Submission of the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) for the Day of General Discussion (DGD) on the right of persons with disabilities to live independently and be included in the community, to be held on 19 April 2016 in Geneva.

ENUSP, the European Network of (Ex-) Users and Survivors of Psychiatry, is the only independent grassroots organization of users, ex-users and survivors of psychiatry in Europe.

ENUSP fully supports the submission already provided to the Committee by the World Network of Users and Survivors of Psychiatry (WNUSP). However, ENUSP would like to take this opportunity to elaborate and share our key concerns on the situation of persons with psychosocial disabilities across Europe in regards to the right of persons with disabilities to live independently and be included in the community.

1. Institutionalization and segregation is standardized practice

As a result of European history up until today, persons with psychosocial disabilities have traditionally not been part of diversity in the communities across Europe so far. Generally, European citizens with psychosocial disabilities are either segregated from the community through institutionalization, or left without sufficient support in the community where they face a large amount of attitudinal and other barriers in regards to participation and inclusion in the community, such as discrimination, stigma, prejudice, fear, exclusion, violence and abuse. The discrimination against persons with psychosocial disabilities in Europe is widely embedded in practice, health care, legislation, policy, courts and culture throughout Europe[1].

Discriminatory laws

National laws and the binding directives of the Council of Europedo not recognize our human right to live in the community fully, andstill prescribe and allow for forced psychiatric interventions and involuntary institutionalizationon the basis of psychosocial disability, either in itself or in combination with additional criteria such as supposed dangerousness or so-called need for treatment.Especially in situations involving higher levels of psychosocial support needs, including in complex and acute situations of psychosocial crisis, the right to live in the community is not recognized.

The existenceof these discriminatory laws provides a basis for public acceptance of these practices, resulting in a lack of political urgency to develop alternatives, as well as impunity for perpetrators, and prevents access to justice for persons with psychosocial disabilities.

- Regarding the normative content of article 19, abolition of these discriminatory laws is a first and necessary step for recognition and realization of the right of persons with psychosocial disabilities to live in the community.

2. Lack of alternative support in the community

It is concealed though acknowledged that a lack of support in the community is the main reason for institutionalization, as is for example illustrated by the following statement from the European Joint Action on Mental Health and Wellbeing: *"Care in the community: Care of people with mental disorders should be provided in the least restrictive environment possible and hospitalization should only be considered when all community treatment alternatives have been exhausted."*[2]

Yet, community based alternatives are generally not in place. In most countries psychiatric hospitals continue to play a central role in mental health systems and consume the vast majority of resources allocated to mental health care. Across Europe, very often the default answer to (higher) psychosocial support needs is institutionalization, either voluntary or involuntary, both in the short and long term. Concerning especially those situations involving higher levels of psychosocial support needs, or complex and acute situations of psychosocial crisis, there is generally a complete lack of alternative support facilities. In a range of European countries the number of persons subjected to forced institutionalization and forced treatments is on the rise annually.

- Regarding article 19.a , the absence of community based support should not be used as an excuse to justify institutionalization.

Instead of a rich informativehistory of inclusion, Europe unfortunately has a long history of segregation of persons with psychosocial disabilities. The CRPD brings an important momentum to change the

[1] See also ENUSP shadow report on the EU implementation of the CRPD, July 2015
[2] JAMHWB, WP5, page 105, point 4

paradigm in Europe, towards anew innovative development of full inclusion of persons with psychosocial disabilities. This will entail challenging existing social structures in the community that have been in place for too long. De-institutionalization without investing in accessible, inclusive communities and the availability of community-based support involves a high risk of resulting in other problematic situations however and needs to be taken into account upstream.

