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# Perspectives for public policies in mental health. Sick or well – a citizen first: The (Ex-)User/Survivor Voice in Democracy

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**Abstract.** The European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP), founded in 1990, is the only independent organization of its kind in Europe - self-governed by people with psychiatric experience only. We provide a means of direct democratic representation and a voice to promote, defend and protect our rights and interests. ENUSP has been called on as a stakeholder in Europe by the UN, the WHO, the EU Parliament, the EU Commission and other mental health and disability non-governmental organizations, in spite of our limited resources. Our contribution to a reflection on how public policies in mental health can be designed, improved and implemented takes a life-long approach to recommend policies throughout the various stages of a person's lifetime. ENUSP recommends an approach based on human rights, social inclusion and well-being where all stakeholders, and especially those impacted by these policies, are meaningfully involved in all stages, rather than the biomedical, top-down approach so often used by States from cradle to coffin. Greater resources must be devoted to high-quality, non-stigmatizing, easily accessible and personalized prevention and support services in the community, as well as for the required involvement of (ex-)users/survivors and our representative organizations. There is no need to reinvent the wheel, as many great instruments and recommendations have existed for a number of years and it is high time they were implemented. ENUSP sees this as an opportunity to develop user-led projects and activities where the goals of our organization match the recommendations of the UN CRPD Committee, EU and WHO policies in order to reach a consensus on public policy in mental health.

**Key words:** psychiatry, mental health, human rights, social psychiatry, alternative to hospitalization, humane care, patients' rights, mental health service user, citizenship, health policy

**Résumé. Malade ou bien portant, un citoyen d'abord : la voix des (ex-)usagers et survivants en démocratie.** Le Réseau européen des (ex-)usagers et survivants de la psychiatrie (ENUSP), fondé en 1990, est la seule fédération européenne indépendante œuvrant dans notre domaine en Europe et auto-administrée uniquement par des personnes ayant eu une expérience en psychiatrie. Nous offrons à nos membres les moyens d'une représentation démocratique directe et une voix pour promouvoir, défendre et protéger nos droits et nos intérêts. L'ENUSP est partie prenante en Europe auprès de l'ONU, de l'OMS, du Parlement européen et de la Commission européenne, ainsi que d'autres ONG de santé mentale ou représentant les personnes handicapées et ce, malgré nos ressources financières limitées. Notre contribution à cette réflexion à propos de comment les politiques publiques peuvent être conçues, améliorées et mises en œuvre est fondée sur une approche tout au long de la vie afin de recommander des politiques pertinentes et appropriées aux différents stades de la vie. L'ENUSP préconise une approche basée sur les droits humains, l'inclusion sociale et le bien-être intégrant toutes les parties prenantes et notamment ceux qui sont impactés par ces politiques qui doivent être impliquées de manière significative et effective à toutes les étapes plutôt que l'approche descendante et biomédicale si souvent utilisée par les États « du berceau jusqu'à la tombe ». Des ressources plus importantes doivent être allouées à des services de prévention et de soutien de qualité, non-stigmatisants, facilement accessibles et personnalisés, ainsi que pour assurer l'implication nécessaire des (ex-)usagers et survivants et nos associations représentatives. L'ENUSP estime que cela représente l'occasion de développer des projets et des activités menés par les usagers où les objectifs de notre réseau correspondent aux recommandations du Comité de l'ONU de la CDPH, à la politique de l'UE et de l'OMS afin d'atteindre un consensus sur la politique publique en matière de santé mentale.

**Mots clés :** psychiatrie, santé mentale, droits de l'Homme, psychiatrie sociale, alternative à l'hospitalisation, humanisation des soins, droit du malade, usager, citoyenneté, politique de santé

**Resumen. Enfermo o sano, primero un ciudadano. La voz de los (ex)usuarios y supervivientes en democracia.** La Red europea de (ex)usuarios y supervivientes de la psiquiatría (ENUSP), fundada en 1990, es la única federación europea independiente con actuación en nuestro campo en Europa y auto-administrada únicamente por personas con una experiencia en psiquiatría. Brindamos a nuestros miembros los medios para una representación democrática directa y una voz para promover, defender y proteger nuestros derechos e intereses. La ENUSP es parte activa en Europa colabora con la

