

2.2 User/Survivor initiatives: Non-professional, peer-based, community support services in Mental Health; successes and challenges to date.

Achmat Moosa Salie

World Network of Users and Survivors of Psychiatry (WNUSP)

Ubuntu Centre South Africa

Cape Town, South Africa

moosa_salie@absamail.co.za

Historical Context

The user/survivor movement emerged simultaneously in many places in Europe and North America in the early 1970s. Linda Morrison (2003) explains the American consumer/survivor/ex-user movement's characteristics and goals as follows:

“The c/s/x movement is not a centralised national movement with well-defined leadership, membership, goals and objectives. It has no official leaders, no official hierarchy, and no ongoing organisational structure. Rather, it exists as a loose coalition of advocacy and activist groups whose members engage in numerous activities designed to promote mutual support, rights protection, alternatives, advocacy, and information flow that will enhance empowerment and choice for people whose lives have been affected by psychiatry“.

The above characterisation of the user/survivor movement had been the experience everywhere until the formation of the World Network of Users and Survivors of Psychiatry (WNUSP) in 1991 as the World Federation of Psychiatric Users. The WNUSP grew out of user and survivor demands for recognition and representation.

The following is a brief chronology of the WNUSP:

1991: Network began as World Federation of Psychiatric Users (WFPU) at the World Federation of Mental Health conference in Mexico

1997: Name changed to WNUSP

2000: Secretariat established in Odense, Denmark

2001: First General Assembly in Vancouver, Canada

2004: Second General Assembly in Vejle, Denmark

2009: Third General Assembly in Kampala, Uganda

Prior to the formation of the WNUSP, a rich tapestry of groups had arisen globally, particularly in North America and Western Europe.

These groups started organising in the early 1970s with the Mental Patients Liberation Movement in New York and also the formation of Support Coalition International which later became MindFreedom International, later in the same decade. Many countries in Europe as early as the 1960s and 70s had already set up national user/survivor bodies and today we find national and local groups in all continents, including Africa, South America and Asia. In fact at the General Assembly of the WNUSP in Kampala in March 2009, participants from more than 50 countries attended.

One individual did much to formalise and capture the ethos of this movement. This was Judi Chamberlin who in 1978 wrote the seminal piece on user/survivor writing, called *On Our Own: Patient Controlled Alternatives to the Mental Health System*. In the initial chapters Chamberlin talks about her experiences in the mental health system, but most importantly in later chapters she elaborates in depth on her experiences in user-run projects in the US and Canada. She also dedicates a chapter in the book to an ideal project, which basically is a “how to” guideline for users considering establishing what essentially would be self-help and self-empowerment projects. It would be too ambitious for this paper to write an exhaustive report on user-run approaches.

This needs to be done, and the writer imagines that it would be the basis of many dissertations to be written in years to come. What are the predominate characteristics of user/survivor-run projects over these last four decades?

It is hard to identify the common threads, but mostly these groups and self-help projects arose out of people's desire to counteract the negative and very often stigmatising impact of the treatments they had received in mainstream mental health facilities and institutions. In other words people with similar experiences drew together in order to gain strength in the solidarity they experienced from fellow members in the groups. There was also an exploration of non-medical and grassroots approaches, which would foster the experience of better mental health through peer-support. Rights advocacy alongside the development of peer-run and self-help approaches became the two tiers of the work of many of the groups.

At the launch of the Global Forum for Community Mental Health in Geneva in May 2007, the writer personally heard Dr Benedetto Saraceno speaking the following words on the meaning of Community Mental Health Services.:

“What we are talking about is not about moving psychiatry into the community, but what can be done in the community to foster better mental health”.

In fact Saraceno here captures what had been the experience of all the user/survivor run projects since the beginning, and this was to find new (maybe rediscover old) grassroots, self-help and peer-support approaches which would improve the lived experience of persons who had experienced burn-out, breakdown, and who were living with experiences of altered states and various kinds of madnnesses. The key ingredient which many found missing in the mainstream was the attention given to maintaining the dignity and the social acceptance experienced by individuals who joined these groups.

