Promoting the rights of people with psychosocial disability in development research and programming

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Background

In the last decade there has been growing recognition of people with psychosocial disability as a marginalised group who have experienced sustained human rights violations. People with psychosocial disability have historically also been excluded from the disability and development movements and health agendas of most low and middle income countries (LAMIC). The most significant barrier to inclusion is the pervasive negative attitudes and discrimination towards psychosocial disability, which along with other barriers (physical, accessibility of information, socio-economic, legislative) results in exclusion across all areas of development including health; education and livelihoods; social inclusion; legal capacity; and restriction of civil and political rights, including participation in mental health policy development (Drew et al. 2011; Kleintjes et al. 2013).

Psychosocial disability has been conceptualised in different ways: from a continuum of tension, stress and distress, to a biomedical understanding associated with mental health conditions including schizophrenia, bipolar disorder, depression and substance misuse. In this paper, the term 'psychosocial disability' has been used to refer to people who self-identify and/or have received a diagnosis of a mental health condition and who have experienced negative social effects including prejudice and discrimination and, in many cases, negative impacts from interactions with health and justice systems. Discrimination and subsequent exclusion is often embedded in widespread debate around the cause of mental impairment and unjustified assumptions regarding the capacity and potential of people with psychosocial disability (World Health Organization 2011).

Mental health conditions can differ in duration, are often relapsing and remitting in nature, so varying in the degree of disability they cause at any point in time. It is important to note that not everybody who has a diagnosis of a mental health condition would be considered to have a psychosocial disability, identify as having a disability, or subscribe to a medical model of mental illness or impairment. Many countries do not have accurate information on the prevalence of disability in general, and countries which have conducted census surveys inclusive of disability may not have appropriately or effectively collected information on psychosocial disability if at all. This limits the capacity of governments and development actors to address the needs of, and to measure, the inclusion of people with psychosocial disability (Goujon et al. 2014).

International development actors are increasingly recognising the need for targeted action to address discrimination and other barriers to ensure people with psychosocial disability are included in, and able to benefit from, development programs (WHO 2010; Hann et al. 2015). The aim of this paper is to examine factors which influence the inclusion of people with psychosocial disability in development and promote understanding as to why and how development actors can improve inclusion. This paper draws on available English-language literature on the inclusion of people with psychosocial disability in development programs, as well as preliminary experiences drawn from the W-DARE project (Women with Disability taking Action on REproductive and sexual health) project. This is supplemented with examples from individuals and organisations with experience in psychosocial disability and/or development.

Factors influencing inclusion of people with psychosocial disability in development

The United Nations Convention on the Rights of Persons with Disability (CRPD) was the 'first comprehensive and legally binding international framework for psychosocial disability,' (Drew et al. 2011:2) which provided a platform for analysing barriers and enablers to inclusion of people with psychosocial disability within development policy and programming. Whilst the situation in some countries has improved since the adoption of the CRPD, there are a number of factors which continue to challenge the inclusion of people with psychosocial disability in development.

Discrimination and exclusion from community

Discrimination and lack of understanding of psychosocial disability is a major factor contributing to exclusion. Human rights abuses experienced by people with psychosocial disability include neglect during time of distress/crisis, as well as detention against their will within their homes, communities and/or in institutions (Drew et al. 2011). Conditions in settings of detention are often squalid and poorly monitored, exposing people to health risks, neglect and abuse. In addition to this, forced/involuntary treatment, whether medical or traditional practices, is prevalent in both communities and institutions. The severity and nature of abuse varies across cultures (Kakuma et al. 2010).

Despite negative attitudes being widely acknowledged as the major barrier to inclusion of people with psychosocial disability, evaluation of strategies for attitude change and reducing discrimination and exclusion have been less well documented (WHO 2010; Kakuma et al. 2010). There is a call for greater international attention to this issue, with one important review highlighting that the most common

human rights violations reported by research participants were experienced in 'community settings in everyday life' (Drew et al. 2011:3). This suggests that social inclusion will only occur when societal attitudes change.

