

# HANDOVER DIALOGUES

UN Special Rapporteur on the Right to Health

A discussion paper on

# Achieving an emancipatory future: rights-based approaches

In this final Handover Dialogue we begin by looking back on the rich discussions in the previous four dialogues, to draw out the key messages that contribute to a deeper understanding of the interdisciplinary and comprehensive nature of human rights-based approaches to physical and mental health. In our first dialogue, each of the three former special rapporteurs frankly discussed their tenures, and the challenges and achievements. Paul Hunt, the first Special Rapporteur, suggested that prior to the establishment of the mandate in 2002, there had been increasing recognition that health was a social right. But he concedes that social rights remain contested and do not fit well with an individualistic liberal ideology that favours non-interventionist government. Dainius Pūras has repeatedly linked neoliberal economics to the dominance of biomedical paradigms in health care, drawing attention in his reports to the focus this brings to pathologizing individuals, rather than addressing the underlying and social determinants of poor health. Anand Grover, the second Special Rapporteur strongly links law to health, and the impact that criminalizing behaviours has on health. Each of these mandate holders has acknowledged the importance of understanding power dynamics in healthcare and society to appreciate people's lives, wellbeing, and opportunities to live lives of dignity. Rights-based approaches to health necessarily encompass this broad spectrum of issues and they require partnerships across sectors and with grassroots groups and communities to effect change.

In this series, we have drawn on the work of partners in global mental health, in law (especially work in decriminalizing drugs, sex work, same-sex relations, and HIV), and in sexual health and rights, to highlight the way activists, grassroot organisations, and academics are advancing these rights. These partners are allies of the mandate, and their work is inspirational. They work to democratize health and mental health, and empower people to claim their rights.

As the former Special Rapporteurs have reminded us, when they engage with governments and other stakeholders of political influence, a recurring question is, what is the alternative to the status quo? They ask, how can we eliminate police violence? How can we eliminate coercive health interventions? How do we promote healthy relationships in the home, in schools, and in communities? The mandate has a dual role to highlight the failings of the status quo and to elevate the success of transformative alternatives. Some of the violations of human rights, resulting in harm including in health and especially in mental health, are now well recognised. But there is a more pernicious problem with the status quo: it hinders our collective imagination of what is possible in its place.

Our second dialogue, on global mental health, warned against looking for simple solutions to complex health issues. The status quo adopts a service lens and can miss ways of supporting people that already exist but which are not spoken about as mental health interventions. It also frames psychosocial distress as an economic burden, not only reducing people to economic units, but also overlooking how our political, economic, and social environment damages mental health. Rather, as the panel explained, we need to understand burdens of disablement and sanism as systems of discrimination and oppression. It's important that people talk about these issues, and that solutions become emancipatory rather than reinforcing old patterns of powerlessness and discrimination.

The third dialogue on decriminalisation encouraged us to rethink criminalisation, to examine the stigma and discrimination associated with it, and as Tlaleng explained, to look at history and the current patterns of colonial influence. She described her patients, who are criminalised, as not having their humanity seen. "If I wanted to succeed as a medical doctor, I had to go beyond diagnostics and treatment and become an activist."

Again in dialogue four on sexual and reproductive health and rights, panellists urged a broad, transformative approach to move beyond the oppressive status quo. Intersectoral collaboration is needed which recognizes the relationship between state laws and policies, the global health architecture, women and gender minorities' sexual and reproductive rights, racial and gendered oppression, stigmatization related to disabilities, and paternalism. As in the previous dialogue, the political influence and disempowering role of development assistance was acknowledged.

In this final discussion paper, and dialogue, we bring together a panel of experts and activists pursuing rights-based approaches in mental health, gender justice, and harm reduction. Together they bring an emancipatory vision, cross-sector collaboration, and an empowering process for the people using their community-led services. These are the alternatives to the status quo to which the mandate can direct those in political circles.