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ONU, OMS, el Parlamento Europeo y la Comisión europea, así como otras ONGs de salud mental o que representan a las personas con discapacidad. Y eso a pesar de nuestros recursos financieros limitados. Nuestra contribución a esta reflexión acerca de cómo las políticas públicas pueden concebirse, mejorar y ponerse en marcha está fundada en un enfoque a lo largo de la vida con el fin de recomendar políticas pertinentes y apropiadas a los diferentes tramos de toda la vida. ENUSP preconiza un enfoque fundado en los derechos humanos, la inclusión social y el bienestar integrando todas las partes activas y especialmente aquellos que están afectados por estas políticas que deben ser implicados de modo significativo y efectivo en todas las etapas antes que el enfoque descendiente y biomédico tantas veces utilizado por los Estados "desde la cuna hasta la tumba". Deben asignarse recursos más importantes a unos servicios de prevención y de apoyo de calidad, no estigmatizantes, fácilmente accesibles y personalizados, así como para asegurar la implicación necesaria de los (ex)usuarios y supervivientes y nuestras asociaciones representativas. ENUSP considera que esto representa la oportunidad para desarrollar proyectos y actividades llevadas por los usuarios en los que los objetivos de nuestra red se corresponden con las recomendaciones del Comité de la ONU de la CDPH, a la política de la UE y de la OMS con el fin de alcanzar un consenso sobre la política pública en materia de salud mental.

**Palabras claves :** psiquiatría, salud mental, derechos humanos, psiquiatría social, alternativa a la hospitalización, humanización de los cuidados, derecho del enfermo, usuario, ciudadanía, política de salud

The European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP) was founded in 1990 and is the only independent organization of its kind in Europe – self-governed by people with psychiatric experience only and providing (ex-)users and survivors of psychiatry a means of direct democratic representation. The purpose of ENUSP is to constitute a European forum for the voice of (ex-)users and survivors of psychiatry to promote, defend and protect our rights and interests.

The aims and mission of ENUSP include defining, promoting and advocating for and improving the full human rights and self-determination of (ex)users and survivors in forums that decide about our lives. ENUSP supports the self-representation of users/survivors, the development of user/survivor organizations, the production and exchange of user/survivor knowledge and alternatives and more recently, the full implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) throughout all of Europe.

This contribution to a reflection on how public policies in mental health can be designed, improved and implemented from the (ex)user/survivor perspective takes a life-long approach to explain how we recommend policies be put in place throughout the various stages of a person's lifetime.

### **Childhood and youth – the importance of talking about “it”**

Childhood and youth are very important stages in life when people learn intensively and build the foundation for their adulthood. This is why it is so important for children to learn how to deal with stress, how to manage emotions and avoid behavior and influences that may lead to serious problems. Young people need to learn how to be attentive to their mental health and strike a good balance between educational and future career aspirations and their mental

resources. Childhood and youth is also the best time to learn how important it is not to stigmatize others and instead, how to support those in need or who may be “different”.

All persons involved in a child's education and upbringing process need to be made more aware of and specifically trained to deal with mental health problems children may experience as they grow up. Teachers, in particular, should be in a position and prepared to provide support and foster the continuing education of youngsters at their own pace. Families need to be informed and to be involved in the care and recovery process as part of a team with the child in the center.

Based on the experience of our members, this type of early intervention could significantly improve the experience and prognosis of individuals early in life and prevent a lot of suffering for everyone involved.

ENUSP recommends that educational programs be established for teachers, for school children and for family members not only *via* official curriculum, but also through regular “talk sessions” in schools. These sessions should include mental health professionals, representatives of non-profit mental health and (ex-)user/survivor organizations, family members with carer experience and above all, individual users themselves who participate by sharing not only their experience, but their opinions and advice. The role of “user-experts” in this case should be that of a promoter, an active educational collaborator under equal conditions with all members of the team and all participants should be remunerated through public funds (see *figure 1*) [1].

