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Committee on Social Affairs, Health and Sustainable Development

Minutes

Public hearing on "Deinstitutionalisation of persons with disabilities", held by videoconference, on Tuesday, 16 March 2021

In the framework of the report currently in preparation on "Deinstitutionalisation of persons with disabilities" by Ms Reina de Bruijn-Wezeman (Netherlands, ALDE), the Committee held a public hearing composed of three sessions.

Mr Leite Ramos, Committee Chairperson, briefly introduced the speakers and welcomed everyone to the hearing.

Ms de Bruijn-Wezeman (as Rapporteur) pointed out that 2021 was an important year for mental health in the Parliamentary Assembly, because it would be laying the groundwork for two key reports: 1) the report on deinstitutionalisation of persons with disabilities already underway and 2) an opinion, for the organisation's Committee of Ministers, on the draft additional protocol to the Oviedo Convention on involuntary measures in psychiatry, the work on which would probably start in autumn. There was an emerging consensus, at both international and European level, that States had a responsibility to transition towards ending coercion in mental health. Ending coercion in mental health and institutionalisation of persons with disabilities was essential to safeguarding human rights and dignity. Institutionalised persons were disproportionally affected by the Covid-19 pandemic, making this question all the more urgent.

<u>Session 1:</u> Deinstitutionalisation of persons with disabilities

Why deinstitutionalisation? What are the benefits of deinstitutionalisation, and how can they be maximised?

- ✓ **Ms Dunja Mijatović,** Council of Europe Commissioner for Human Rights
- ✓ **Mr Gerard Quinn,** UN Special Rapporteur on the rights of persons with disabilities
- ✓ **Mr Andreas Accardo,** Head of Unit, Institutional Co-operation and Networks, European Union Agency for Fundamental Rights (FRA)
- ✓ **Mr Luk Zelderloo,** Secretary General, European Association of Service providers for Persons with Disabilities (EASPD)

Ms Mijatović underlined the urgency of addressing the issue of involuntary institutionalisation of persons with mental health conditions or psychosocial disabilities. In her 2021 issue paper on "Protecting the right to health through inclusive and resilient health care for all", the Commissioner had made recommendations to the member States on how to deal with mental health issues, including the following: making quality services accessible to all; transitioning from institutionalisation to community-based services; and eliminating coercive practices. These approaches should support the integration of mental health into primary care within the framework of the UN Convention on the Rights of Persons with Disabilities (CRPD). The fact that the work continued on the draft Additional Protocol to the Oviedo Convention was regrettable, as it was based on a biomedical approach that reduced mental health problems to mental disorders and enabled forced confinement with virtually no limit on its duration. It was therefore paramount to call on the member States to put an end to the approaches that had been proven to be inefficient, and to prevent practices that perpetuated dehumanisation.

[1]The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 15 April 2021, held via videoconference.

Mr Quinn highlighted the need for the Council of Europe to spread a unified message on deinstitutionalisation and community inclusion. Institutionalisation caused three different types of damage for the individual and for the community: firstly, the intimate bond between the person and the space called “home” was broken, as a portal to human interaction; secondly, in an institution, “voice, choice and control” were silenced; lastly, the relationship with the community changed in a congregated setting, as a “group home” did not reflect the personality of the individual living in it. The Covid-19 pandemic had demonstrated that deinstitutionalisation was not only a human rights issue, but also a public health one. It had exposed the need to use the EU recovery funds to endorse a new human rights-based healthcare model. As Europe moved towards deinstitutionalisation, an intersectional approach had to be developed and the Council of Europe could be a role model in this process.

Mr Accardo presented six lessons, drawn from practical experience in the EU member States, that could help the transition from institutionalisation to community-based living. First, the aim was not mere deinstitutionalisation of the persons with disabilities, but genuine transition to independent living. Second, international strategies had to be adequately funded, independently monitored and complemented by national strategies. Third, communities needed to change attitudes towards persons with disabilities - paternalism and stigma had to be addressed. Fourth, achieving independent living implied more engaging work for local communities. Fifth, guidance had to be provided for applying law and policy to daily realities. Finally, effective community-based services needed to be put in place and tailored to support this transition.

Mr Zelderloo reminded the members that deinstitutionalisation was not only about persons with disabilities, but also children, seniors, the homeless, people struggling with mental health issues and, ultimately, it was about building a more inclusive society. That required developing inclusive education, labour markets, cultural participation and empowerment. This process demanded awareness raising, support for families and communities, and investments in services.