The above paragraphs form the background to the successful projects run by users all over the world of which a few will be discussed now in more detail. The agenda of these groups had never been solely liberatory or even anti-psychiatry in its objectives. Mostly, the feeling of the writer has been that self-organizing

and mutual support restored people's humanity to them, whereas going through the services had for many people often been dehumanising and traumatic.

So it is no surprise that much of the advocacy activity coming out of this movement had been around rights and restitution for harm done to individuals.

The writer will in the rest of this paper talk about some of these projects and for the purpose of brevity only use one example from each of the following continents; North America, Europe, Africa and South America.

Freedom Center and The Icarus Project¹

"Freedom Center is a support and activism community run by and for people labeled with severe 'mental disorders.' We call for compassion, human rights, self-determination, and holistic options. We create alternatives to the mental health system's widespread despair, abuse, fraudulent science and dangerous treatments. We are based in pro-choice harm reduction philosophy regarding medical treatments, and include people taking or not taking medications" (Freedom Center website²).

"The Freedom Center is one of a collection of grassroots organisations springing up across the country in reaction to the prevalence of medication in America. It alerts people to the downside of psychiatric drugs but does not try to force people off them: it seeks instead to help sufferers find the best methods of coping, even if their solution is unconventional by the standards of the medical establishment"

(Forbes Magazine, 2004).

The Freedom Center was started in 2001 by a group of users/ex-users/survivors which included Will Hall and Oryx Cohen in Northampton Massachusetts. One of the first activities set up was a weekly support group, where "people gather to

¹ **The Icarus Project** is a website community, support network of local groups, and media project created by and for people struggling with bipolar disorder and other dangerous gifts commonly labeled as "mental illnesses." The Icarus Project is creating a new culture and language that resonates with our actual experiences of madness rather than trying to fit our lives into a conventional framework (<http://theicarusproject.net>)

² <http://www.freedom-center.org>

share stories of frustration and hope, recommend resources and recovery strategies, and plan our educational and advocacy campaigns for change”. (Freedom Center website). Since its beginnings in 2001 the Freedom Center has had many achievements, which include:

- a free weekly yoga class
- regular writing group
- free weekly acupuncture clinic
- Madness Radio, a weekly radio show hosted by Will Hall; since its launch in 2005 more than 100 shows have been aired.
- the Freedom Center along with the Icarus Project³ published a 40 page guide called, the Harm Reduction Guide to Coming Off Psychiatric Drugs (2007).
- drafted Peer Educator Guidelines (2007)

The Berlin Runaway-house (*Weglaufhaus*)⁴

The Berlin Runaway-house was opened on January 1, 1996. It “is a place for people who want to get out of revolving-door psychiatry and have decided that they want to live without psychiatric diagnoses and psychiatric drugs. It opens up a space outside or beyond the (social) psychiatric net that keeps people dependent, a space in which the residents can try to regain control over their lives. Here they can recover, regain their strength, talk about their experiences and develop plans for the future without psychiatric views of illness blocking access to their feelings and their personal and social difficulties” (Hölling, 2006). The Runaway House is a project of the Association for Protection against Psychiatric Violence (Verein zum Schutz vor Psychiatrischer Gewalt e.V.) which was founded in 1989. The Runaway house is based at Villa Stöckle in a quiet suburb on the northern edge of Berlin. It is named after Tina Stöckle, one of the co-founders of the association, and it was donated to the association in 1990. The following comes from an English article on the website of the runaway house, called, *The Runaway House at a Glance*:

⁴ <http://www.weglaufhaus.de>

Who lives in the Runaway House?

The house accommodates homeless (ex-) users and survivors of psychiatry who escaped from the psychiatric network and who are determined to manage their lives on their own again. Not accepted are alcoholics and drug addicts as well as those whose accommodation could not be cancelled prematurely and/or those who are detained in forensic institutions because of criminal offences.

Who works in the Runaway House?

The house employs qualified staff who have had their own experiences with diagnosed craziness, psychiatric institutions or other hardship in life and have gotten over it. They are in 24/7 service for the residents.