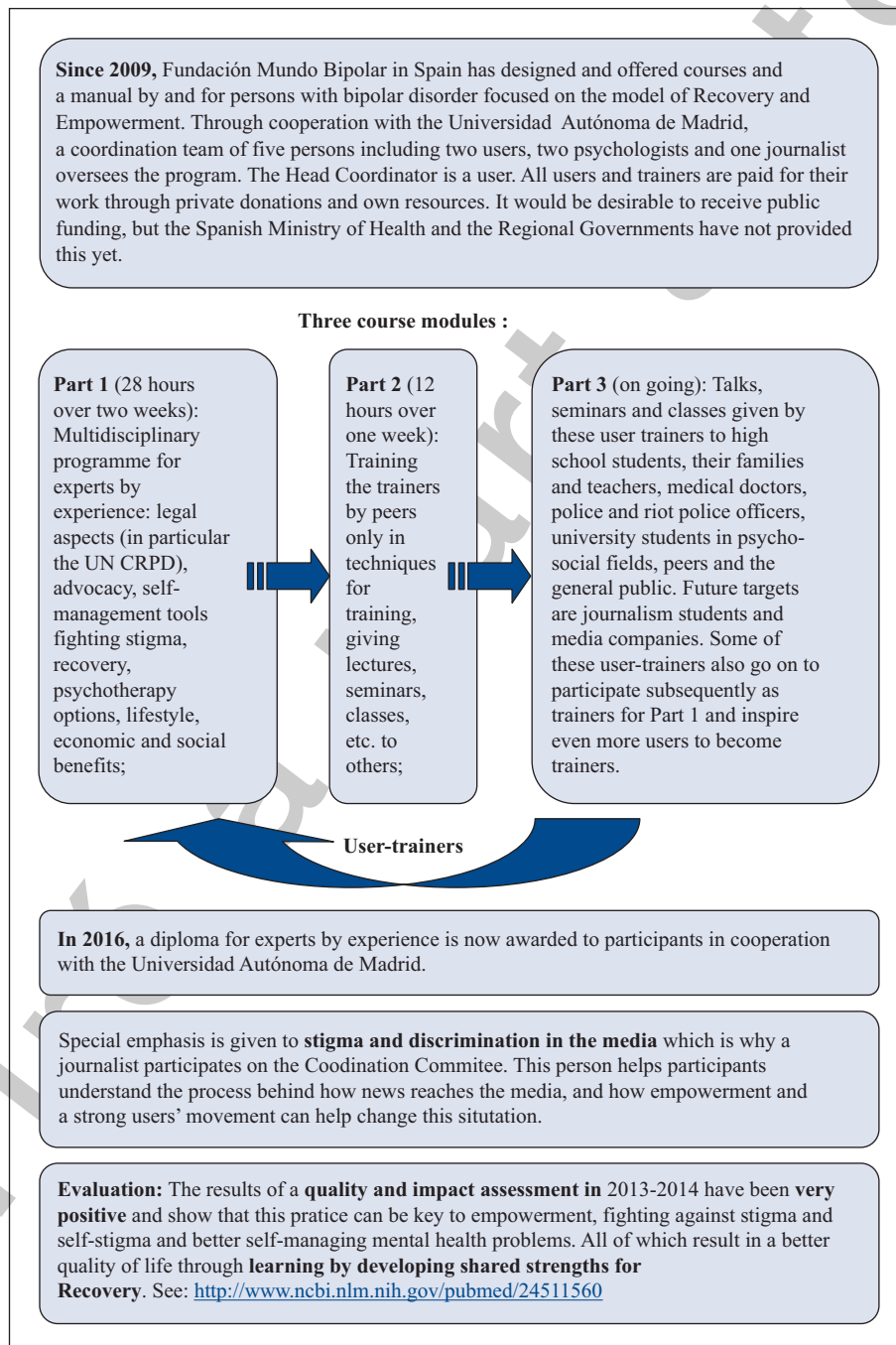
Formal university curricula for teachers should include information on all learning disabilities children may experience due to anxiety, emotional distress, depression, etc. and again including presentations and training dispensed by (ex-)users and survivors of psychiatry.

