‘Psychiatric services users: the WHO perspective’

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Dear colleagues, dear service users

It is a pleasure and an honour to be here with my good friends of WAPR. We started several months ago thinking to this event and now we are here. I am happy because this is one of the most significant initiatives in my tenure as WHO director of Mental Health. It is also nice for me to do this in collaboration with WAPR an organization of which I have been president many years ago and which now is led by a person I respect and admire, Angelo Barbato.

I am also happy to be in Milano a city I left 10 years ago to move to Geneva and to WHO. However, I am here to talk about the WHO and not about myself. Indeed, WHO is a UN agency and we its officials must forget our personal views and try to capture the perspective of the organization which in fact represents 190 member states through their Ministers of Health.

If we look at the history of WHO there is not very much attention paid to mental health service users. In the past the programme of mental health has been more concerned with the perspective and agendas of psychiatrists than with the perspective and agenda of other stakeholders. And this is my first remark today among many others.

I will talk about 4 issues:

1. The past and present relationship between WHO and users
2. Some key WHO principles driving our action
3. Some challenges in working with users
4. The way forward

1. The history of the relationship between WHO and psychiatric services users is indeed very poor. I have not found any record of serious attempt in the past of even understanding user's position in WHO mental health programme. When I became director I found 3 boxes of unanswered letters from users from all over the world addressed to WHO: denouncing human rights violations, presenting their perspective, sometimes presenting bizarre or ununderstandable theories, sometimes funny ideas or most of the time showing suffering and hope to be listen by the WHO.

That’s it.

I have selected some of these letters and published in a booklet entitled *Voices from the Shadows* with nice introductory remarks from some of you (Sylvia Caras and David Oaks from the US, Theresja Krummenacher from Switzerland, Achmat Moosa Salie from South Africa).

Nice initiative but not very substantial in terms of a serious involvement of service users. We were aware that a much more serious involvement was urgent and necessary.

Let me mention four initiatives we have created during the last 5 years.

1.

a) during the WHO mental health year, in 2001, when our then DG, Gro Harlem Brundtland launched a major movement of awareness and global mobilization, WHO organized a meeting in Geneva attended by different stakeholders including family representatives, mental health professionals, policy makers, politicians. On this occasion German and a Swedish service users took the floor and made clear their perspectives about human rights violations, abuse perpetrated by psychiatry and other controversial issues. It was the first time that these voices were heard in an official event and people were impressed. Not all the statements made were agreed by WHO staff but the point which was clearly made by myself on this occasion was that the issue is not the agreement or the full agreement but rather the

opening of the Organization to different point of views. Democracy is not agreement of all on all, but freedom of saying and disagreeing in all possible settings.

b) After this experience we felt that a more systematic consultation with users was needed. We conceived a Global Council for Mental Health, sort of Parliament where different stakeholders with different and even contradictory agendas and perspectives were given the possibility to express them and reach influentially WHO ears. There is no time today to explain why this idea was never implemented. Let me simply say that we were changing DG and administration, we were significantly impoverished due to a substantial reduction in funds to the programme and this forced us to postpone the project of the Global Council. However, and this is what matters here today, we organized three preparatory meetings with three different groups of stakeholders: parliamentarians committed to mental health, family associations and service users associations. We had the opportunity to listen to much criticism to WHO and to the way the organization was substantially ignoring the service user's point of view. It was not easy for us to deal with this criticism. Many disagreements were fundamental and not solvable, but we discovered also that many agreements were there and not jointly implemented. We agreed that more consultation was necessary when WHO was drafting its normative documents, more work was necessary to promote service users movement across the globe, a more clear position was necessary to be taken by WHO about the most blatant abuses and human right violations.

c) In 2004 we were asked by the ministers of health to brief them about mental health activities of WHO during the annual WHO assembly. We were given only thirty minutes and we decided to invite a service user from Africa to present his perspective. Once again the voice usually unheard of consumers were heard in a much formalized environment like the WHO assembly and many ministers were shocked. As a follow up of this event we funded the creation of the secretariat of the Survivors and Service Users Pan African Organization.

d) Finally, let me mention the recently published WHO resource book on mental health, human rights and legislation. This is a very long and articulated document aiming at advising countries in improving their mental health legislation. In doing this huge effort we consulted more than hundred experts across the globe and among them some representative of service user's organizations. Once again, there was agreement and disagreement but at the end the users involved accepted to be formally acknowledged in the book. At the very last minute one of the service users discovered a sentence not enough clear about condemning ECT with no anaesthesia and informed consent. He wrote to me highlighting the contradiction between my past statement about this issue and the sentence. We acknowledged the inconsistency and modified the text accordingly. These are difficult experiences for WHO but also learning experiences.