Legislative context

In many settings policies and laws continue to contradict the rights outlined by the CRPD. In some instances, mental health legislation may actually undermine the rights of people with psychosocial disability (Pan African Network of People with Psychosocial Disabilities 2011). The Office of the United Nations High Commissioner for Human Rights found that in most countries it surveyed, people with psychosocial disabilities continue to be deprived of their right to vote on the basis of constitutional or legal provisions that link their political rights to legal capacity (UN 2011). In India for example, a person who is perceived as having a mental impairment is automatically deemed to be under 'legal incapacity' and may not only lose their right to vote, but under family laws can lose their right to marry, stay married, choose to have a baby or terminate a pregnancy, inherit land or make a will. Without 'legal capacity', people may be denied their right to 'associate', creating barriers to the establishment of self-help groups, and in some circumstances creating an environment whereby people are too afraid to speak out or advocate for themselves due to the fear of legal repercussions (Davar 2012).

In many settings, women with disability, particularly women with psychosocial and/or intellectual disability, are more likely to experience violence, including sexual violence, when compared to women without disability or men with disability. Despite this, women with disability are often not considered in the design and implementation of SRH programs.

Individual and collective voice of people with psychosocial disability

Development programs are increasingly seeking to engage with Disabled People's Organisations (DPOs) to support inclusion. DPOs often provide a platform for the individual and collective voice of people with disability to be meaningfully represented. Yet within cross-disability DPOs, people with psychosocial disability are often excluded and their views not represented. Exclusion from DPOs is usually due to lack of awareness and recognition of disabilities that are seen as 'hidden', and DPO members' often fear that being associated with more 'stigmatised' types of disability will have negative consequences for their own inclusion in the community (WHO 2010; IDC 2014).

Globally, the views of people with psychosocial disability have until recently been largely filtered through service providers and family members. The lack of organisations of people with psychosocial disability in many contexts has been identified as one reason for continuing human rights violations (WHO 2010). This includes social isolation which can make it difficult to identify champions for inclusion within research and development programs. In turn this can place significant pressure on the limited numbers of people who do speak out and inhibit collective advocacy.

Economic exclusion

Persistent exclusion places people with psychosocial disability at a higher risk of poverty. Conversely, poverty, conflict, poor access to health and social care, and social inequity increase the risk of poor mental health and the vulnerability of people with psychosocial disability. Employment rates vary for people with different types of disability, with people with psychosocial and/or intellectual disability experiencing the lowest employment rates. Early research found 90 per cent of people with psychosocial disability were unemployed compared to other people with disability. This may be indicative of the level of disempowerment and discrimination experienced by people with psychosocial disability. Likewise, the social isolation experienced by many people with psychosocial disability limits access to social networks which might help facilitate employment (WHO and World Bank 2011).

Lack of quality community mental health programs

Although there is increasing recognition of mental health as an essential part of a person's health and development, it remains a neglected area within development practice. National budgets of LAMIC s continue to place low priority on mental health services, making up less than one per cent of health budgets. Resources that do exist are often channelled into hospital-based services at the expense of community-based programs (Saxena et al. 2007). Much of the abuse experienced by people with psychosocial disability is experienced in institutions such as prisons and mental health facilities. This is particularly pertinent for countries where the absence of community-based psychosocial support systems is resulting in the growth of warehousing type of institutions. Such institutions are difficult to monitor or safeguard the rights of people inside, let alone ensure peoples' right to live independently in the community (in-line with Article 19 of the CRPD), or support their inclusion in development programs in-line with Article 32 of the CRPD (World Network Users and Survivors of Psychiatry et al. 2015).

Given the complex and varying nature of barriers to people with psychosocial disability it is important for development programs to include adequate contextual analysis to inform design of subsequent activities. The following case study provides information gathered during the W-DARE project and some of the actions taken to include women with psychosocial disability in sexual and reproductive health (SRH) programming.