Indeed, regarding this point, the recent European Framework for Action on Mental Health and Wellbeing [2] states that:

*“(...) the analysis of different countries revealed that teachers and school staff are not always fully equipped to cope with this responsibility, particularly when it comes to the detection of early signs of mental and behavioral disorders, for prompt referral purposes, as well as lacking training in effective programmes to prevent mental disorders and promote mental health.”*

As user-experts, we feel it is important to promote and ensure wellbeing, rather than to increase reliance on medication. The aim is to support people with a healthy lifestyle

from a young age: enough sleep, physical exercise, good eating habits, relaxation techniques, etc. and information about the dangers of drugs, alcohol and bullying, the risk of suicide and what to do about it. In addition, attention must be paid to supporting the individual development of children and youth, their self-realization, social integration, positive relationships with family and friends. This means taking action on the first line of fire and trying to solve problems before they get pathologized. For depression in children and young people, for example, NICE guidelines recommend “stepped care” and psychotherapy before medicalizing young people in the



**Figure 1.** Education: a key tool for recovery and the fight against stigma.

case of mild forms of depression [3]. The Open Letter petition to the DSM-5 Task Force and the American Psychiatric Association launched by the Society for Humanistic Psychology obtained 15,400 signatures from professionals and concerned citizens worldwide that the DSM-5 was “*likely to result in the pathologizing of normal variations in human behavior*” [4].

This is particularly a risk for children in care homes and foster care, where widespread prescribing of psychotropic drugs has occurred. According to the U.S. Government Accountability Office and the Children’s Defense Fund, nearly one in four children in foster care is taking at least one psychotropic medication – more than four times the rate for all children. Nearly half of children living in residential treatment centers or group homes take psychotropic medications. Children in foster care are more likely to be prescribed multiple psychotropic medications at very high doses, although research shows higher doses can result in serious side effects [5, 6].

Access to high-quality, non-stigmatizing prevention and support services in the community must be made very easy so that young people and families know immediately who to reach out to when they experience a mental health problem or crisis. Receiving a “diagnosis” in itself is very stigmatizing for a young person.

Likewise, user-experts should regularly be called on to participate in the training of mental health professionals and general practitioners with real input and not simply guinea pig-like testimony as is too often the case [7]. When young people are in the care of child psychiatrists, they need to be provided with much more information, educational tools for the family and truly open communications.

The added value of these types of more personalized and humane educational and health care policies which include the input of (ex-)users and survivors of psychiatry would be the elimination of stigma and discrimination against children with psychosocial disabilities, early prevention and the promotion of mental health for all. Less chronicity and less valuable years lost in terms of young people’s academic, employment, emotional, family and social lives would also be gained [8].

## Adulthood and being part of the community

Adults should feel free to reach out to mental health services in the community, know easily where help is available and receive immediate attention. Currently, this is far from the case due to a number of factors, including stigma, fear, a lack of access and a lack of funds devoted to high-quality community mental health care. Laws to ensure parity between mental and physical health care and insurance coverage are necessary.

In ENUSP’s opinion, community care must take a much more holistic approach with the involvement of medical doctors, psychologists, nurses, social workers, occupational

therapists, non-profit user and carer organizations, as well as paid user-experts working as peers. Some of the main quality indicators of community care should include the satisfaction level of users, their involvement in the design, implementation and monitoring of services and whether the right of patients to plan and review their own care plans, including advance directives, is respected. Once again, the excessive reliance on pharmaceutical treatments to the detriment of therapeutic alternatives, such as psychotherapy, stress management and personal development have in fact led to greater chronicity, disablement and the denial of our rights as (ex)users and survivors of psychiatry to be full-fledged citizens as active, participating members of the community. Therefore, additional quality indicators of community care should include those aspects impacting the patient’s well-being, such as therapeutic alternatives, psychotherapy options, whether pharmaceutical treatment can be refused, whether physical health is taken care of and if training is provided to manage stress and have a healthy lifestyle. Quality indicators should also cover whether self-help groups, peer2peer contact and personalized care plans are available.

The lack of awareness and humanity often displayed by mental health, primary care and emergency care professionals is not their fault and can be due to a lack of training in communications with patients and families, a focus on a biomedical approach under the pressure of the pharmaceutical industry and an underfunded mental health care system. This has caused great damage.

A personalized, humane approach is especially needed in the case of mental health care, and here is the challenge. It is not easy to put a personalized approach in the system, because systems are not personalized. They work like machines. This is why additional efforts are needed in order to build a system that is as personalized as possible.

Additionally, because of the UN CRPD and its impact on mental health care particularly, we have a great challenge ahead of us: it is necessary to activate communities, unite them, make them informed and supportive for people with different needs. Without ‘small places close to home’, implementation of the UN CRPD is simply not possible. Trying to achieve good results without activation of communities is like expecting large blood vessels to deliver oxygen to all parts of the body, without working capillaries. The distance between the person and the necessary service may become lethal if others around are not responsive, informed and ready to help each other. Also, people will continue to develop mental health problems and existing problems will get worse if society is intolerant, ignorant and not ready to support those in need.