Ms Fresko-Rolfo asked what the experts’ view was on how people with disabilities could achieve an independent meaningful life, free from multilevel discrimination.

Baroness Massey asked how serious the impact of institutionalisation was on families, especially with regard to the Covid-19 pandemic.

Ms Wonner pointed out that the hearing was a step in the right direction. Ms Wonner’s most recent report dealt with the stigmatisation of people with chronic illnesses and disabilities and called on member States to ensure that everyone enjoyed equal rights, including with regard to access to health insurance and the labour market. Unfortunately, people with psychosocial disabilities faced stigmatisation in many countries where institutionalisation had increased.

Mr O’Reilly recalled that, apart from being an urgent human rights issue, deinstitutionalisation was also beneficial to the economy, and asked the speakers what the Parliamentary Assembly could do to further stress this point.

Ms Tanguy asked what the situation was in terms of the transition towards community-based services, and what member States should do with respect to their public policies to achieve deinstitutionalisation, especially of children.

Mr Zenderloo commented that the economic argument could be very effective: people in institutions had to be fully supported while in community-based services they not only needed less support, but they could also be empowered to contribute themselves towards the well-being of their communities.

Mr Quinn suggested that a new social contract was needed. Families and women, who played an important role as informal caregivers, had been heavily penalised in the past; that was why it was also important to work co-operatively. Moreover, the transition from institution- to community-based services could only be possible if there was strong political will, since the necessary tools were already well known.

Mr Accardo stressed the urgency of encouraging member States to use Covid-19 recovery funds for deinstitutionalisation and of ensuring the conformity of national strategies with the new European Disability Strategy. Moreover, monitoring how the funds were spent would be crucial for ensuring the effectiveness of recovery strategies.

<u>Session 2:</u> Ending coercion in mental health

How can we best protect persons with mental health conditions or psychosocial disabilities from violations of their fundamental rights and their human dignity? What is the emerging consensus on how to end coercion in mental health? What are States' responsibilities?

- ✓ **Ms Ritva Halila,** (Finland), Chair of the Council of Europe Committee on Bioethics (DH-BIO)
- ✓ **Mr John Patrick Clarke,** Vice President**,** European Disability Forum (EDF)
- ✓ **Ms Jolijn Santegoeds,** Board member, European Network for (ex)-Users and Survivors of Psychiatry (ENUSP) *(NB: Unfortunately, due to technical connection problems Ms Santegoeds was not able to participate in the hearing. Her contribution has thus been included as an appendix to these minutes.)*
- ✓ **Ms Reina De Bruijn-Wezeman,** former PACE rapporteur on "Ending coercion in mental health: the need for a human rights-based approach"

Ms Halila pointed out that, from a medical perspective, psychiatric disorders were treatable and, in some cases, curable diseases. Hospitalisation was sometimes needed in emergency situations, similarly to the case of highly contagious diseases, when the patients could be hospitalised without their consent. In these situations, the balance between the right to self-determination and the right to life was at stake. As requested by the Committee of Ministers, the aim of DH-BIO was to create an international legally-binding instrument that reduced involuntary measures as much as possible without, nonetheless, abandoning a patient in need. The draft additional protocol to the Oviedo Convention viewed involuntary measures as the last resort, and included protective measures, such as the possibility to submit a complaint to a court, the right to legal assistance, the right to a second opinion and the monitoring of measures. All restrictions of human rights had to have a legal basis.

Mr Clarke explained that involuntary treatments were violations of patients' fundamental rights: they created trauma, solidifying discrimination through paternalistic approaches. The only way to protect these persons was by using a human rights-based approach. Despite an overall international consensus on deinstitutionalisation, the discourse was likely to depend too much on the institutional "territory", as different representatives intervened in different settings. Member States should comply with the legally-binding provisions of the CRPD, rather than legitimise the outdated contents of the draft Additional Protocol to the Oviedo Convention.

Ms de Bruijn-Wezeman reminded the members that already in 2016 the Assembly had adopted Recommendation 2091 making the case against a Council of Europe legal instrument on involuntary measures in psychiatry, and had reiterated that message in 2019 with its unanimously adopted Resolution and Recommendation on ending coercion in mental health. Unfortunately, the Committee of Ministers had not heeded the central recommendation and had allowed work on the draft Additional protocol to the Oviedo Convention to be continued. However, guidelines on ending coercion were also now being drafted, providing positive examples of voluntary measures. Member States should stop practices that did not respect human rights and had not be proven fruitful or cost effective.

Ms Halila expressed her full support for deinstitutionalisation of people with disabilities, which was in line with her current work.