What happens at the Runaway House?

Needless to say, there are no psychiatrists, no psychiatric diagnoses and no therapies. But there is quite a lot to do, both in personal areas of life (such as housing, work, education, „office works“, doctor and lawyer appointments, interaction with relatives, friends and colleagues) and regarding common household issues (such as grocery purchases, cooking, washing, repairing things, gardening etc.)

The runaway house has been in operation since 1996.

Mental Health Uganda (MHU), experiences with self- help groups.

MHU founded in 1997 is an indigenous National NGO and it is a membership based organization for users/survivors of psychiatry. The mission of MHU is to create a unified voice of people who influence the provision of requisite services and opportunities for people with mental health problems.

MHU core activities are: group formation, self- advocacy, livelihood promotion, raising awareness, membership formation, family and community education, influencing policy, advocacy and lobbying and legislation in favor of users and survivors of psychiatry.

MHU operates in 18 districts of Uganda; West (6 districts) Central (6 districts), East (4 districts), North (2 districts).

Mental Health programmes are needed most in the North because of the effects

and trauma caused by a rebel group, the Lords Resistance Army (LRA) and the ensuing displacement of people.

MHU's advocacy involves; lobbying for Mental Health service provision, inclusion into other development programmes, policy advocacy and legislation, community Mental Health education, and research and documentation on Mental Health. User-directed interventions include: addressing psychosocial needs, support for Income Generating Activities (IGA), savings and credit schemes support (through establishing revolving funds), support to community MH volunteers and support to delivery of MH services. Capacity building encompasses: skills training according to identified needs, entrepreneurship skills, group formation, leadership and group management, resource mobilisation and advocacy skills.

MHU, along with an international conference organising committee, hosted the WNUSP's third General Assembly and world conference in Kampala in March 2009.

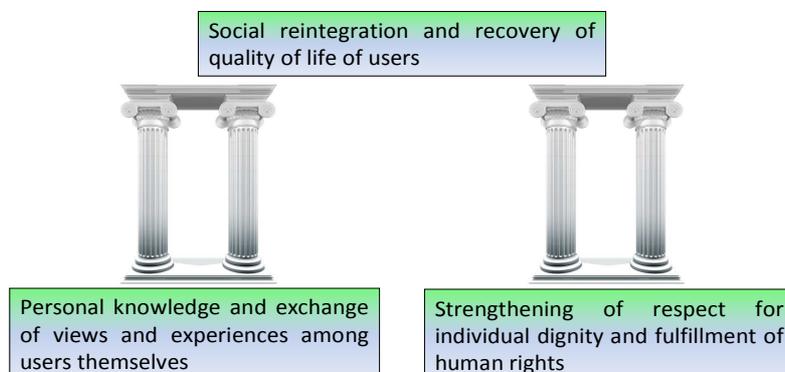
Alamo Peru

Alamo Peru was started by Elena Chavez in 1991. It remains the only user-run association, supported by their families, in Peru to date. Barrionuevo (2009) writes about the goals of Alamo:

“Alamo arises from the need to provide a proper service to users of psychiatry and their family's environment. Alamo's main objectives are the users' personal knowledge and exchange of views and experiences among themselves in order to strengthen the respect for individual dignity and the observance of Human Rights; pillars of social reintegration and recovery of the quality of life of users involved in this project.”

The following diagram illustrates Alamo's 3 tiered/pillared approaches:

Alamo Peru – WNUSP:



Barrionuevo further states regarding the importance of Alamo:

“Initiatives such as Alamo are indispensable in our country due to the lack of work plans in mental health, the non existing enforcement of the ones already created as well as lack of budget provided by the government. In Peru there is no psychological therapy or counselling, and no training for users and their families through conferences or other means. That is why it becomes a priority to create organised civilian groups”.

Alamo has to date worked with more than 400 users and their families. It continues to struggle with capacity problems, being under-funded and under-resourced. Four of Alamo's youth leaders attended the General Assembly and World Conference of the WNUSP in Kampala Uganda in March 2009. Alamo is at present busy planning to host a meeting of young users from South America early in November 2009.