# Introduction: community-led recalibration

Dainius Pūras has stated that overcoming reductionist biomedical models of mental health care requires transformative human rights action, including initiatives that target populations, relationships, and other determinants. "The locus of the action must be recalibrated to strengthen communities and expand evidence-based practice that reflects a diversity of experiences. Such community-led recalibration enables the necessary social integration and connection required to more effectively and humanely promote mental health and well-being."

Historically, mental health has been neglected in policy-making and in health and social support budgets, domestically and in development assistance spending. In 2017, the World Health Organization noted that less than half the 139 countries surveyed for the Mental Health Atlas had a dedicated policy framework for mental health.<sup>2</sup> Moreover, less than 2% of all public health spending is dedicated to mental health, and mental health receives less than 0.5% of all official development assistance. More research is required, but it appears most mental health spending goes into institution-based, medicalized 'care', with support for community-based supports limited or non-existent.<sup>3</sup>

Because of the intertwined nature of physical health and mental health, the lack of parity between mental healthcare and physical healthcare undermines the effectiveness of healthcare systems and the right to health overall. The way in which mental health care is provided, how budgets are used, and how care is defined, determine whether or not there are barriers to accessing mental health care. Most mental health care around the world is provided in an institutionalized, medicalized context where coercion is present and human rights are violated.

#### What is a rights-based approach?

A rights-based approach to mental health and psychosocial support can be understood within an international human rights framework, incorporating law and policy. Individual autonomy and self-determination are key considerations, along with culturally acceptable and accessible service provision. Rights-based approaches focus primarily on entitlements.

Mental health is closely linked to social, economic, and political factors in the community, such as access to a livelihood, freedom from violence and discrimination, and social inclusion. These population- and community-level determinants of wellbeing must be considered and addressed as part of rights-based approaches to mental and physical health, as must discrimination against individuals with disabilities (or those assumed to have them).<sup>4</sup>

The importance of considering social determinants is that it helps understand a person's mental distress as part of a collective wellbeing, rather than an individual pathology. This promotes responses that can improve social equity and provide community-oriented support.

Rights-based mental health care services or mental health supportive systems must preserve individual rights and avoid discriminatory practices that infringe on the rights of disabled persons. These responses promote both individual wellbeing in the form of promoting human rights and relief from suffering, and address social, economic, and political determinants of community wellbeing.

#### Examples of broad-based support programs

In Kenya, the Kamili Mental Health Organization incorporates microfinance and small industry to support livelihoods. This is undertaken in conjunction with counselling, education, peer support, and biopharmaceutical intervention.<sup>5</sup>

Huertomanias in Ecuador is a community of people living with what are typically referred to as psychotic disorders whose mission is to achieve financial and social autonomy through livelihoods projects, such as gardening.<sup>6</sup> A similar model called Clubhouse is used in the United States and Europe in which service users are 'members' who receive education, work opportunities, and together build a community that provides peer support and social inclusion.<sup>7</sup>

The Basic Needs organization operating in parts of Africa, Latin America, and Asia uses a combination of livelihoods generation, peer support, and social inclusion activities as adjuncts or alternatives to individually-focused mental health interventions.<sup>8</sup> These programs address economic and social determinants of mental wellbeing, but focus more at the individual level than at the community level.

Community healing and social inclusion approaches to wellbeing can help transform mental health practice from individualized treatment to holistic models. For example, The Banyan in Chennai, India, focuses on the experience of wellbeing in context, recognizing that exclusion from family, society, and community is an impediment to wellbeing. It provides holistic and culturally acceptable responses.<sup>9</sup> Open Hands, run by Friends of Diversity in Botswana provides direct counselling and support services for LGBTQI individuals experiencing distress and addresses the causes of the distress through mediation with families. It also advocates for policy changes to reduce stigma and help prevent violence against people in the LGBTQI community.<sup>10</sup>

Phola, in South Africa, focuses on using traditional African mental health healing practices in people affected by trauma and violence, and promoting community cohesion and prevention of distress.<sup>11</sup> Discrimination and structural violence contribute to individual distress and programs that seek to change these structural determinants affecting community wellbeing are important.