The W-DARE project—a case study

W-DARE is a three year participatory action research project aimed at improving access to quality SRH, including protection from violence for women with disability in the Philippines. The project was conducted in Quezon City in Metro Manila and in Ligao City in Albay Province. Phase one of the project included collection of extensive local

quantitative and qualitative data to better understand the experience of women with disability, including their SRH needs and factors which prevent their access to comprehensive SRH information and services. This informed the development and support for a range of pilot activities aimed at improving access to SRH information and services in Phase two. Phase three involves the evaluation of the pilot activities to help develop disability-inclusive, gender-sensitive guidelines for the provision of SRH services for women with disability (Vaughan et al. 2015).

W-DARE did intend to include women with *all* forms of disability, however about one year into the project it was recognised that women with psychosocial disability were under-represented within the research team and as research participants. There are numerous factors which may have contributed to this. Information and understanding of psychosocial disability in the Philippines is limited, with limited representation of people with psychosocial disability within the disability movement. While there is at least one advocacy organisation, Psychosocial-Disability Inclusive Philippines, in the country, negative attitudes towards people with psychosocial disability, including within some aspects of the disability movement, made it difficult in the initial phases of the project to identify women with psychosocial disability for inclusion in the research team.

Because of this and a broader lack of understanding of psychosocial disability there was a subsequent under-representation of women with psychosocial disability as research participants as well. Phase one findings may therefore not have adequately reflected the specific SRH needs and priorities of women with psychosocial disability.

Promoting our understanding of the SRH needs of women with psychosocial disability

To address this, the W-DARE team supported a small qualitative sub-study to gather data specific to women with psychosocial disability. A researcher with lived experience of psychosocial disability was engaged to conduct the study during July–August 2015. Five women with psychosocial disability were purposively recruited from the networks of the researcher to participate in an in-depth interview. Participants were asked about their understanding of SRH, their sources of information on SRH, access to services including barriers and enablers to accessing appropriate SRH information and services, perceptions on violence perpetrated towards women with psychosocial disability, and, what they feel are the needs and priorities that should be addressed to improve SRH for women with psychosocial disability.

The findings highlight a number of similarities to women with other kinds of disability (Vaughan et al. 2015). These include that many women with psychosocial disability, particularly those who are poor, do not have sufficient knowledge about SRH; about how to access appropriate services including violence prevention and response services; and on their rights to quality SRH. Yet for women with psychosocial disability, the inter-connectedness between experiences of violence and participants' mental health was a far more prominent finding compared to women with other kinds of disability. Most of the women interviewed in the sub-study highlighted experiences of violence and abuse and described the negative impact this had on their mental health, exacerbating their pre-existing condition as well as causing new difficulties. This was further compounded by barriers to accessing justice and support services.

A key finding from the W-DARE project was of the need to improve access to violence response services, including access to justice, for women with all disabilities, especially for those who are also experiencing poverty. The need to provide better support for women with psychosocial disability to also access general health and wellbeing services to support optimum mental health was consistently highlighted. To achieve this, service providers and the general community require much better understanding of how to support women with psychosocial disability to access the services they require. This is especially so when accessing services in response to violence, where the impact of violence can exacerbate mental health conditions.

Achieving better understanding of how to support women with psychosocial disability access quality SRH programming, including in response to violence, requires disability inclusive development research actors to better ensure people with psychosocial disability are meaningfully included in both research processes and benefits.

Promoting awareness of psychosocial disability

The W-DARE team has been actively creating opportunities to promote inclusion of women with psychosocial disability, ensuring better representation and involvement in subsequent project activities. These include:

- Ensuring development of women with psychosocial disability in training for service providers and development partners.
- Developing promotional material to improve knowledge on the rights of women with psychosocial disability to access quality SRH information and services.
- Whilst not specific to psychosocial disability, W-DARE have developed a series of short videos emphasising the strengths and capacities of *all* women with disability, for dissemination through social media.

Whilst challenges remain to mainstreaming psychosocial disability within development in the Philippines, Psychosocial-Disability Inclusive Philippines continues to positively collaborate with a number of cross-disability organisations and government agencies relevant to disability to promote the rights of people with psychosocial disability.

