Accessibility as a right of users and survivors of psychiatry/ people with psychosocial disabilities:

Submission of the World Network of Users and Survivors of Psychiatry (WNUSP) to the Committee on the Rights of Persons with Disabilities for its Day of General Discussion on CRPD Article 9

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0. A note on language

In this paper, the term "users and survivors of psychiatry" is used as defined in the WNUSP Statutes:

"A user or survivor of psychiatry is self-defined as a person who has experienced madness and/or mental health problems and/or has used or survived psychiatry / mental health services." For more information see www.wnusp.net.

"Persons with psychosocial disabilities" is a synonym for users and survivors of psychiatry, and "psychosocial disability" is further explained in the International Disability Alliance (IDA) Submission to the OHCHR Thematic Study on Legal Measures Necessary for Ratification and Implementation of the CRPD, available on the IDA website www.internationaldisabilityalliance.org.

1. Introduction and definition of accessibility

Accessibility is an important principle for the mainstream disability community, but users and survivors of psychiatry have not often applied the concept to our own situation.

Accessibility is broadly the right to have access to anything that is generally available to the public, on an equal basis with others. It implements the right to inclusion and participation by proactively removing features of an environment that constitute barriers to participation, or adapting the environment to greater participation by providing alternatives.

Accessibility overlaps with both reasonable accommodation (accommodation to individuals' diverse needs and realities) and inclusive design (incorporation of a wide range of diverse needs and realities into an overall plan).

Accessibility usually refers to the environment rather than to the specific needs of individuals. It can refer to any kind of environment, such as the physical or informational environment, or to services.

Accessibility requires adherence to measurable guidelines, since it refers to an

environment shared by everyone. However, these guidelines can include provision for individual assistance or accommodation to meet individuals' needs related to an environment, as recognized in Article 9.2.e.

2. Accessibility for users and survivors of psychiatry

a. Social and legal discrimination as barrier to access to services, public facilities and public spaces

We first identify discrimination, particularly social and legal discrimination, as the main barrier for us to access environments and services of any kind on an equal basis with others. Discrimination creates barriers to our access to employment, school, political participation, and religious, cultural and social activities – all aspects of ordinary life. The absence of people with apparent psychosocial disabilities in ordinary life reinforces the perception that we belong in institutions and segregated mental health programs.

One particularly acute example is discrimination that creates a barrier to equal access to health care. Having a record of psychiatric diagnosis is treated as a master status that leads health professionals to ignore physical health complaints or treat them as manifestations of "mental illness," resulting in worsening health and even death. (The failure to pay attention to our communications about our own health condition applies also to complaints about adverse effects of psychiatric drugs.)

On the basis of psychiatric diagnosis and the belief that we therefore need specialized medical services we are often excluded from easy-to-access crisis intervention services for general population. This kind of exclusion spreads to other important community services and prevents us from accessing their help (shelters for battered women, counseling and support services for asylum seekers, debt services etc.).

Discrimination creates barriers to disability-specific services and environments, as well as those in the mainstream. The mental health system can be the most inaccessible environment for those seeking its services.

Discrimination also deprives us of equal access to public facilities and public spaces, when people express hostility and violence towards someone known to have a psychiatric history or someone showing the effects of psychiatric drugs, or who is acting in unusual ways. Police may enforce discrimination by scapegoating the person identified by others as "mentally ill," not taking our complaints seriously, violently assaulting us, and removing people from public spaces to psychiatric institutions.

b. Barriers to requesting reasonable accommodation

Of the three overlapping concepts of accessibility, reasonable accommodation and inclusive design, we have used reasonable accommodation the most, reflecting the diversity and specificity of our needs as individuals, and the high value our community places on individual uniqueness.

Many of us experience barriers to requesting reasonable accommodation, both internal and external. Other people's disbelief and questioning of our needs can foster a feeling of shame about unusual personal needs. If our needs are not apparent, we have to struggle to frame the request in a way that allows us to maintain our dignity. And if we are in the midst of a crisis that makes communication difficult, this difficulty itself has to be accommodated.

There is always the risk that disclosure of psychosocial disability will be met with violence and discrimination, including forcible confinement and forced or coerced drugging and electroshock, especially at the times when we have the greatest need for accommodation.

c. Environmental analysis and peer knowledge

Accessibility poses a question about how to create environments that are most conducive to comfort and inclusion of people dealing with trauma and/or intense internal experiences. We can develop recommendations based on our first-person experiences and on work our community has done in peer support and advocacy, creation of respite centers, and trauma-informed and first-person-centered approaches in mental health services.

Here are some examples related to the physical, information and communication environments and services that were suggested in preparation of this submission. (It should not be assumed that any particular individual needs a particular adaptation.)

- Trauma-informed architecture and environmental planning could address concerns about privacy and surveillance, for example by designing professional consultation spaces as closed rather than open-plan, and without monitoring devices.
- No one should be evicted for being unwilling to give up a beloved pet/companion animal, and people should be welcome to bring these animals to mental health service settings.
- Assistance by a personal guide should be made available to people who have difficulty navigating complex physical environments for mental and emotional

reasons.

- People who need extra time and help processing and responding to information should be offered human assistance and accommodation.
- Communication should be sensitive to feedback and not press for engagement when a person may be preoccupied with internal experiences, unless it is a true emergency (e.g. a fire; not a psychiatrically-defined emergency).
- Reasonable accommodation can include self-defined individual support by people one chooses and trusts.

3. Recommendations

To implement the rights of users and survivors of psychiatry to accessibility, States should:

- Investigate social and legal discrimination, including barriers faced in requesting reasonable accommodation, as a barrier to access to environments, services, public facilities and public spaces.
- Develop standards for the elimination of these barriers, based on legal and environmental analysis undertaken by users and survivors of psychiatry, in areas such as:
 - * Repeal of discriminatory laws that restrict the legal capacity, liberty, and any other rights or responsibilities, of people with disabilities;
 - * Public awareness-raising to identify and eliminate attitudinal barriers:
 - * Education and training of those responsible for specific environments, services, public facilities and public spaces;
 - * Providing reasonable accommodation when the need is not apparent or communication difficulty exists; and
 - * Technical specifications that trauma-informed and relevant to local cultures and circumstances, for specific environments, services, public facilities and public spaces.
- Call on users and survivors of psychiatry trained in fields such as environmental planning, architecture, landscape architecture, and environmental psychology, as well as those who are experts in interactive,

non-hierarchical, phenomenological, trauma-informed approaches to communicating with people in crisis or in need of healing, to apply their knowledge to accessibility of all types of environments, services, public facilities and public spaces.

- Define accessibility and accommodation for users and survivors of psychiatry in social rather than medical terms, and describe needs rather than categorizing them according to diagnosis or type of disability.
- Ensure that users and survivors of psychiatry in each country and locality can develop recommendations suited to their cultures and circumstances; and facilitate international cooperation among users and survivors of psychiatry, particularly through user/survivor-run organizations, to exchange expert knowledge and skills for this purpose.

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