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VOICES FROM THE FIELD

Global Mental Health, Human Rights and Development

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Mental Health Worldwide (MHWW) is a volunteer-run, global network of individuals and organizations working to improve the human rights and conditions for those living with mental health concerns and/or psychosocial disabilities. Many MHWW members are graduates of the International Diploma Program in Mental Health Law and Human Rights. We are advocates for the ratification and implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by all countries. Mental Health Worldwide represents the diversity within the mental health field and our members include experts by experience, mental health professionals, family members and carers, lawyers, professors and students, non-government organizations, government staff and so on. The opinions and experiences within mental health are as wide as our oceans but at MHWW we all agree that conditions need to improve and human rights violations have to end for those with psychosocial disabilities (see www.mentalhealthworldwide.com for more information).

The pathologisation of the Global South under the guise of global mental health is a valid concern. This concern is evident in the Cape Town Declaration of 16 October 2011 by the Pan African Network of People with Psychosocial Disabilities (PANUSP) (reproduced in this special issue). The Declaration states that 'No medicines or sophisticated western technology can eradicate poverty and restore dignity. The history of psychiatry haunts our present. Our people remain chained and shackled in institutions and by ideas which our colonisers brought to our continent' (2011:2).

Some of the greatest human rights violations in the mental health field lie in the nature of the relationship of the so-called 'helper' and the receiver of this help. Typically, mental health professions, such as psychiatry, have an unequal power relationship, where at its extreme, the professional can force involuntary treatment on the patient. Psychiatry worldwide needs to recognize that this power relationship has to change and mental health care consumers, like general health care consumers, want to be directly involved in the management of their care. Moreover they have the right to do so.

The Cape Town Declaration states 'There can be no mental health without our [user/survivor] expertise… We are the experts … We must be the masters of our life journeys' (2011:1).

The establishment of the UN Convention on the Rights of Persons with Disabilities (CRPD or Convention) (adopted by the UN General Assembly in 2006) makes participation and equality in all aspects of life a right for persons with psychosocial disabilities. Many countries of the Global South have signed or ratified this Convention. The Convention represents a shift from the reliance on a medical model where persons with disabilities are viewed as sick and in need of a cure (Kanter, 2007). Persons with disabilities are no longer treated as 'objects' of charity, medical treatment and social protection. The Convention requires a shift to a human rights model where persons with psychosocial disabilities are rights-holders, including the right to self-determination based on free and informed consent as well as being active, contributing members to society. All societies need to adopt the principles of the Convention including 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity' [from CRPD Article 3; General Principles (*d*)]. (See the UN enable website for background and up-to-date information on the UN CRPD www.un.org/disabilities).

The UN CRPD principles are based on a social model of disability and require a focus on the supports needed for persons with psychosocial disabilities to overcome the barriers they face in society. The social model of disability recognizes that the greatest barriers for persons with disabilities comes from society itself (Kayess and French, 2008). For persons with psychosocial disabilities, the greatest barriers can be stigma and discrimination from those around them, including helpers. The Convention encompasses the social model of disability and, therefore, requires governments and societies to provide the supports needed for persons with psychosocial disabilities to participate fully and equally in society including the right to vote, marry, have a family, education, employment, the highest standard of healthcare - including making their own mental health treatment decisions - and so on.

For all of those involved in the mental health field, there needs to be a recognition and acknowledgement regarding the diversity of mental health experiences and preferred treatments (including the option of no treatment). Persons with psychosocial disabilities are the experts on their own experiences and have the right to make their own treatment decisions. Any form of mental health treatment is not 'one size fits all'. In 2013, the Users and Survivors of Psychiatry in Kenya (USP-K) held workshops to raise human rights awareness for persons with psychosocial disabilities (USP-K report, 2013). Persons with psychosocial disabilities from various regions in Kenya as well as their families participated in the workshop. The workshops were facilitated by a disability law graduate as well as executive members from USP-K. All participants found the training valuable and requested that it be expanded and more frequent. Examples are given in the report regarding the diversity of experience by the participants. For example, one person felt Electro Convulsive

Therapy (ECT) was a form of torture, another felt that ECT had been a positive and helpful experience. But in both cases, free and informed consent did not occur when the ECT was given. Often persons with psychosocial disabilities will experience not only a lack of informed treatment process but a significant lack of basic human rights of being treated with respect and dignity by 'helpers' (for examples, see WHO, 2010). Cruel and inhumane treatment can also occur by traditional healers or in spiritual camps.