## Parenthood

Throughout Europe, many persons with mental health problems or diagnosed with a psychiatric “disorder” are firmly discouraged or even prohibited from becoming a parent. If they already have a child, the issue of custody



becomes a central focus, breaking the hearts of parents or taking away their dreams to have a family of their own [9]. Coerced contraception, abortion and forced sterilization, particularly for persons with intellectual disabilities and increased prenatal testing are also issues which concern ENUSP.

Special mental health support is necessary for pregnant women and young mothers and fathers, and not just those with psychosocial disabilities. Pregnant women may be victims of home violence. When there are family conflicts, pregnant women with psychosocial disabilities should have the right to move to a shelter, rather than be sent to a psychiatric institution as is often the case in Georgia, for example, where women's shelters do not accept pregnant women with a psychiatric diagnosis.

In addition, measures to eliminate stigma are necessary and psychiatrists must take the reproductive health of their patients seriously. Therefore, we recommend that a multidisciplinary team advise and inform patients in an appropriate and accessible way about the potential adverse effects of medication on reproductive health, ascertain what the plans of the patient herself are and provide appropriate treatment according to her reproductive plans. All risks must be explained to patients and they should subsequently make the decision themselves once informed. Finally, facilities which care for both mothers and their child together, including overnight care and hospitals, can make all the difference in the life of both the parents and their children.

## Hospitalization

If and when a person's mental health necessitates hospitalization, it should be remembered that this is a crucial and exceptional stage in a care pathway, particularly when it comes to a first hospital admission. The experience of being hospitalized, often equated with giving up and letting someone else take care of you, has been one of the most traumatic experiences our members have ever had in their lives. This is particularly true with the case of forced hospitalization.

ENUSP is against forced hospitalization and treatment. "Care" cannot be given without the consent of the person concerned and again has a major impact on prognosis. Institutional, long-term systems are still too often the only solution, when smaller, community-based overnight facilities where the person going through a difficult time can rest, be taken care of, feel safe and recover, particularly with the assistance of peers, are far more preferable and have proven to be more efficient and cost effective. There are an increasing number of such good practices, including open dialogue and peer-run initiatives, along the lines of the Soteria network in a dozen U.S. States<sup>1</sup> [10] and crisis and respite

centers open 24/7 every day of the year. There are even a few closer to home here in Europe, in Sweden and Germany, which are funded by the public health authorities. This type of care also leads to greater efficiency, significant cost savings, "concordance" of patients with their care and better outcomes [11-13].

Perhaps due to the prevailing paternalistic, top-down, repressive and fear-based approach in Europe, these initiatives are still few and far between here. This is one of the reasons an essential and often forgotten aspect is so important – human rights in psychiatry. The concluding observations and recommendations of the UN CRPD Committee issued to many States and the European Union as a whole are clear on this point<sup>2</sup> [14]. Quality indicators and quality control must be developed in close collaboration with user/survivor organizations. If we consider the reform of the system, not medical or societal beliefs or considerations, a human rights approach should be the first reason for change. All players involved, including medical practitioners, psychiatrists, nurses, social services, judges, lawyers, patients and families themselves need to be trained and made more aware of human rights in psychiatry and the rights of persons with psychosocial disabilities under the UN CRPD. These persons, including user-experts can go on to train others. When these rights are violated, national and local entities with legal advisors and lawyers to defend people with psychosocial disabilities must be available and the results channeled to the European Union and the United Nations authorities.

The UN CRPD Committee has also recommended that the European Union develop an approach to guide and foster de-institutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.

Several ENUSP members have developed good practices to avoid hospitalization and institutionalization by working upstream with persons in need, such as the "Personal Ombudsman" program in Sweden operated by PO Skane which is a user-run service with personal mediators for users of psychiatry and particularly those who are isolated and the hardest to reach, or the "Eindhoven Model" launched by Stitching Mind Rights in the Netherlands for supported decision-making using "Family Group Conferencing" in psychosocial crisis situations to avoid forced psychiatric interventions and substitute decision-making [15]. These

<sup>1</sup> Soteria network (U.S.): <http://www.power2u.org/peer-run-crisis-services.html>, Hotel Magnus Stenbock (Helsingborg, Sweden), Berlin Runaway House (Germany): <http://www.weglaufhaus.de/>

<sup>2</sup> Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities - The right to liberty and security of persons with disabilities (Adopted at the CRPD 14th Session 17 August-4 September 2015), see: <http://search.ohchr.org/results.aspx?k=Guidelines%20on%20Article%2014%20CRPD>

practices ensure that users are informed of service options and are in a position to choose the care they prefer based on support for their own decisions.