These approaches all have their roots in local knowledge and experience and are not based on the Westerncentric biomedical model that dominates in psychiatry. More evidence is needed, particularly in the Global South, where there is a significant lack of locally relevant, participatory, and 'subject near' research to underpin the development of rights-based practices.<sup>12</sup>

# Models of human rights-based responses

Dainius Puras has suggested that a "rights-based pathway to achieving more local relevance in global mental health might be to move away from evidence-based practice to practice-based evidence, which takes as its starting point local realities, possibilities and understanding of care."<sup>13</sup> Elements of such pathways can be seen in the examples below.

A movement of patients and ex-patients/survivors of psychiatry formed in the United States and Europe in the latter half of the 20<sup>th</sup> century. They represented human rights-based dissent against the medical model of coercive psychiatric practice and their innovations demonstrate transformed mental health care systems. Patients, survivors, ex-patients, and users-and-refusers of psychiatry worked to form their own rights-based practice models of mental health care outside medical systems, each relevant to the local social, economic, and political system, and each with goals to alter that environment.

These models are all explicit about using human rights and emphasizing individual wellbeing in the context of community wellbeing. Each stresses the elimination of violence, non-coercion, free and informed choice, meaningful involvement of persons in their own care, universal legal capacity, and continuity of support as key elements in the implementation of rights-based approaches to mental health. Each seeks to make change not only at the individual level, but at social, economic, and political levels.

#### Berlin Runway House

Established as Germany's only anti-psychiatric institution, the "Villa Stöckle" Runaway House, has been in existence for over 25 years. Ex-users and survivors of psychiatry in Germany fought for such an institution and in 1989 they founded the Association for Protection against Psychiatric Violence. After a long struggle, a service contract with funding from the local government was signed in 1996 and the first residents were admitted. Attaining this service contract was a groundbreaking achievement in Germany which is deeply rooted in credentialism and institutional power, and where support for mental health services is rarely available outside government financed structures. It is an example of a service modifying the wellbeing of the community and at the community level, paving the way for change that has led to the financing and provision of other peer run, alternative mental health approaches.

The Runaway House is a villa on the outskirts of Berlin that operates as a peer run respite. It has a garden with a pond, two common rooms, a kitchen, a mixed floor, one floor for women lesbians inter non-binary and trans\* people.

The "Villa Stöckle" Runaway House concept has five pillars:

- I. We do not work with diagnoses. The description of the residents and their definitions of their experiences are in the foreground.
- II. Residents can decide for themselves whether they want to take psychotropic drugs, whether they want to start or stop taking them.
- III. Our work is as transparent as possible. Residents can view their files and participate in shift changes and team meetings. All contacts and correspondence with third parties are discussed and decided

jointly. Transparency also applies to work structures. Residents can become part of the project and the association. Several former residents are currently working in the team and the board of the association consists mainly of former residents.

- IV. At least half the team are ex-users and survivors of psychiatry.
- V. The team which consists of social workers and students from different disciplines works collectively without management. All decisions are made together in a grassroots democratic manner.

Individual rights and wellbeing in the social context are the focus of support at Runaway House. People who come to the Runaway House, or who take part in the counseling and social services provided, are assisted in their efforts to gain and assert their rights, and to resolve and clarify conflicts in social relationships, including with relatives and partners. The team supports individual rights to basic income and housing by helping people to get an identity card and secure their residence status, which are necessary to claim social benefits. People are also given support to resolve their debts and identify housing options. Individual legal rights are attended to, including help to dissolve legal guardianships and arrange legal counsel. Bodily and personal autonomy are supported by helping people access outpatient therapies and take steps towards transition, if wanted. The residents are listened to, understood, accepted, included, and protected. They are supported to accept and present their own identity, with their own history and experiences.

Runaway House applies this wellbeing lens primarily at the individual level in its efforts to meet the needs of people who come for assistance, and to help them to understand their rights and entitlements in the legal and social context of Berlin. It also applies the wellbeing lens at the social level, not only in its financing arrangements, but also in providing an accepting and supportive community at Runaway House and at its offices, changing the social context to one of acceptance and healing.