Several European countries have started a process of deinstitutionalization, however the ambitions are generally dramatically low. For example, Romania aims to deinstitutionalize1300 persons in the next 8 years by building day centres and group homes(also see attachment 1). Hungary proposed a deinstitutionalization strategy covering 30 years and moving persons to “community based living centres” for up to 50 persons. Czech Republic’s deinstitutionalization strategy was ended after 3 years without plans for follow up. DPOs have not been meaningfully involved in these plans, and as a result, these plans and changeshave ignored certain fundamental issues, among others: the lack of a profound understanding of what institutionalization entails, the focus solely on the interests of service-providers, no alternative community-based services, the conditionality of support upon certain living arrangements etc. Several studies[3] point to one of the main drivers of institutionalization - the deprivation of legal capacity that continues to be allowed also in the national legislation, and that is currently not a priority in the governments’ programs of deinstitutionalization.

Across Europe, the current paternalistic mental health care system and the discriminatory laws enjoy widespread public acceptance, and overall the political urgency to realize alternatives is low, since institutionalization is considered to be of so-called beneficence. As a result, support in the community has not been developed, and due to a lack of support options, communities often reject persons with psychosocial disabilities and resort to institutionalization, representinga vicious circle of segregation.

- Regarding the normative content of article 19 and article 19.a, 19.b and 19.c, to stop the vicious circle of segregation, all laws, policies and practices, including for mainstream services, need to be reviewed and modified.

- Regarding the normative content of article 19 and article 19.b , collective reflection by all communities, especially by psychiatric professionals and family members, is needed to get science and practice off the wrong track, and to rethink on human rights, mental health and psychosocial disabilities.

- Regarding the normative content of article 19 and article 19.a, references to claimed beneficence of placement and treatment of persons with psychosocial disabilities without free and informed consent of the person concerned are misplaced and constitute discrimination, which should be flagged and eliminated.

- Regarding the normative content of article 19 and article 19.a and 19.b, deinstitutionalization cannot be a legitimate process unless it responds to the rights, preferences and needs of people currently living in institutions.

- Regarding the normative content of article 19 and article 19.a and 19.b, deinstitutionalization requires that any laws authorizing the denial or restriction of legal capacity on the basis of disability be abolished.

- Regarding the normative content of article 19, DPO involvement is crucial to identify effective and appropriate measures to facilitate full enjoyment of the right of persons with psychosocial disabilities to live independently and to be included in the community.

Existing barriers to living in the community

Due to the immense prejudice and stigma, persons with psychosocial disabilities face many paternalistic barriers and discrimination in virtually all aspects of life.

Discrimination, stigma and prejudice

Across Europe, the terminology used to refer to persons with psychosocial disabilities in policy and practice is overall still not CRPD compliant, such as “persons of unsound mind”[4], “persons unable to

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[3] Romania, Thematic study on the right of persons with disabilities to live independently and be included in the community Report of the Office of the United Nations High Commissioner for Human Rights, http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session25/Documents/A-HRC-25-29_en.doc
Czech Republic, see NGO information to the UN Human Rights Committee Submitted by the Mental Disability Advocacy Center (MDAC), European Disability Forum, League of Human Rights (LIGA), 14 June 2013

[4] “Persons of unsound mind” is the term used in the European Convention on Human Rights, art 5.1.e.

give consent”[5] , “persons unable to adequately judge the situation” and “persons posing a danger due to mental disorder”[6].

The individual status of ‘mental capacity’[7] is widely used to deprive persons with psychosocial disabilities of their legal capacity, including by placement under full or partial guardianship regimes.In addition to the incapacity doctrine, there is also a deep-rooted prejudice of presumed ‘dangerousness’ of persons with psychosocial disabilities, leading to deprivation of liberty on a discriminatory basis.[8]These deeply-rooted and often primitive prejudices of incapacity and dangerousness are widely embedded in European cultures at all levels, often merging the prejudices into terminologies of “need for protection or treatment” as a claimed justification for the deprivation of our rights on the basis of psychosocial disability.

- Regarding the normative content of article 19, all terminology, as well as policies and practices need to be revised, with special attention to removing all references to incapacity and dangerousness, in order to stop such stigmatization and discrimination.

- Regarding the normative content of article 19, public awareness raising is needed to end discrimination and stigmatization of persons with psychosocial disabilities and to refute the claimed beneficence of the deprivation of rights based on psychosocial disability.

