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FOSTERING COMMUNITY RESPONSIBILITY

Perspectives from the Pan African network of people with psychosocial disabilities

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Introduction

I got involved in organizing people with psychosocial disabilities after being retired from paid work on the basis of my disability. I co-founded Mental Health Uganda (MHU) which later connected me to the World Network of Users/Survivors of Psychiatry (WNUSP). After being co-opted as WNUSP board member representing the African region I co-founded the Pan African Network of Persons with Psychosocial Disabilities (PANPPD) and was later chosen to represent Ugandan civil society in negotiating the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). I was also involved with the International Disability Caucus and the International Disability Alliance. In this chapter (based on conversation with Jasna Russo) I share my experiences and views on both Ugandan as well as international organizing of people with psychosocial disability – which is my preferred way to identify.

Broadening the action agenda in the African context: Working towards inclusion

We began under the name Pan African Network of Users and Survivors of Psychiatry as a branch of the World Network of Users and Survivors of Psychiatry. Later when we convened in Cape Town for another general assembly, we changed the name because people felt that the terms ‘users’ and ‘survivors’ are somehow stigmatizing and also present a bad image to our service providers – psychiatrists. We felt that ‘people with psychosocial disabilities’ is a more friendly and respectful way of referring to ourselves. I also use the term ‘people with mental health challenges’ to try and minimize stigma.

In Uganda we did have a national organization which was user-founded and user-led. But there was also a mental health organization founded by professionals where there was a lot of coercion and the user voice was not coming out. We then founded My Story Initiative in order to train what we call self-advocates. This is peer-founded and peer-led organization with peer support as its central value. The concept of raising awareness is very important because you cannot demand your rights if you do not know them. We train people about the CRPD and
about Sustainable Development Goals (SDGs), which is the United Nation’s programme. We are using the latter because we want to be included in their Agenda 2030 – Leaving Nobody Behind. This is a more general agenda, it is much broader than just mental health. We realize that after a stay in a mental health institution or after a crisis a human being has all the same needs as any other person. For that reason, we need the broader inclusion agenda. The Global North can learn from this non-coercive approach. It is also cost effective to work with people in the community. It mitigates stigma and fosters community responsibility.

Community responsibility means that when a person living with mental health challenges is confused or having a problem they quickly come and say: ‘Oh this is a son or daughter of so and so, we know him/her, (s)he is our person and we are responsible for helping him/her’. When a person is in a crisis, perhaps moving up and down and before they get into an accident or something difficult happens – people take responsibility and inform the parents or the next of kin and they see how best to address the situation. Or when a person comes back out of an institution – they are scared, they fear that person and think that maybe they are a danger to the community. Of course, there are communities with no awareness, but the communities that are sensitized, they actually know what to do and are being helpful. We see it as our responsibility and also the obligation of the government to sensitize the community – so that people with mental health challenges are also included and can have independent living within the society.

Awareness raising of course costs money and creates a need for finances which we think should be a government obligation, but we also know that the government may not see it as a priority. So civil society can address this; especially those of us who are passionate about it and who have gone through such experiences. People can then see the benefits that result. Because if I talk and explain that somebody can have challenges but nonetheless remain human and become a professional and do lot of things which are beautiful and when I give myself as an example, then people get the message.

For some of the difficulties I have – like anxiety and depression – you need to find out their cause. Instead of just medicating, you talk to that person, find out about the cause and try to address it. Now we have a programme, a mainstream initiative that we call peer support. We talk to our peers and encourage them that there is a life after crisis and encourage them to learn about themselves and seek help.

We are trying to advocate for community services but the Global North in contrast invests a lot of money in psychiatric facilities. When you arrive in a mental health institution in Uganda they are already thinking about using drugs on you – it is the fall-back position. For them it is about financial cost, but these drugs cause lot of side effects to our bodies. Such new developments could be useful, but the negatives are hidden and they are never told to people. In the long run we have discovered that a lot of damage has been done. Maybe some of these new drugs are even being tested on us and that’s the problem. This is our fear. They may try drugs to find out whether they really work and our peers are treated as guinea pigs.

**Challenges and potentials of international advocacy work**

My experience with WNUSP is that it combines people from the northern and southern globe, with different levels of economic growth. Our members in the northern globe generally have welfare and services from the state. But for us in the southern globe, our service users have nobody to care for them apart from their core families. So that is the challenge that I’ve seen. And another challenge I have seen is that our friends in the North are being coerced into treatment. Yet in the Global South, there are virtually rudimentary mental health units so there are all together less conventional psychiatrically based services given to the people. So,
our colleagues from the North are really negative about coercion because their situation is very different.

Those are the challenges I experienced in international advocacy because sometimes they don't understand why I talk about family. To us family is very important. I am also against coercion but to some extent we have to be realistic. Before we become stabilized we need psychiatric services. When they are not there someone's condition can become severe. My approach is holistic and pragmatic – combining the medical model with a social and human rights-based model. Then I believe we can come with good, hybrid solutions. At one point we need the medical model because sometimes natural remedies and alternatives might not help you as psychiatric medication can help you, but of course with informed consent. The medical treatment should always be with personal consent, not coercion. We are emphasizing the right to informed consent and doing away with guardianship and caging, which is not care but torture. We are advocating for community mental health services as opposed to institutionalization.

People from the Global North and Global South can work together because we face similar conditions: depression is depression, anxiety is anxiety. We can share the best practices: what has been done in the Global North and what has worked in the Global South. We can work together with mutual respect for one another's opinion. In the Global South building family networks is a very beautiful thing. In the Global South, families have worked well in caring for people with psychosocial disabilities. The North can buy this practice from the South. I believe we can share success stories. The North can also share some success stories. In both the Global North and Global South we need to amplify user voice, the voice of persons with psychosocial disabilities so that we are recognized as equal before the law and that we eradicate the use of phrases such as ‘of unsound mind’ which causes a legal death and which de-personalizes our humanity and our dignity.