#### The Wildflower Alliance

The Wildflower Alliance (formerly known as the Western Mass Recovery Learning Community "RLC") was founded in Massachusetts, USA, in 2007 with the vision of centering a right-based approach grounded in the wisdom of people who have lived through life-interrupting challenges and oppressive systems. It is a grassroots organization that promotes individual wellbeing and rights as well as community wellbeing through peer-to-peer support, advocacy, and learning opportunities for people in a variety of roles.

Peer support draws on local knowledge, trusting the inherent wisdom of each person, and only giving advice or interpretation of what a person is going through when they ask for that support. Face-to-face peer support is offered in four community centers and in a peer run respite. The respite is an alternative to hospital care<sup>34</sup> a house with three private rooms<sup>34</sup> that provides a non-coercive opportunity to rest and have access to one-onone peer support or groups and community services. Support is also available on an internet social platform, Discord, used to host an online peer support and community space. There are also bridging services, with Community Bridgers, who are peers that can ease the transition from hospital back to community.

Wildflower Alliance promotes community wellbeing by providing advocacy and learning opportunities and routine consultancy to clinicians. It advocates alongside people seeking to have their needs met and rights respected by the systems such as housing, treatment, basic needs, and other support services. They are firmly opposed to the use of force, coercion, restraint, seclusion, and other forms of violence in "treatment" and "rehabilitation" settings.

The Wildflower Alliance training team engages in community wellbeing promotion through systems change.

It offers emerging and established peer supporters and peer support organizations courses such as leading Hearing Voices Network groups, Alternatives to Suicide, and practical training, Starting a Peer Run Respite and Developing a Recovery Learning Community. It also helps develop strategies for organizations: Moving Beyond the Medical Model. Courses addressing individual human rights include Anti-Oppression, Systemic Oppression and Peer Support, Power Imbalances in Mental Health Settings and as it relates to many different environments, relevant beyond the constraints of the mentalhealth systm, Understanding and Transforming Language, Gender and Sexuality.

Each component operates with an emphasis on the importance of real choice, the healing power of speaking truth, and the value of having space to make one's own meaning and to choose from many paths forward. Individual human rights are supported by ensuring that individuals are engaged in a valid consent process that takes into account their own vision of their wellbeing. Consistent with the ethos of community wellbeing, Wildflower Alliance operates within a de-medicalized, anti-oppression framework that sees human struggle within the context of each person's life, and moves away from labeling people's adaptations and efforts to survive as "the problem." This approach limits discrimination against individuals, and draws attention to the context of the experience of problems within family, social, cultural, and political structures.

### Intentional Peer Support

Intentional Peer Support (IPS) was developed in the 1990s by Shery Mead, and grew out of the peer organization she started in protest against her own loss of individual rights and those of others she encountered within the psychiatric hospital system. Mead had her first encounter with the mental health system as a teenager. It was a time when most people in psychiatric institutions were over-medicated, shock treatments were routine, and people were not asked about trauma and abuse. She was offered a life in a halfway house and a limited future and fell into leading the life of a "mental patient."

Finally, when threatened with loss of custody of her children (based simply on psychiatric diagnosis), she decided she'd had enough. She realized she and many others in her situation had a choice: the choice of saying "no more." Soon after, Mead started a peer organization whose focus was specifically "unlearning the mental patient role." Thereafter change began. She developed training programs for judges and lawyers about making reasonable custody decisions in cases where one parent has a psychiatric diagnosis; she developed groups for women trauma survivors using music to speak out; she created New Hampshire's first peer run crisis respite program; and she started training mental health professionals and peer support workers locally, nationally, and internationally.

IPS is different from traditional support services because while the approach aims to improve individual wellbeing, it is expressly and operationally focused on the relationship between two or more peers and aims to improve community wellbeing and create social change.