<u>Session 3:</u> Good practices regarding voluntary measures in psychiatry

Which good practices can be identified? How can they be transposed across borders? How can their effectiveness, and the continued satisfaction of users, be monitored?

- ✓ **Ms Michelle Funk,** Unit Head, Policy, Law and Human Rights, Department of Mental Health & Substance Use, World Health Organization (WHO)
- ✓ **Ms Ritva Halila,** DH-BIO Chair
- ✓ **Ms Stephanie Wooley,** ENUSP
- ✓ **Mr Jose Maria Solé Chavero,** EASPD Board Member

Ms Funk presented WHO's QualityRights initiative to improve the quality of care in mental health and social care services. WHO had developed a new series of guidance materials, to support the development of health services that did not use coercive practices, but rather promoted participation and community inclusion by addressing work, family, and education. The recommendations were accompanied by seven technical packages, each encompassing a specific category of service required for a fully responsive mental health system (crisis services, hospital-based services, networks of services, and others). At the end of each package, examples of practical actions were included, to facilitate implementation.

Ms Halila explained that in addition to the preparation of the draft Additional Protocol, DH-BIO was collecting examples of good practices that promoted voluntary care and prevented involuntary measures. In the last few years, DH-BIO had been doing valuable work on collecting and sharing such good practices already, but these were now being collated into a study.

Ms Wooley explained that in her view the draft Additional Protocol would worsen the situation if it was adopted. One of the main problems was the lack of alternative choices, so that people often ended up in an institution "by default". Moreover, Lived Experience Advisory Panels were needed to develop a system that would be in compliance with human rights, with dignity and autonomy, with the right of equal recognition before the law and the right to be free from all forms of torture and ill treatment. Therefore, possible ways of facilitating the transition were: full involvement of the recipients; training of professionals; improvement of physical environments; effective co-operation at the local level; monitoring and reviewing of any use of coercion, and implementation of specific guidelines and recommendations.

Mr Solé Chavero presented a practical example of deinstitutionalisation, stating that 17 years ago his organisation had succeeded in closing a mental health institution in Catalonia that had housed more than 500 residents. The first step had been to block new admissions and to reinforce community-based mental health services. There were many different impeding factors, but there was only one solution for all of them: strong political engagement and commitment. In the future, there would be many obstacles to deinstitutionalisation, including lack of funding for community-based services. The most important obstacle could be noncompliance of national legal frameworks with the human rights-based approach as enshrined in the CRPD.

Mr Amraoui highlighted the need for raising awareness of the situation of women in the context of institutionalisation, which was different and often more difficult.

Conclusions

Ms de Bruijn-Wezeman thanked all the speakers and the audience, reiterating that the times required investments in people rather than in buildings. She agreed with the speakers who believed that the draft Additional Protocol to the Oviedo Convention was not compliant with the CRPD and called for the reinforcement of a human rights-based approach.

Appendix I

European Network of (Ex-) Users and Survivors of Psychiatry

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PACE AS/Soc Public hearing on Deinstitutionalisation of persons with disabilities, 16 March 2021 (on the KUDO platform)

Contribution by Jolijn Santegoeds, board member of the European Network of Users, Ex-users and Survivors of Psychiatry, ENUSP.
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Hereby my written contribution, because a power cut prevented me from delivering my speech and further participating in the hearing.

I would like to react to the comments made by Ms Ritva Halila, Chair of the Council of Europe Committee on Bioethics (DH-BIO). She mentioned that the Draft Additional Protocol to the Oviedo Convention is intended as a legal instrument to prevent abuse and set more uniform standards on the use of coercion, and that this would prevent harm and save lives.

I strongly disagree.

Forced interventions in mental health care, such as solitary confinement, restraints, forced medication and forced institutionalisation are very harmful and do more harm than good.

There is no therapeutic purpose. For example: Being confined does not increase well-being.

> (I can testify from my own experience here. I was locked up and tied to a bed myself, at age 16, after a suicide attempt, which was called "being a danger to myself", and that phrasing led to long-term solitary confinement, and the national law justified these measures. But it was horrible and made me lose faith even more, leading to more suicide attempts. The people that who were supposed to help me did horrible things, and it became a chain of escalations).

Coercion does not lead to more safety, or recovery of mental health. On the contrary: By suffering, powerlessness, and a lack of support, the risks for increasing psychosocial problems and escalation increase. Coercion is the opposite of care. Fear, resistance, crying and screaming are some of the typical first reactions given by persons subjected to coercion, which actually clearly illustrate the counterproductivity of coercion on wellbeing and mental health.