## Middle age

In addition to the so-called “mid-life crisis” many people go through, it is important to remember that people who develop mental health problems later in life can easily lose their job and often their family as well. This can be due to misunderstandings, stigma and in certain cases, the burden placed on the other, unprepared members of the family. Here again, more attention must be paid to information, family relationships and the impact of mental health difficulties. Adverse effects of medication often cause sexual dysfunction and need to be dealt with seriously and openly by mental health professionals. This is when information in order to overcome the stigma and lack of understanding of other family members becomes so important, as well as support in other social aspects of life.

## Senior citizens - the “golden years”

Depending on how persons with psychosocial disabilities or mental health problems have “been cared for” or have experienced recovery in earlier stages of their lives, their golden years will be more or less a positive time for them. It is now a well-known fact that persons who have been under psychiatric treatment have a life expectancy which is 10 to 25 years less than the general population. In spite of this, not enough initiatives are being taken to ensure their wellbeing.

In addition, more than 800,000 people die by committing suicide every year—around one person every 40 seconds - according to the WHO’s first Global Report on Suicide Prevention published in September 2014 [16]. Even more shocking is the fact that suicide rates globally are highest in people aged 70 years and over and are in many cases unaccounted for. Six European countries are in the top twenty countries with the highest estimated suicide rates globally in spite of their higher standard of living and suicide prevention strategies. Something is not working right.

Society and the community have a lot to do with this situation and the complaints or the poor physical and emotional state of the elderly are still too often ignored, as if it were normal not to have a proper set of teeth to eat or to be depressed because you are “old”.

The excessive prescription to the elderly of antipsychotics without being evaluated by a mental health professional, particularly in nursing and care homes for behavioral problems and dementia has led to greater mortality and the risk of falls and accidents [17]. In the end, are we being medicalized from “cradle to coffin”?

Recent initiatives in the area of intergenerational homes [18, 19] in a number of countries are proving to be a solution. This answer to the growing crisis situation to find a response

to housing needs for the booming elderly population can save on costs, avoid institutional care and help seniors gain the independence, security and emotional support we all need at any stage of life.

Engagement with and support in the community, regular contact, including by phone and home visits for the elderly and particularly follow-up for those who have attempted suicide, are essential.

## Reinventing the wheel?

Many proposals, papers, instruments, action plans and incentives have been designed throughout the years calling for improvements in mental health care, de-institutionalization, community care, as well as user and carer involvement. Most of them have resulted in no or very little implementation, suffer from a lack of national commitment and financing and seem to constitute wishful thinking.

Many of these great proposals relegated to oblivion could be regenerated, starting with the recommendations of the 2001 World Health Report – Mental health: New Understanding, New Hope [20], which called for the involvement of communities and the inclusion of families and consumers in the development and decision-making of policies, programs and services. The purpose of this involvement was to lead to services being better tailored to people’s needs and better used, taking into account age, sex, culture and social conditions so as to better meet the needs of people with mental health problems and their families.

The 2005 Mental Health Declaration for Europe [21] announced in Helsinki was another great instrument providing hope to our community for the support and involvement of non-governmental organizations active in the mental health field, as well as the empowerment of vulnerable and marginalized people and advocating their case. The States which signed on to this Declaration promised to actually “stimulate” the creation of non-governmental and service user organizations so that they would be in a position to engage in developing their own activities, including the setting up and running of self-help groups, training in recovery competencies and providing community-based services involving users. A little over 10 years later, this does not appear to have become the case for ENUSP member organizations, which continue to struggle with insufficient funding.

More recently, the EU European Pact for Mental Health and Well-being (2008), the resulting Joint Action for Mental Health and Well-being (2013-2015) and now the European Framework for Action on Mental Health and Wellbeing launched in January 2016 and the Millennium Development Goals also contain similar recommendations welcomed by ENUSP.