Improving inclusion of people with psycho social disabilities in development programs

Inclusion in International Agreements

UN conventions and the processes which support their implementation can be a powerful catalyst for change, and the CRPD has prompted recognition of the need for better inclusion of disability in the Sustainable Development Goals (SDGs) (UN 2015). The global disability movement was a part of this process, becoming increasingly visible during public consultations by the UN Development Programme on the development of the SDGs. Yet more could be done to ensure psychosocial disability is better incorporated in the implementation of such international frameworks.

Specifically for the Asia–Pacific region, the Incheon Strategy (IS) is recognised as an important framework to support the inclusion of people with psychosocial disability within the context of the SDGs, as it provides a platform for the collective voice of people with psychosocial disability to be heard. Particularly in relation to advocating for IS Goal 2 (participation of persons with disabilities in the political process and in decision-making) and Goal 9 (harmonise national legislation with the CRPD) which are often compromised due to the denial of the right to vote and citizenship (WNUSP et al. 2015).

Supporting legislative change

Inclusion of people with psychosocial disability in local policy development and analysis is essential, so that specific needs and contributions are not lost. Barriers to this level of inclusion, particularly in relation to legislative environments and the right to political participation need to be addressed. In order to ensure people can exercise their right to political participation on an equal basis with others, States Parties to the CRPD are required 'to take appropriate measures "*to provide access by persons with disabilities to the support they may require in exercising their legal capacity" Art 12(3)*'. In many countries people with psychosocial and/or intellectual disability continue to be deprived of their right to vote on the basis of constitutional or legal provisions that link their political rights to 'legal capacity'.

Many countries in the Asia–Pacific region are in the process of developing mental health laws. It is important that such laws do not create new barriers to inclusion. This requires such laws to comply with the CRPD, particularly in relation to Article 12 (equal recognition before the law). Removal of legal barriers to association and exercising political rights will support people to individually and collectively advocate for their rights and provide a clear message that people with psychosocial disability have the same rights to be heard as others (Davar 2012). Other key Articles relevant to international development include Article 14 (liberty and security of the person); Article 19 (living independently and being included in the community); and Article 25 (the right to health).

Promoting inclusion of people with psychosocial disabilities within their communities

Inclusion of people with psychosocial disability within development programs is essential in supporting one of the most marginalised groups of people to attain their human rights, and makes a very important public statement acknowledging these rights, encouraging the view that they are equal members of society. Any approach to inclusion requires the promotion of positive attitudes and beliefs about the capacity of people with psychosocial disability. Prejudice and discrimination are crucial barriers, and challenging these can result in empowerment and greater inclusion.

Strategies for empowerment include approaches to build individual confidence, and providing opportunities for meaningful participation in community consultations and DPO decision-making forums. Existing representative groups recommend efforts to include people with psychosocial disability by making reasonable accommodations; for example, accepting that communication and rapport-building processes may be interrupted if a person is experiencing distress. Sharing stories of the lived experience of disability is both empowering for the individual and known to reduce negative attitudes of others. One author highlighted her experiences of empowering people with psychosocial disability when involved with Youth Champs for Mental Health. The organisation found intentional strategies were effective to support people with psychosocial disability to participate in community and political life, through the use of media, family support, and creating safe spaces for self-expression (Devine et al. 2014).

The number of organisations of people with psychosocial disability, including regional networks, is increasing. Where they do exist, there are positive examples of successful cross-disability networks, for example in Asia, which have collaborated across disability organisations to address inclusion. One author reported from her experience in India, cross-disability inclusion was the most effective strategy available for giving voice to human rights of people with psychosocial disability (Bapu Trust 2014). Developing more opportunities for the collaboration between organisations of people with psychosocial disability and cross-disability organisations may therefore play an important role. Similarly, encouraging multi-stakeholder engagement within development programs and mental health advocacy networks, which are inclusive of people with psychosocial, may also support greater inclusion (Hann et al. 2015).