The collective experiences of users, ex-users and survivors clearly show that such measures have nothing to do with protection of rights. Obviously, coercion is actually a deprivation of rights.

Coercion in mental health care is causing tremendous suffering and powerlessness with consent of the authorities of the State, and the people subjected to it are made voiceless by deprivation of legal capacity and liberty, which disable the person from defending themselves or challenging those decisions, and therefore **these practices amount to torture and ill-treatment**.

And obviously, torture must be banned.

Ms Halila claims that in cultures without **legal structures and rights**, there is "mistreatment". Yet, ENUSP flags that also with the legal frameworks in place, there is mistreatment and the situation is no different – except that those measures are no longer viewed as illegal but become "acceptable practices".

> (As an illustration: perhaps you know about the Dutch scandal several years ago, where a boy was tied to a wall in the Netherlands for 3 years, and that practice was considered "legal" because the assumption was that the boy could become agitated, and under the Dutch laws the presumed "danger" justified continuing the restraints, and since the presumption of danger was present throughout the years, there was no actual end to it, so the legal standards were in fact met. This caused public outrage, and eventually he was freed).

Such practices should not be legalised at all. To create acceptance of such practices by legislation is actually not progress, it is deterioration because **it creates impunity for human rights violations.**

The UN CRPD is clear in the call for abolition of involuntary treatments and for deinstitutionalisation, and Europe should lead the way forwards, not backwards.

The Draft Additional Protocol to the Oviedo Convention is setting the bar even lower than the previous global standards dating from 1991, and **the supposed safeguards of "least restrictive option, only as a last resort, as short as possible, as little as possible" all have not worked out,** as we see in the way that coercion is on the rise all over the world. We witness in Europe that the number of cases of coercion has been on the rise for decades, including in countries with legal frameworks, such as France for example. The conditions of institutions around Europe have been documented by various organisations and show unacceptable, gross and systemic human rights violations, where people are "stored", deprived and restrained under very degrading and harsh conditions, with e.g. rats running around and other serious neglect. This is inhuman. This can never be the norm of how persons with disabilities are treated. A need for support should never result in human rights violations.

For many decades coercion has been allowed in Europe, and was considered justified **"in the absence of alternatives".** Which made pure negligence a justified excuse for torture, giving States leeway to use cheap and harmful measures of social control, and to avoid investments in the development of supportive mental health services. Currently the absence of alternatives is still dominating the current situation in most countries, and the supposed "last resort option" of involuntary treatment is a widespread default practice, causing thousands of people to suffer.

The only thing that actually makes a difference in real practices on the ground, is the existence of so-called "alternatives". Once again it should be noted that the human rights based practices should not be referred to as "alternatives", but actually show the **"support gap"** in the basic spectrum of services that support inclusion, and this absence of proper support has caused up until today a culture of torture.

In practice, in most countries there is this support gap and there are no actual "alternatives" to coercion. The right to health and the right to be free from torture and other cruel inhuman or degrading treatment or punishment actually demand that a proper baseline of services be set up and no recourse to coercion ever taken again. And this cannot wait. The abolition of torture is not an issue of progressive realisation, but it has to be done without any delay. The doors must be opened, and all persons must enjoy freedom of choice in treatment and in residence. Community-based support should facilitate independent living and inclusion in the community.

The lack of community-based support is actually the core driver of institutionalisation, and this is not only limited to a lack of specific psychosocial support, but also to a lack of mainstream support options, which can lead to poverty, homelessness, exclusion and violence towards persons with psychosocial disabilities, which are all used as reasons for institutionalisation. The lack of community-based support is not decreased with the use of coercion, and the situation is not getting any better by continuing along these lines. It is purely facilitating exclusion.

The conditions in psychiatric institutions are not those of a wellness resort. In most places it is the total opposite, a dreadful place, especially in central, eastern, and southern parts of Europe, but not only. Institutionalisation as an answer to psychosocial support needs is obsolete, since support need not be linked to a fixed location, but could be mobilised, so **there is no need for deprivation of liberty to provide psychosocial support.**

Ms Halila mentioned "shared decision making" which is a paternalistic interpretation of **the right to legal capacity and the right to support in the exercise of legal capacity**. Mental capacity and legal capacity are distinct concepts. Mental capacities vary from person to person, but the right to legal capacity is the same for everyone. Legal capacity means being entitled to all fundamental human rights on an equal basis with others, including the right to be recognised as a person under the law, with one's own legal standing and legal agency. In simpler words, it comprises the right to decide about your own affairs. To take that right away is taking personhood and identity away, since our choices and decisions reflect our character and make us who we are, and we are a diverse population and not a uniform mass. Depriving a person of legal capacity is therefore often called "civil death".