Paternalistic barriers in all aspects of life
Support for decision-making by persons with psychosocial disabilities is generally not established in practice, since substitute decision-making regimes enjoy wide public acceptance, including among family members. The number of persons with psychosocial disabilities under guardianship or under forced treatment regiments (CTO) in the community is on the rise.

In daily life in the community, the discriminatory ‘protective’ and paternalistic attitude towards persons with psychosocial disabilities is also wide spread. The opinions, preferences, views, expressions and complaints of persons with psychosocial disabilities are often disregarded, neglected and devalued by others, especially when others have another opinion on what would be best or right for us. This also affects many components of article 19, such as the right to have choices equal to others in choosing a place of residence and where and with whom to live. In practice, our families, caregivers and others in the community can request measures to obligate us to live in a particular living arrangement, for example in institutions, social homes, under guardianship, supervision etcetera. Our control and influence over any aspect of our lives can be taken away by any of these so-called ‘protective measures’. In many occasions our right to choice is limited to being only allowed to express preferences within a margin that is predefined by others, which is not giving us a real choice on an equal basis with others. This can affect any of our rights and choices, including where and with whom to live, the right to marry, to found a family and have children, medical treatment, employment and so on.

In Europe, the medical model-approach of “persons of unsound mind” gave rise to a biomedical industry, which has developed many harmful, invasive and irreversible treatments, such as electroconvulsive therapy (ECT), neuroleptics and other harmful psychopharmaceutic drugs, with the aim to correct the disability. Within Europe, the biomedical explanation of the word ‘dignity’ is often misused against persons with psychosocial disabilities in order to promote non-consensual invasive and irreversible interventions aimed at repairing, correcting or alleviating a psychosocial disability without free and informed consent of the person concerned, instead of the human rights based approach to dignity as the lived experience of the person. In this way, the right to respect and protection of bodily and psychosocial functioning of persons with psychosocial disabilities on an equal basis with others, is violated and even nullified on the basis of the existence of a psychosocial disability or diagnosis, which is a clear form of discrimination.

- Regarding the normative content of article 19 and article 19.a,, decision-making by persons with psychosocial disabilities must be recognized as valid, and our decisions should be respected on an equal basis with others. Support in decision-making must be based on the will and preferences of the person concerned.

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[5] Council of Europe, Oviedo Convention
[6]Similar terminology in most domestic legislation in European countries.
[7] The Committee addressed concerns already in its General Comment on article 12
[8] as explored by the Committee in the Guidelines on article 14.

- Regarding the normative content of article 19 and article 19.a, awareness raising is needed to refute the discriminatory idea that other persons carry a responsibility for the acts of persons with psychosocial disabilities, and to ensure the right to legal capacity of persons with psychosocial disabilities, including the right to act and to develop our own identities ourselves.

- Regarding article 19.a, public awareness raising is needed for a true understanding of the term 'dignity', the term 'social protection', as well as the term 'adequate standard of living', which should be interpreted in the spirit of the CRPD, and the difference between the paternalistic concept and the human rights based approach to social protection needs to be clarified.

Degrading living conditions

Persons with psychosocial disabilities are often disproportionately subjected to horrible living conditions in the community, as well as in institutions, in jails, on the streets, at homes, in certain traditional settings, leading to a visibly poor quality of life, which increases discrimination, stigma, prejudice and segregation. Not only the support for psychosocial needs is often lacking, but also the support for basic needs for existence is generally insufficient or absent. Poverty and unemployment is a huge problem amongst persons with psychosocial disabilities, leading to an even more disadvantaged position in the community. Persons with psychosocial disabilities themselves experience this as a life without dignity.

In several countries in Europe, resources for basic needs, such as housing, affordable food, sheltersand support are not available for the general population. Without support for the needs of persons with psychosocial disabilities, conflicts of interest onresources and property may arise as an additional reason for segregation and institutionalization of persons with psychosocial disabilities.

