot work, as being economic burdens and this in turn contributes to people's feelings of suicidality and to suicide. She added that the UK mental health system has been shown multiple times to be institutionally racist.

Alberto Vasquez warned that when shifting the conversation towards structural aspects of human suffering, including exploitation, patriarchy, racism, transphobia, climate change, and more, there is the risk of medicalizing these issues and taking a wrong approach to resolving them. We need to work closely with movements of people who take a social disabilities view to determine what our role should be in engaging with structural aspects of mental distress.

Participant Jarrod Clyne: Alberto Vasquez raises a good point here. It seems that even the words we choose, 'distress, disturbance' and so on, have a negative slant, suggesting a response, possibly medical, to fix people. This justifies and sustains the medical model.

Response from Participant Michelle Karen: Quote below from an article of the medical response to someone becoming depressed after losing employment during COVID – It's important to explicitly say medication is not the response, rather than simply not naming it as a response during COVID... *In May, Duckworth was laid off…She began to feel an old adversary, depression, creeping up on her. When a therapist's office told her its earliest appointment was several weeks away, she burst into tears. (The office called back as soon as it had a cancellation.) For the first time in her life, she filled a prescription for antidepressant medication.*

Participant Liam MacGabhann: In response to your query on intergenerational trauma Alex. Despite some minor enlightenment within some mental health policy and disciplines discourse, it would seem [in society and in governments] there is a blindness to systemic intergenerational trauma. Particularly in colonised nations. It would be great if this seemingly unconscious phenomenon was made more conscious as part of the global mental health movement discourse, that is, based on rights-based supports, not health care provision.

Participant Sabine Dick: In addition to Liam's remark, individual trauma as part of a larger community trauma, is often passed on in time and space. Mental health interventions unfortunately mostly do not seem to target 'healing', but only fixing, or even harming, and are not sustainable at all. How can we move from treatment, ensuring our rights, to support and to healing? And not feel harmed and destroyed by the response to suffering?

Alex Cote: Julian, you seem quite optimistic, and said that you are taking a positive outlook on the changes that are happening. Is this justifiable?

Participant Jasna Russo: In response to Julian Eaton's assessment about the 'profession making progress' – have you seen Appelbaum, P. S. 2019. "Saving the UN Convention on the Rights of Persons with Disabilities – from itself." World Psychiatry. Official Journal of the World Psychiatric Association, 18 (1). I hope for us all to move on in the direction as outlined by Bhargavi and Alberto but I could not resist challenging their optimism.

Julian Eaton: Yes, there has been a reaction. When you raise these issues of coercion, responses are often framed in terms of the most extreme cases, "I'm a clinician, what would I do in this situation?" And people take it very personally, because I suppose it's quite an insult being accused of some of the issues that we're raising. So it's not a surprise to me that there's a there's a resistance and obviously, a very eloquent one. There are times when rights seem to contradict each other in either an individual case or in principles. I personally, am an optimist, but I think things have changed. And people are being challenged. I think a younger generation is thinking differently. But I am also disappointed in the lack of any discussion or thinking and educating the professionals around CRPD. I would say that the very great majority of mental health practitioners in the world never heard of the CRPD, let alone had the opportunity to discuss its nuances in the way we are here. So there will be resistance. But the way we're going to change things is by engaging and

discussing and carrying people along and standing up and resisting some of the false arguments that are made. Change happens with a real diversity of approaches and so it's really important that that people stand up and protest and shout as well. We need to sit within institutions of power, and say, "This is a new way of thinking, it has a legal backing to it, this is the weight of evidence that goes towards things that can practically be done to change and maybe make your professional life better, make your profession appear better in the eyes of others".

Alex Cote: I would like now to invite Jonas Bull from Mental Health Europe, to speak about the campaign around the Oviedo protocol, which, in many ways, exemplifies this reaction and resistance to change.

Participant Jonas Bull: I am speaking on behalf of Mental Health Europe, which is the largest European network bringing together organizations and individuals working towards positive mental health based on human rights. We're also a member of the European Disability Forum, defending the rights of persons with disabilities in Europe. For a couple of years now, we have been observing the development of the Draft Additional Protocol to the Oviedo Convention at the Council of Europe and we are starting a campaign to advocate against it. This draft protocol would essentially be a new legal instrument that would allow for involuntary treatment and placement in psychiatry, and will be attached to the Oviedo Convention at the Council of Europe. Further information is available here:

For more information on the campaign against the Oviedo Protocol: https://www.mhe-sme.org/what-we-do/human-rights/withdraw-oviedo/

Here are some useful links around the draft additional protocol to the Oviedo Convention at the Council of Europe: https://www.withdrawoviedo.info/join; and the launch discussion of the campaign #WithdrawOviedo with colleagues from Human Rights Watch, ENUSP, Validity Foundation, the CRPD Committee and UN Special Rapporteur Quinn: https://www.youtube.com/watch?v=jwXHqQ8coIk&t=4022s

Alex Cote: The politics of language is being raised. How can we talk about the impact of mental health related issues without contributing to labelling of people who would face those kinds of issues?

Participant Richa Sharma: How does the language used in mental health discourse affect the field and contribute to the labelling culture? Especially when words like burden, lost years, unproductive, and so on, are used.

