

**5. Congress of the European Network of (ex-)Users and Survivors of Psychiatry
(A joined congress of ENUSP and the World Network of Users
and Survivors of Psychiatry - WNUSP):**

**"Networking for our Human Rights and Dignity"
(July 17 - 21, 2004 in Vejle, Denmark, Idrætshøjskole)**

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Networking for Human rights and dignity – from an African Perspective

Keynote speech from Monday, July 19, 2004

Friends, colleagues, members of the boards of the WNUSP and ENUSP, honoured guests, fellow survivors; I greet you and wish upon us all, good health and success for our proceedings over the next few days. It is a great honour for me to be addressing you here today. It has only been five years since I have become a user of psychiatry; however the cause of improving the lot of other users and survivors has become the passion of my life since then. This explains why I have come so far as to be standing here in front of you today.

As an African and a South African, I must at the outset state that the experience of African users or consumers of psychiatric services are very different to those in the developed world. Not only do we have to contend with the abuses experienced in psychiatric hospitals, mostly having access to only second grade and older medicines or none at all, most of us also have to contend with many more difficulties. These include poverty, lack of infrastructure and development within our communities, poor schooling, crime, stigmatisation and ignorance. Very few, such as myself are privileged enough to have access to medical insurance and to be living in a modern urban environment. By far the vast majority of African users are not as lucky, living in rural and undeveloped villages far from the big cities.

Even those living in the cities are often kept locked up and hidden away from the rest of the community by family members who have to leave them to their own devices, as they need to go out to go and work or seek employment. The state's health services are often unable to cope with the large amount of people they have to provide services for and this leads to, for example having to discharge patients before they are properly stabilised. Our consumers/users are very different from the users/survivors that are sitting here today. They are not as sophisticated and informed, as all of us are, and have very little insight and understanding of their "illnesses". All of this is compounded in many African states by civil war and anarchy which have destroyed these countries' infrastructure. We cannot afford the luxury of debating issues such as the question of the "medical model versus the social model" or whatever the issue may be. For us it is the bread and butter issues that take precedence.

It is in the context of these difficulties that I want to approach my topic today. To quote the former director of a user group in Rotterdam in the Netherlands, Huub Beijers, who spoke at a conference in Cape Town in December 2001, he said; that what the consumers need is only three things and that is "funding, funding, and funding". I have been involved in the development of a user/survivor group in my home town, Cape Town since 1999. I have also been involved in trying to extend the user network throughout our province and the rest of South Africa. I will try to share some of the lessons learnt by myself, with you today. The model that we used was that of working within the system in a co-dependant relationship with the local mental health NGO. This has lead to many

positive spin-offs. Not only have we gained credibility within the system, but we have also gained representation on a variety of local and national, mental health and disability structures.

Our experience with working within the system, in other words, in partnership with all the local role-players have resulted in our group having made a considerable input into the improvement of mental health services. Networking with everyone and becoming known by everyone has engendered a lot of goodwill amongst service users and service providers. We are even using our new found credibility to mediate on behalf of members who have complaints against mental health service providers. In the context of the new democratic South Africa, with the most advanced constitution in the world and its Bill of Rights, there is a lot of positiveness, so that the whole culture of human rights has become entrenched in the consciousness of the people.

This is however, is where I want to critically assess this type of liaison of user groups and service providers. My feeling is that it is necessary that user groups should cooperate with everyone as far as common interests are concerned, but should not to compromise on principles. It is therefore very important that user groups should be independent organisations, and well funded so that we can be the authentic voice of the users/survivors. We have to remain on friendly terms with user groups who are in co-dependant relationships with service provider organisations. Our guiding principle should be the concept of “strength in unity”. Therefore all efforts should be made to foster bonds with all kinds of user groups, be they support groups, advocacy and lobbying groups as well as user groups in co-dependency relationships. This should eventually lead to the establishment of firstly local networks and finally national and regional survivor/user networks.

A note of warning however needs to be sounded. If user groups remain perpetually in co-dependent relationships with service providers, there is a danger of their being manipulated and controlled to the extent that the user/survivors in these groups would only be used as window dressing in order for the service provider organisation to gain credibility, and thus securing their source to funding. In other words the users/survivors can become the pawns in the hands of people and organisations that have not really transformed themselves in a progressive manner. Therefore the users/survivors face the risk of having their human rights doubly abused. Firstly as a result of the abuses within the mental health system; be it by losing one’s freedom when one is placed in a locked ward or being pumped with toxic and dated medication, and when we allow ourselves to be used as pawns, in a very sophisticated “freak show”.

In the African and Third World context a lot of work still needs to be done. Not only do we need to build independent, financially viable user/survivor organisations, we also need to do a lot of talking and educating in order to truly empower ourselves and getting the support and the ear of the thinking public. Today the world’s attention is focussed on conflict and the HIV/AIDS pandemic, yet the issue of the Rights of the Disabled, and in our case of those living with mental disability, is not gaining the required attention. Yet, by far the greatest burden on the world’s economy, when it comes to loss of productivity is as a result of conditions such a Depression and other Mental Disabilities.

My appeal today is therefore for the delegates from Africa to come together and to join forces in order to improve on the conditions experienced by the untold thousands of our fellow Africans who have no chance of ever seeing an improvement in their circumstances if we do not take the lead. Finally I want to end my talk here today with the slogan of the oppressed peoples of South Africa, when they were fighting for freedom and their human rights against the tyrannical Apartheid government. And it is as follows.... Amandla! Ngawethu! -
Power! To the People!

I thank you.