How persons with psychosocial disabilities are treated by helpers, and by their society and culture, needs to be addressed in global mental health actions. These actions need to have a human rights based approach as outlined by the CRPD. In this arena, treatment needs to be a choice with informed consent and treatment options, and treatment needs to happen in a context where the person with the disability is considered to be the expert on his or her own condition and future treatment direction. The shift from the medical model in mental health does not mean that medication is not helpful. For some people with psychosocial disabilities, including those in the Global South, medication is helpful and they want this to be a treatment option. Yet low resource countries typically experience a lack of sufficient, consistent and advanced psychiatric medication (for example, see Hooper, 2013).

Changes need to occur in the mental health treatment framework and approach worldwide including the recognition that there needs to be treatment options such as peer counselling and a shift to community-based treatment, and not the sole option of medication. And helpers need to ensure that, if needed, supports are provided such that persons with psychosocial disabilities can make their own decisions, including treatment decisions even during a crisis. For example, the Open Dialogue Approach in Finland is a network based, language approach to psychiatric care (Seikkula et al. 2003). Here the helpers work with the possibility of finding a natural way to defuse crisis situations and the person with the disability is considered to be the expert. Comparison studies found that Open Dialogue participants were hospitalized significantly less frequently, fewer needed medication and in a two-year follow-up participants were much more successful on work/disability measures.

Anyone and any organization in the mental health helper role both within the Global South and outside of it need to have a solid understanding of the CRPD and incorporate these principles in their work and in their relationships with persons with psychosocial disabilities. If organizations outside of the Global South are helpers they need to be sure that they are first seeking the expertise of the persons they are helping. The question needs to be 'how can we help?' What are the support and resources you need to live full and equal lives in your society? Rather than assuming or imposing this support.

A study conducted in India by Kumar et al. (2012) found that persons with psychosocial

disabilities can and want to complete their own psychiatric advance statements. Advance Statements are documents where persons with psychosocial disabilities outline their treatment preferences in the event that they become unwell and are not able to state their preferences. Currently the common belief by mental health professionals, carers and society in general is that persons with psychosocial disabilities do not have the capacity to make their own decisions including treatment decisions, especially if the person becomes acutely and severely distressed. In this study, all of the participants were patients of psychiatrists and had been given a diagnosis of schizophrenia or schizoaffective psychosis. All of the participants that completed their psychiatric advance statements wanted future treatment if they were not able to state their preference at the time and they also specified what type of treatment they wanted, where and for how long, in their advance statements. Advance Statements need to be included in mental health treatment and expanded to not only psychiatric Advance Statements but other treatment options as well.

Charlene Sunkel (2012) in South Africa was diagnosed with schizophrenia in 1991. Her challenges and experiences in mental health care led her to establish the Gauteng Consumer Advocacy Movement as well as many other initiatives. Charlene believes that the highest priority for global mental health is the partnership between those with psychosocial disabilities and mental health professionals and researchers. The goals for mental health care in low and middle-income countries will only be reached if people with psychosocial disabilities are empowered, and genuine partnerships are established between people with psychosocial disabilities and mental health professionals.

Global Mental Health cannot be discussed or implemented without the inclusion of a rights based approach as outlined by the CRPD, and including the right to self-determination. The right to self-determination includes recognising the role played by the community, relationships and support so that persons with psychosocial disabilities can genuinely make their own treatment and life choices (Quinn, 2009). But being the holder of human rights does not automatically translate to changes on the ground, as evident in the Cape Town Declaration,

> Poverty, human rights and psychosocial disability go hand in hand. We know that there can be no dignity where poverty exits. No medicines or sophisticated western technology can eradicate poverty and restore dignity (2011:1-2; also reproduced in this volume).

A 2008 Needs Assessment Survey conducted by The Gauteng Consumer Advocacy Movement (GCAM) in South Africa revealed that lack of employment was the number one need identified by the persons with psychosocial disabilities surveyed (Sunkel, 2013). Over

80% surveyed were unemployed. Poverty is known as both a cause and effect of disability (Kayess, 2009).

The 2013 Statement of Mr. Shuaib Chalklen, the Special Rapporteur on Disability of the Commission for Social Development with a special focus on Africa, highlights that 'it is impossible to genuinely achieve internationally agreed development goals, including the Millennium Development Goals, without the inclusion and integration of the rights, well-being and perspective of persons with disabilities in development efforts at the national, regional and international levels' (report for UN Commission for Social Development, 51st Session, p.3). It will be impossible to achieve global mental health goals without the simultaneous and collaborative implementation of human rights and extensive development.

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