Bhargavi Davar: Many of us cannot find a name for our experiences and we struggle without categorizing or naming it for years. Then when a doctor comes and offers a classification or label, it's like, "Yes, I have my diagnosis…" Many of the members of TCI arrive and say I'm schizophrenic, I am bipolar, I have OCD. So a language comes into our movement, and people have not really deconstructed this. In early conversations with members we say, okay, does this label come close to your lived experience? And there are many of us who do not resonate with these diagnostic labels, because there are tags attached to these labels and they are not empowering. After heated debates between the labellers, and those with lived experience within TCI membership, we eventually decided that we were not schizophrenic or bipolar; it might be one part of our life, like having diabetes, but we don't find the label useful and especially because of the really negative experiences within the system. I'm particularly concerned about children who get labelled in schools. We've started using the language of distress, disturbance, and disability, and this is our preferred language.

Participant Diana Samarasan, Disability Rights Fund (DRF): I am wondering whether you are seeing an evolution in the global disability community towards more inclusion of people with psychosocial disabilities? This is something DRF has been supporting at national levels, but it is still tough. There are often

— even in women's rights legislation — exceptions for coercive services for persons with psychosocial and/or intellectual disabilities.

Bhargavi Davar: The answer is a resounding yes.

Participant Bapu Trust For Research on Mind and Discourse, Pune: I would like to raise the question of duality. While we speak about structural and social inequalities, we have on the other hand increasing pressure to keep addressing mental health as an 'individual's problem'. There is a growing discourse towards regularisation and law making which still reiterates the biomedical framing. Consensus building has been a long struggle. But how do the panellists see the movement towards cross movement empowerment? And especially given how in the pandemic a number of development goals in LMICs have been undone.

Concluding comments from panellists on top priorities or issues:

China Mills: I have two interrelated comments. The first one is about the importance of process. So it's not just about what is done, but the methods and the processes of doing that: diverse lived experience of distress must inform the learned experience and the process. It's important to recognize that lived experience is not homogenous, and it looks very different across different contexts. We must make sure that those voices are key. Secondly, Dainius and the wider team's work has been brilliant already in this. I'd love to see the mandate further engage with what Tlaleng called 'the root causes' — those bigger socio political, economic factors that determine mental health. It must build on the South-South partnerships and the transnational alliances that already deal with those root causes, and show intersections of mental health with other global issues: climate justice, disability justice, sexual and reproductive health, fair trade, and more. This captures the nuance, the complexity, and the intersectionality in mental health and moves beyond binary thinking.

Julian Eaton: Coercion is a common cause we can all get behind, including a diversity of sectors and stakeholders. It shames us all. Everyone knows it's not therapeutic and it's totally contrary to CRPD. This mandate, and in other spaces of advocacy, could work to stop the routine coercion that is sometimes explicit and very brutal, sometimes in everyday power relationships, but wherever it is, we need to address it.

Alberto Vasquez: We need to look at psychosocial diversity and psychosocial disability with a positive lens embracing it as part of human diversity. Although we have worked towards de-pathologizing and moving away from medicalized approaches, we have not said that hearing voices and having different ways of perceiving things is not a bad thing. It can be part of your identity and you can be happy with that.

Bhargavi Davar: I have two asks for the future. One, we need people to do what they say they want to see done in the sector, that is, putting commitments into practice. The other is resizing mental health; it's not that we don't want mental health services, we really do want mental health services of many kinds so can we be offered choice and let people choose their own solutions.

Dainius Pūras: We should use the public health crisis of the COVID pandemic as an opportunity to show how important it is to promote mental health and human rights-based ways of support, and not to pathologize when people are anxious or sad. It can also help us to abandon the legacy of institutional care, which as we know, now, are dangerous hotspots for any virus. I am also feeling positive about research in adverse childhood experiences. Researchers searched for biological markers for many years but finally they have identified the key to a healthy body is a healthy relationship between a baby and primary caregivers. Avoiding toxic stress in infants prevents mental health issues and non-communicable diseases later. This

shows how important our relationships are as determinants of mental health. I dream that mental health and human rights will reach a critical mass, as happened with the AIDS movement, when everybody, including policymakers, understood that the best way to address an epidemic was to apply a human rights-based approach.

Tlaleng Mofokeng: In response to some participants who have been asking about the move to individualization, I believe this is something we have to push back on. The systems and the structures that people have to navigate every day are so difficult: when you look at the people who are suffering the most, it's none of their doing. This idea of, "pull yourself up by the bootstraps", when you don't have the boots to begin with — that's a very different conversation. Communication in healthcare around mental health can perpetuate stigma, discrimination, and harmful stereotypes about people with various mental health conditions. So it is important to amplify the campaigns globally, and regionally, to communicate differently and supportively. I think if we just look, for example, at the issue of the many physicians who die by suicide every year, it's really problematic. So there may be an opportunity to have a sector specific response to mental health, with guides as to how those specific industries can respond.

Another important issue is gender-based violence and the intersection with mental illness. Women who are survivors of gender-based violence often have to cope with sexist and misogynistic healthcare providers and society. Society needs to understand that coercion itself is a rights abuse, and coercive control in relationships can make it very difficult for women who are dependent on their partners for shelter, for survival, for food, and for their children. Whatever support and solutions communities come up with must consider all possible scenarios for all people, including those who are the most vulnerable, and make sure that national policy is revised accordingly. We also need accountability at all levels.

Indigenous knowledge and spirituality is also important in mental health. I see this a lot as an abortion provider, where a lot of women will come back, not because the abortion went wrong or they need clinical support, but because they may be undergoing some spiritual processes. We must try to integrate indigenous knowledge and traditional health systems into the mainstream, westernized medical systems in many parts of the world, because many patients consult spiritual or traditional healers before conventional doctors.

These important discussions must continue, and help lead us to decolonize healthcare systems. We must recognise the racism that still exists within healthcare systems, in particular, in the Global South and in previously colonized countries. Inequitable access to health is not just gender and class related, but it is also racialized. These issues are really, really important.