Positive family and wider community support play an important part in the process of empowerment. Support is needed for these and other comprehensive community-based approaches to mental health and wellbeing, ensuring meaningful participation in the planning, decision-making and implementation of programs. This includes advocating for increased dedicated funding from health budgets to community-based mental health service development.

Access to appropriate health and development programs

Interventions addressing the social determinants of poverty and health are likely to have a positive impact on the mental health of populations. Likewise, interventions supporting mental health and providing psychosocial support may improve the capacity of populations to respond to the complex problems that create barriers to development (Eaton et al. 2014; Lund et al. 2011).

Development programs play a crucial role in promoting access to mental health support and social determinants for populations, and need to provide a greater role in ensuring access for people with psychosocial disability, including access to community-based care and violence prevention and response programs. The WHO Mental Health Action Plan 2013–2020 outlines a central role for the provision of community-based care and greater emphasis on human rights to better align mental health programming with the

CRPD. It emphasises the importance of the notion of recovery, and addresses the need for income generation and educational opportunities, and other social determinants of mental health such as violence prevention, housing and social services (WHO 2010; WHO 2013). It also highlights the growing recognition of international agencies of the need to actively ensure the participation of people with psychosocial disability in relevant processes.

The *World Report on Disability* specifically describes strategies for development of 'enabling environments' as those fostering support service infrastructure; ensuring consumer choice and control; supporting families as support and service providers; increasing training and capacity building; and improving the quality of services (WHO and WB 2011). A focus on 'providing a wide array of services, developed in consultation with user/survivor organisations, which may include peer support, crisis hostels and places of safe respite, and advocacy' is also needed (WNUSP 2008: 20). Central to this is the right to refuse treatment, the right to information, and freedom from coercion in consent mechanisms for treatment, as provided for in Article 25 of the CRPD.

Community Based Rehabilitation (CBR)—increasingly referred to as Community-based Inclusive Development—is one such strategy that has been revised from an individual-focused approach, to be more community-oriented and implemented using a rights-based approach, including equalisation of opportunity, poverty reduction and social inclusion of people with disability (WHO 2010b).

Linked to this is the need to focus on cultural acceptability of many mainstream treatments, which are generally developed in high income countries with vastly different cultural contexts to most LAMIC. Programs need to individually tailor services using a diverse range of culturally appropriate and acceptable options. An example of this is the Bapu Trust for Research on Mind and Discourse in Pune, India, which has developed psychosocial elements of community mental health using Eastern healing techniques. They utilise the culturally significant roles of informal cadres within urban slum communities, integrated with professional psychological and medical support services (Bapu Trust 2014; Transforming Communities for Inclusion 2016; Jain nd; Mendenhall et al. 2014).

Economic empowerment

Given the relationship between poverty and disability and high rates of unemployment for people with psychosocial disability, their inclusion in education, income generation, skills development and economic empowerment programs is vital. Mental health programs should be made available within educational settings, supporting children with mental health conditions to remain engaged in education and reduce the likelihood or severity of ongoing psychosocial disability. These could include programs such as anti-bullying, stress management and life skills programs (World Bank Group 2016). This could in turn increase the number of children completing education, further enhancing work opportunities and improving economic development of communities as a whole.

Responsibility of governments and international development organisations

Governments and international development organisations have a responsibility to ensure the inclusion of people with psychosocial disability in all development programs. This could be supported by high-level recognition and advocacy of psychosocial disability as a key development issue, particularly in the implementation of the Sustainable Development Goals. Other opportunities include promoting inclusion of people with psychosocial disability in research, policy development and programing (UN 2013). If people with psychosocial disability are excluded from development research processes and in the collection of data, they are more likely to be excluded from subsequent development programs. Our experience with W-DARE has shown that efforts do need to be made to ensure people with psychosocial disability are appropriately represented in research, as their specific needs and priorities with SRH need to be understood in order to be addressed within development programs. Now is the time for the development community to work alongside people with psychosocial disability, to change the pattern of past injustices, and prevent these being repeated in the future.

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