- Regarding article 19.c , to enable participation and inclusion in the community, an adequate standard of living, social protection and support must be ensured, including provision and facilities for independent living of persons with psychosocial disabilities.

Barriers to social participation

Persons with psychosocial disabilities in the community face many barriers to social participation in virtually all aspects of life, such as discrimination, poverty barriers, an overall lack of support, and a lack of freedom and rights on an equal basis with others, including limitations of 'the right to act', which results in a limited life, bereft of options, chances, choices and opportunities that others have.

Attitudinal barriers and discrimination form a major obstacle preventing accessibility, participation and inclusion of persons with psychosocial disabilities on an equal basis in the community. Discrimination of persons with psychosocial disabilities in the communities across Europe takes many forms, ranging from abuse in local communities to formal exclusion from education or workplaces, from being disowned of one's possessions to being exploited in unpaid work or in work "shelters", from lifelong institutionalization to full neglect as a homeless person. The common factor in all these forms of discrimination throughout life in the community, is the discrimination in itself, which is a major obstacle for independent living of persons with psychosocial disabilities.

Across Europe, many children with psychosocial disabilities are rejected from mainstream schools and referred to special schools or segregated institutions, which often only provide basic and elementary learning. Unemployment rates are strikingly high amongst persons with psychosocial disabilities, which affects independence, and again illustrates the marginalized position in the community. Persons with psychosocial disabilities are at a four times higher risk of being exposed to violence and abuse than their non-disabled peers[9]. ENUSP has received testimonies of police violence, where persons with psychosocial disabilities were taken by the police and transported out of the local community and dropped off somewhere else, or taken to jail, sometimes including beatings by police officers[10], often with impunity.

- Regarding article 19.c, attitudes throughout the community need to be changed to foster accessibility, participation and inclusion of persons with psychosocial disabilities as valuable and equal members of the human family.

Barriers to advocacy

[9] WHO Violence against adults and children with disabilities 2012http://www.who.int/disabilities/violence/en/

[10] Amongst others in Czech Republic and Belgium (R.I.P. Jonathan Jacob)

The existence of legal norms contrary to the CRPDon substitute decision-making, forced institutionalization and forced psychiatric treatment is an insurmountable barrier to access to justice for people with psychosocial disabilities. Existing domestic and regional monitoring mechanisms often lack awareness of the right of persons with psychosocial disabilities to live in the community.

- Regarding 19.c, training and awareness raising ofdomestic and regional monitoring mechanisms on the CRPD is needed, as well as inclusion of persons with psychosocial disabilities in the monitoring mechanisms, and the true independence of such monitoring mechanisms from the State.

DPOs of persons with psychosocial disabilities do not exist in all countries in Europe. Discrimination based on perceived psychosocial disability or diagnosis may prevent persons with psychosocial disabilities from successfully registering or obtaining funding for their DPO.

- Regarding the normative content of article 19, persons with psychosocial disabilities should be enabled and supported to organize and represent themselves independently.

3. Segregation in the community

Mainstream services for the general population, such as housing services, shelters, schools, work places, recreational activities quite often exclude persons with psychosocial disabilities and may refer to 'specialized services'. Currently, under the flag of de-institutionalization or 'specialized'community based initiatives, several institutional habits are finding a way into the community, such as segregation in smaller-sized institutions (transinstitutionalization), sheltered unpaid /underpaid work, and outpatient forced treatment such as Community Treatment Orders (CTOs).

Forced treatment in the community

Community Treatment Orders (CTOs) are an extension of forced psychiatric treatments into the community, which implies a conditional suspension of forced institutionalization subject to compliance with forced psychiatric treatment regulations in the community, such as taking psychotropic medication, which is in itself a form of social control. Anyhealth care treatment should be based on free and informed consent of the person concerned.

- Regarding article 19.b, like any other form of forced psychiatric treatment, Community Treatment Orders should be regarded as acts of torture and other cruel, inhuman or degrading treatment or punishment, and should be absolutely prohibited.