This last instrument and the EU Joint Action clearly stressed the necessity to revise and update mental health legislation in line with the principles of recovery and in accordance with the provisions of the UN CRPD. But States

have failed to promptly enact the required domestic legislation to ensure that persons with psychosocial disabilities enjoy full legal capacity, the right to decide about their lives through supported decision-making systems, the right to live in the community and to enjoy equitable access to resources such as education, employment, health care and social and legal support systems. Only one EU Member State (Ireland) has yet to ratify the UN CRPD ten years after it was enacted.

Above all, the UN CRPD and the concluding observations and recommendations of the UN CRPD Committee represent the most important step ahead for persons with psychosocial disabilities, including (ex-)users and survivors of psychiatry. Indeed, the key principles to promote and protect our rights enshrined in this Convention explicitly include:

- article 12 on equal recognition before the law of persons with psychosocial disabilities, i.e., enjoyment of legal capacity on an equal basis with others and the right to “supported” decision making and not “substitute” decision making;

- article 14 on liberty and security of the person which prohibits deprivation of liberty and forced treatment of persons with psychosocial disabilities as unlawful discrimination;

- article 19 on living independently and being included in the community, i.e., the right to choose your place of residence and access the necessary support;

- article 33 on national implementation and monitoring of the Convention, requiring that persons with disabilities and their representative organizations be involved and participate fully in this process.

ENUSP has continuously provided input to the United Nations and the UN CRPD Committee from the time the Convention was drafted to each stage of the monitoring process<sup>3</sup>.

The above instruments and recommendations are very important and it is high time they were implemented. Public policy in the field of mental health must be built based on a consensus reached between policymakers and citizens concerned themselves. ENUSP sees this as an opportunity to develop user-led projects and activities where the goals of our organization match the recommendations of the UN CRPD Committee, EU and WHO policies.

## Conclusion

In order for the above recommendations to be implemented, a stronger service user/survivor movement is necessary. History has shown that a number of groups faced with similar types of discrimination and treatment, such as the suffragettes, AIDS patients and the LGBT community

<sup>3</sup> ENUSP. Shadow report on the UN CRPD implementation in the EU, 2015. See: [https://ru.scribd.com/doc/299341410/ENUSP-Shadowreport-on-EU-and-Submission-of-ENUSP-for-the-Day-of-General-Discussion-\(DGD\)-on-the-right-of-persons-with-disabilities-to-live-independently-and-be-included-in-the-community](https://ru.scribd.com/doc/299341410/ENUSP-Shadowreport-on-EU-and-Submission-of-ENUSP-for-the-Day-of-General-Discussion-(DGD)-on-the-right-of-persons-with-disabilities-to-live-independently-and-be-included-in-the-community), 2016. See: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CallDGDtoliveindependently.aspx>

have been able to achieve recognition, enforce their rights and become full-fledged partners in all public policies concerning them. (Ex)users and survivors of psychiatry are still at a stage where they are ignored and instrumentalized, not only by governments but also by professionals.

However, before speaking about the meaningful involvement of (ex)users/survivors of psychiatry, we need to address “the power differentials that exist between users/survivors and professionals... the question that is seldom frankly addressed by professionals”, as well as the fact that “the term ‘involvement’ often means very different things to different participants” [22].

In order to achieve a stronger user/survivor movement, representative organizations deserve proper recognition not only in preach, but also in practice. This requires that our organizations have access to funding both on the national and on the EU level *via* support and proper accommodation. ENUSP member organizations and our representatives throughout the years have insisted on the importance of being at the center of all processes impacting our lives. Today, we congratulate ourselves for being interlocutors in Europe, with the United Nations, the WHO, the EU Parliament, the EU Commission, other mental health and disability non-governmental organizations, in spite of extremely limited resources, but at what cost to our activists’ personal and professional lives? So much more could be done to improve the situation of persons with psychosocial disabilities and to improve and promote the mental health of all people if the representative organizations of these persons had sufficient financial resources.

Public policy must be co-designed by those persons impacted by it, based on equal conditions of representation, and in our field, with (ex)users and survivors of psychiatry who act in the capacity of partners, promoters and colleagues to our elected officials and health authorities, as well as in mental health care settings. Only this will lead to a true consensus on what we all can do to improve public policy together.

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