Support in the exercise of legal capacity is something fundamentally different from depriving people of this core human right. Support may comprise assisting a person in understanding the matter at stake, yet **the actual decision-making power should remain with the person, as a core human right.**

The Draft Additional Protocol to the Oviedo Convention perpetuates stigmatising terminology such as **"persons unable to consent"** which is mostly based on a harmful stereotype and puts for example a derogatory label on the persons who scream that they do not want to be locked up or to be drugged with psychopharmaceuticals against their will, or do not want electroshock therapy and to be treated this way.

The Draft Additional Protocol to the Oviedo Convention suggests **measures such as guardianship** to deprive the person of the ability to have a final say over their own affairs, in order to subject the person to the decision

of others on treatments and placements against their will, even when there is clear resistance. In my opinion, the deprivation of legal capacity is actually the key to all other violations as well, since to stop listening means to stop seeing the other person as a person.

The deprivation of rights by coercion in mental health care as an answer to psychosocial support needs is not a solution, it is a problem. Continuing these practices is certainly not in our "best interest".

The argument by Ms Halila, Chair of DH-BIO, that a choice for **"reduction of coercion" instead of abandoning coercion** would be a strategic choice so as to find a common ground through the Draft Additional Protocol to the Oviedo Convention, makes no sense, since coercion has become unacceptable under mental health support practices. It is not strategic to give leeway to human rights violations and to neglect the right to the highest attainable standard of physical and mental health. There is no compromise possible when it comes to banning torture. The only right thing to do is to end coercion and realise deinstitutionalisation by realising community-based support.

What is needed is a moratorium on all forms of coercion in mental health care. The simplest solution that can start today is to NOT to start any new torture cases, and NOT to start preventative and arbitrary detention based on presumptions, such as 'dangerousness" or "need for treatment". Also NOT to start any new admissions in institutions, because institutionalisation demonstrates a failure to include a person in the community.

We cannot wait to take action until after the Covid-19 pandemic, because the suffering inside institutions is horrible and unacceptable. The Covid-19 pandemic has in fact worsened the situation for persons in institutions even more, and the human rights crisis in mental health care has actually doubled.

Outside institutions, in the community as well, people are suffering without having their psychosocial needs met due to a lack of community-based support in both specific and mainstream services, which eventually leads to psychosocial suffering of the population without available support, and a further rise in institutionalisation as well as psychosocial crisis situations and escalations, not to mention an over-reliance on psychotropic drugs. This can be witnessed throughout Europe. The Covid-19 pandemic also sharpens these existing gaps in the community.

There is an **increasing shortage of actual psychosocial support across the board,** and the Covid-19 pandemic has worsened the situation even more.

The WHO constitution states: *"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."* Yet, while tireless efforts are made to enable medical support during the Covid-19 pandemic, only little efforts are made to protect the psychosocial health of the population, or to support persons with psychosocial disabilities in their needs.

What is needed now, is to give high urgency to the development of community-based support practices, and to actually disable any recourse to coercion or institutionalisation and to make large investments in community-based support in a wide variety, from informal to formal support, from disability specific to mainstream support, and with specific attention for vulnerable and oppressed people such as migrants, youth, persons with disabilities, persons identifying as LGBTQIA and more.

And while the DH-BIO Committee still stoically argues that their Draft Additional Protocol to the Oviedo Convention is "in line with the CRPD" in their opinion, it obviously is not in line with the UN CRPD, as shown by the fact that the UN CRPD Committee itself calls publicly on States to oppose and withdraw the Draft Additional Protocol to the Oviedo Convention.

Persons in crisis deserve more than just another procedure to deprive them of their rights. It is time to actually realise human rights-based support in the community, and the time is now.

ENUSP recommends:

- Withdraw the Draft Additional Protocol to the Oviedo Convention.
- Issue a Council of Europe recommendation on putting an end to coercion in mental health care and promoting good practices.
- Install a moratorium on all forms of coercion in mental health care with urgency.
- Remedy the support gap by establishing a large variety of community-based support options, to be realised with high urgency.
- The Covid-19 pandemic must not cause delay, but rather speed up the process of deinstitutionalisation.
- All parts of the processes must be done in close consultation with persons with psychosocial disabilities through their representative organisations.

Committee on Social Affairs, Health and Sustainable Development
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