IPS offers a way of thinking about and inviting transformative relationships. Its methods help peers use relationships to gain new perspectives, develop greater awareness of personal and relational patterns, and support and challenge each other in trying new approaches. IPS relationships are viewed as partnerships that invite and inspire both parties to learn and grow, rather than one person 'helping' another.

IPS support does not start by assuming there is a problem. Rather, it draws attention to how each person has learned to make sense of their experiences, then uses the peer relationship to create new ways of seeing, thinking, and doing. IPS examines lives in the context of mutually accountable relationships and communities— looking beyond the mere notion of individual responsibility for change. Mead explains, "Intentional Peer Support is about conversation. It's about how we know, how we create new 'knowing' through dialogue, and about how

we as human beings interrelate by beginning to practice the art of connection<sup>3</sup>/<sub>4</sub> with ourselves, the people in our lives, and the people on the planet we may think we have nothing in common with."

IPS aims to build stronger, healthier, interconnected communities. While it emphasises that individuals must have a say in the development of their own wellbeing, and thus on individual human rights, the locus of action is at the social and community level, and promoting community wellbeing. Mead says it is not about developing more effective services, but rather about creating dialogues that have influence on all of our understandings, conversations, and relationships.

## MH First Oakland

MH First Oakland, an initiative of Anti Police-Terror Project, is a cutting-edge model for non-police response to mental health crisis. MH First responds to mental health crises including, but not limited to, psychiatric emergencies, substance use support, and domestic violence situations that require victim extraction.

It has a free hotline on Friday and Saturday nights when there are currently no other mental health support options available.

It leads with the principle that police should not be involved when responding to a crisis unless asked by mental health responders as a last resort. Crisis response services should support people through quality follow up and on-going care regardless of their ability to pay. Oakland is the second city now operating this service; MH First Sacramento started in January 2020.

The purpose of these initiatives is to interrupt and eliminate the need for law enforcement in mental health crisis first response by providing mobile peer support, de-escalation assistance, and non-punitive and life-affirming interventions. This then decriminalizes emotional and psychological crises and decreases the stigma around mental health, substance use, and domestic violence, while also addressing their root causes: white supremacy, capitalism, and colonialism.

# Challenges and opportunities for the replication of rights-based models

Despite decades of activism to establish survivor run and other independent sources of support, the list of truly rights-based efforts in the world is remarkably short. There are numerous challenges to overcome if a new paradigm is to be realized. Rights-based approaches by definition can only thrive outside of traditional coercive institutional psychiatry. Social attitudes also remain a barrier, especially stigma and discrimination, at individual and structural levels and criminalization of mental health challenges underpinned by racism. Lack of specific policy promoting human rights in mental health, or indeed dedicated coercive policy, historic lunacy laws, and legal capacity continue to act as barriers to good practice.

There remains a general lack of political will, resource mobilisation, and development assistance for mental health, despite calls for change and investment in best practices. Institutional care still dominates, underpinned by bio-psychiatric models of care and treatment. In some places concerns remain about what to do with the massive infrastructure of psychiatric facilities if they are deconstructed in favour of better models.

Despite the challenges, rights-based approaches to physical and mental health are becoming increasingly accepted in policy, discourse, international best practice guidelines and driven by social movements for change. But the fruits of the mandate on the right to physical and mental health are being slowly realised, especially with the reports and UN Resolutions on mental health now adopted.

Over the past decade there has been a groundswell movement to interrupt the prevalence and continuation of an outdated bio-psychiatric approach to treatment, service provision, and support for people with mental health difficulties and/or psychosocial disabilities. From grassroots organisations, advocacy groups, regional alliances, through global dialogue and United Nations policy shifts, what once might have been seen as alternative is taking shape as a new paradigm for how people, communities, and services respond to and support people on their own terms, underpinned by human rights. There are numerous milestones and positions that influence this transformation, amongst them: Turning the Tables<sup>14</sup>; Final Bali Declaration 2018<sup>15</sup>; Special Rapporteurs Report 2017<sup>16</sup> and 2020.<sup>17</sup> In particular the Special Rapporteur's report in 2020 envisions a new paradigm where personal choice, human rights, inclusion, and effective community-based support becomes the norm. It is important to also note the landmark launch in June 2021of the World Health Organisation's <u>'Guidance on community mental health services: promoting person-centred and rights-based approaches'.</u>

The elevation of rights-based practices that engage with the social, economic, and political determinants of wellbeing, particularly those grounded in local knowledge and experience, is especially important in light of the current moment in global mental health, wherein calls for greater investment and attention to mental health are being made from multiple, and influential, sectors.