2. And this last remark takes me to my second point: the WHO perspective in mental health and mental health care. This is not the moment for me to give you a comprehensive vision that you may easily find in many of our official documents including the World Health Report on Mental Health published in 2001. I would like simply to remind you few key principles that characterize all our work:

a) WHO is an intergovernmental agency of the U.N. Its direction depends mostly from the mandate given by Governments. If national or international organizations of citizen want to influence WHO they should influence their respective governments. WHO cannot say whatever its officers want or think but WHO should essentially advise governments on technical matters and implement the resolutions voted by the World Health Assembly. Let me stress how technical opinions when dealing with controversial issues result from scientific evidence but also from the vision coming from member states.

b) WHO listens to and collaborates with different stakeholders and it should take into consideration the different perspectives and opinions: policy makers, professionals, scientists, consumers, families, communities and civil society in general. No one single stakeholder should prevail on the others.

c) WHO pays a very special attention to the needs of the poor: individuals, groups, communities, nations. The perspective of low income countries is particularly relevant for us and often we do not pay too much attention to problems coming from rich nations. These should be addressed internally, the limited resources of WHO impose a clear prioritizing of the problems and the demands coming from the poor.

d) The violation of human rights of health services users including psychiatric services users and the recognition of their role and rights as citizens are a main concern for WHO. WHO thinks that no treatment can be credibly provided in a context which systematically violates human rights. There is a global emergency for the human rights of people suffering from mental health problems. I insist on the word "global" as people tend to believe that these kinds of violations always occur somewhere else when, in fact, they occur everywhere. Human right violations can be denied access to treatment but also and often consists in treatment itself which is inhumane or simply of very bad quality. The most common human right violation is linked to the context of psychiatric care: lack of privacy, confinement, isolation, physical constraints. Human right violations have nothing to do with poverty or limited resources. Indeed, we can see this kind of violation in rich and poor countries. The misery attached to the asylum is an independent variable, namely it is something that is attached to a way of conceiving psychiatric treatment and not just to the resources available. Key international human rights standards and norms both promoted by the UN and regional human rights systems (European, African and InterAmerican systems) represent a key reference for WHO.

e) Finally, the massive gap between untreated and treated among people in need for treatment represent a priority to be addressed. The fact that in most of the countries more than 80% of people with mental problems have no access to services or medications or psychosocial treatment represent a fundamental concern for WHO.

3. Only taking into account these five points you can understand the frame where the interaction between WHO service users may occur and the related challenges. Let me mention four main points about this interaction:

a) listening to, consulting with service users is very complicated. Who is who, who represents whom, the issue of representativeness and legitimacy is extremely challenging and we need your help to understand how to move on. Overall to users' movement seems to be very rich and diverse but also fragmented and expressing a broad range of positions (from a radical anti-psychiatry approach to the sympathetic support for psychiatrists in improving their work with patients). Some consider family organizations as potential partners, while some others not. Equally diverse seems to be the objectives of the different groups, ranging from denouncing violations to organizing self help groups. Some organizations accept funds from pharmaceutical industry and some other not.

b) The broad spectrum of perspectives and positions in the users movement make difficult to WHO the understanding of the priorities which often seem even in contradiction. One example for all: many say WHO should help us in getting psychotropic medications for free in poor countries, while many others say WHO should help them in fighting against the use of psychotropic medications. Therefore, some consider WHO concern about treatment gap a shared concern, while some other say that less people are treated by psychiatrists better is for their well being.

c) The very small number of users organized in structured groups in developing world and in non western countries creates a bias unacceptable to WHO. Too many organizations and individuals from Europe, US, Canada and Australia ask for interacting with WHO. Too few from Asia, Latin America, Africa. We are not sure that all the problems relevant for the people from these few, rich, selected countries have the same relevance for the rest of the world.

d) WHO believes in treatments based on scientific evidence but WHO does not believe in science and medicine if they are against human rights of people. WHO believes in holistic model of care where the medical model is just one among others. WHO believes that mental problems result from a combination of biological social and psychological factors combined in complex and often unknown mix. Therefore WHO believes that treatments for mental problems and disabilities should combine psychological, social and medical interventions. People need to be listened to, need to be emotionally taken care of, need to be respected, need to be helped in every day tasks. Mental health services should include housing or working opportunities. People with mental health problems are first of all citizens and therefore the full enjoyment of their citizenship should be kept as a vital framework for any medical intervention. In other words, WHO believes that science and research are not only bioscience and medical research but also other approaches and model should contribute to the understanding and treatment of mental problems and disabilities. Some users may disagree in part or in total with these statements. However, the existence of disagreements between some users groups and WHO should not prevent the identification of common goals and mutually beneficial influence. I strongly believe in this possibility and I see a number of possible collaboration and common goals.

4.

a) Mapping the reality and the diversity (criteria, collaborations, etc…) of service users. WHO needs your help to design a Global Atlas.

b) Promoting users organizations in low income countries. Cross-disability and developmental organizations everywhere can and must play a pivotal role in helping to build the organized voice of psychiatric users in low income countries. WHO is willing to support these initiatives.

c) Identifying few common issues related to human rights (large asylums, ECT) and promote awareness and debate around them. For example:
   - WHO strongly believes that Mental health services should be in the community and large asylums should be replaced by community services … or …
   - WHO believes that even if ECT is considered by many psychiatrists an acceptable treatment, nevertheless, due to the great debate surrounding this practice this should be at least considered controversial. WHO would like to stress that involuntary ECT or ECT without anaesthesia should be considered unacceptable.

d) Finally, we would like to explore the feasibility of a global convention of service users, maybe in 2009.

Is this a dream?

Maybe but let's work to make it a reality.