Reinstitutionalization/ Transinstitutionalization

In many countries the deinstitutionalization strategies entail relocation of persons with psychosocial disabilities in group homes or living centres of a different size, which however maintain the same attitudes and result in the same segregation under a different name.The general prison population has increased in all EU countries (between 16% and 104%), which is suggestive of reinstitutionalization and possibly a result of general attitudes towards risk containment in these societies[11].

Segregated workplaces

A growing number of persons with psychosocial disabilities are placed in segregated work settings or work under segregated contracts, by which they earn less for their work than non-disabled persons do by law, or earn nothing at all, which compromises the opportunity to achieve independence.

- Regarding article 19.b, initiatives that maintain social inequality and segregation of persons with psychosocial disabilities must be put to an end.

Conclusion

The CRPD guarantees the equal enjoyment of all human rights and all fundamental freedoms on an equal basis to all persons with disabilities, including those with psychosocial disabilities. Among these rights are legal capacity, liberty, freedom from torture and other ill-treatment, and the right to health care based on free and informed consent. There is no room under the CRPD for a separate and unequal regime of non-consensual interventions applicable solely to persons with real or perceived psychosocial disabilities[12],[13]. This should be reiterated in the General Comment.

[11] JAMHWB, WP5, page 30

[12] General Comment on article 12

[13] Guidelines on article 14

Attachment 1: Deinstitutionalization in practice in Romania

Summary received from Romanian ENUSP members, Monica Obreja and Amalia Jurj, on deinstitutionalization in Romania:

In late January, the Romanian Government issued a proposal regarding a program of national interest on the protection and promotion of the rights of disabled people titled "The development of social services such as day centers and protected housing with the aim of deinstitutionalizing people with disabilities living in institutions and preventing the institutionalization of disabled people in the community". According to this program, 1300 disabled people (adults) will be deinstitutionalized between 2015-2023: 516 people with the help of European funds, and 784 with national money. By funnelling national and EU monies into establishing smaller institutions (group homes) and day centers in the community, this program was designed without any participation of disabled people formerly or currently living in institutions. The government has no further plans to comply with the CRPD requiring explicitly the involvement of disabled people, including those with psychosocial disabilities, in the process of deinstitutionalization. Also, the government deliberately chooses to ignore the Thematic study on the right of persons with disabilities to live independently and be included in the community Report of the Office of the United Nations High Commissioner for Human Rights[14], that emphasizes the dangers of further promoting institutionalization through a said deinstitutionalization process that ignores certain fundamental issues, among others: the lack of a thorough understanding of what institutionalization entails, the focus solely on the interests of service-providers, no alternative community-based services, the conditionality of support upon certain living arrangements etc. The Thematic study also points to one of the main drivers of institutionalization - the deprivation of legal capacity that continues to be allowed also in the Romanian national legislation, and that is currently not identified as a human rights infringement in the government's program of deinstitutionalization.

In February, an informal Romanian group of users and survivors sent a position statement to the government in response to the government's proposal, by detailing all of the above barriers to a legitimate process of deinstitutionalization (with particular reference to Articles 19, 12 and 14), while also commenting on the power relations that institutional culture is founded upon and that will continue to be reproduced in smaller institutions, as well as in the functioning of other community services like day centers, unless they are substantially challenged and replaced by alternatives designed and controlled by disabled people themselves and by a culture of support and supported decision-making between equals. The official letter of reply from the government disregarded all suggestions and comments made, by making clear once more that the only people involved in designing and implementing this national program further will be those who are already in a position to control the lives of people currently living in institutions while also deciding on their behalf, thus instantiating an ableist discourse oblivious to the systematic denial of human rights that disabled people living in institutions experience in Romania.

- Deinstitutionalization cannot be a legitimate process unless it responds to the rights, preferences and needs of people currently living in institutions.
- Deinstitutionalization requires that any laws authorizing the denial or restriction of legal capacity on the basis of disability be abolished.

[14] http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session25/Documents/A-HRC-25-29_en.doc