The historic neglect of mental health notwithstanding, there is a degree of momentum in the global mental health movement. For example, the World Bank's Spring meetings in 2021 placed special attention on the role of mental health support in the context of COVID-19.<sup>18</sup> Similarly, in May 2021, the largest ever public-private partnership in mental health and neuroscience, the Healthy Brains Global Initiative, was launched.<sup>19</sup> Each year since 2018, health ministers have met at the Global Ministerial Mental Health Summit to gain commitments for domestic resource mobilization for mental health.<sup>20</sup> Philanthropies and private actors are also showing increasing interest in mental health, through facilities such as the Wellcome Trust's priority area on mental health, and the Upswing Fund, supported by Pivotal Ventures.<sup>21</sup> Pharmaceutical companies, too, have invested significant resources in promoting mental health as a priority area, and have partnered with governments in some parts of the world to expand markets for their products.<sup>22</sup> But caution is required to ensure that these initiatives do not simply support biomedical paradigms that disempower people experiencing mental distress.

Many of the community based initiatives described in this paper above have the potential to be applied broadly and to challenge the traditional overemphasis on biomedical and psychiatric approaches. Investing in community-based mental health support that seeks to address individual needs should be accompanied with efforts to foster wellbeing in society. Our examples are exemplary in their engagement with the individual experience of mental health and wellbeing (or lack thereof), as well as the broader social, economic, and political determinants of wellbeing that are intrinsically related to individual experience. With this uniquely significant moment in the field of global mental health, uplifting these holistic approaches and generating investment and political impetus for their uptake is crucial, and represents an opportunity to shape the future of mental health policy and practice. A concomitant promotion of social, economic, and political equity through legal reform and macroeconomic policy is needed to achieve social cohesion and community-building which are key determinants of mental health.

#### **Concluding comments**

As we now reach the conclusion of the handover dialogues, we reflect on their contribution to the mandate. As previous Special Rapporteurs have commented, government ministers will frequently ask for examples where rights-based approaches have been used, and have brought about sustainable positive improvements in health and wellbeing. Throughout all of these dialogues, our partners have brought this evidence into the conversations. We have seen examples from around the world where rights-based approaches have effected change, and empowered people. These are the partners, colleagues, and mentors that are available to the mandate to provide evidence, advice, and inspiration as the Special Rapporteur works to influence global, regional, and national level change in policy and programs in health.

Our focus has returned frequently to mental health not just because mental health is historically overlooked and underfunded; mental health presents the opportunity to think in creative, dynamic, and holistic ways to

our understanding of health. We have seen throughout the series of dialogues that mental health can only be addressed through interdisciplinary, comprehensive programs that include law, social determinants such as housing, income, education, security, and provision of rights-based services. This same comprehensive understanding of a person's mental health is also necessary in physical healthcare, but is absent in nearly all physical healthcare services. The social determinants of health have long been known, and have received high level attention through WHO, and the SDGs. But physical healthcare lags mental health programs such as those described above where people are supported through their mental distress with legal, housing, financial, and psychological help, and crisis management. These are the contributions that rights-based approaches to mental health can make to our understanding of what human rights in all healthcare might look like.

The mandate has a unique opportunity to engage with grassroots initiatives as they work to transform traditional understandings of mental and physical health into tools through which human rights can be claimed. The Special Rapporteur is in a privileged and pivotal position, whereby she can bring these transformative conversations and initiatives to an influential, global audience.

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