CRPD Committee 15th Session side event

Independent Living and Inclusive Communities for Persons with Intellectual and Psychosocial Disabilities: Solutions and Challenges from Europe and Africa

SPEAKERS' NOTES

(Unedited)

Chair: Catalina Devandas, UN Special Rapporteur on the Rights of Persons with Disabilities

Speakers:

- **Oana Gîrlescu**, Lawyer, MDAC. "Moldova: Successes and challenges in deinstitutionalisation"
- **Derrick Kizza**, Executive Director, MHU. "Uganda: Peer support, micro-finance and preventing abuse"
- **Miroslav Cangár**, FORUM: "Slovakia: Measuring quality in community-based services"
- **Emina Ćerimović**, Researcher, Human Rights Watch. "Deinstitutionalisation of children with disabilities"
- **Dragana Ciric Milovanovic**, Director, MDRI-S. "Tackling the problem of trans-institutionalisation"
- **Steven Allen**, Campaigns Director, MDAC. "Minimum State obligations under Article 19 – law, policy, practice"

SPEAKER ONE:

“Moldova: Successes and challenges in deinstitutionalisation”

Oana Gîrlescu, Lawyer, Mental Disability Advocacy Centre

Thank you for attending this discussion and I hope you will find it useful for developing the General Comment on Article 19. Today I will briefly discuss the lesson that we learned from the DI process in the Republic of Moldova, 6 lessons that, in our experience, are relevant for the whole Central and Eastern Europe and beyond.

Background

Moldova has 6 big residential institutions, where about 2,300 people with disabilities live. On the 3rd of March 2016, the Moldovan Ministry of Labour has approved its first comprehensive DI plan. While there are disagreements on some of its content, there is optimism within the Moldovan civil society, with many believing this plan will bring about change. If you are interested we can provide you with more information on it but now, due to the shortage of time, I would like to present you the most important lessons learned from what happened in Moldova :

LESSON ONE: The need for a moratorium on new admissions

In the past years, in Moldova the number of people in institutions hardly changed. While there were 185 people deinstitutionalised, as there was no moratorium, there were 130 new admissions. As this numbers show, the DI process can become, without a moratorium, a vicious circle.

LESSON TWO: International assistance can be crucial, but States still have the primary obligation to achieve deinstitutionalisation

All deinstitutionalisation in Moldova was initiated by NGOs, with funding from international donors. The Government only took over the services for 6 of those deinstitutionalised. Such approach is not sustainable on long term. While international funding and support is to be appreciated, it has to be clear that the State is the main duty-bearer on allocating resources and leading on the process; the State, not NGOs, not local services and not international donors.

LESSON THREE: No one must be left behind.

In Moldova first initiatives of deinstitutionalisation were targeted at children. That happened in Bulgaria as well. While we acknowledge the importance of ensuring children their rights, we want to underline that, within DI strategies, nobody can be left behind: not the elderly, not the most isolated and not the ones with more severe disabilities.

LESSON FOUR: Monitoring is essential

Under articles 16 and 33 of the CRPD, States have the obligation to monitor the DI process, as well as services provided along this process. Besides monitoring institutions, community based services need to be monitored as well. This is necessary to ensure such services do not perpetuate institutional culture. One other important aspect is to ensure access of independent monitors to such services.

LESSON FIVE: Right to independent living in community must be enshrined in law

The right to live in the community needs to be explicitly provided for in national legislation. This enables people to litigate on the issue. Also, segregation in institutions needs to be explicitly recognised as a form of discrimination. Rights that cannot be reinforced through available legal mechanism remain hollow, with those who need them having difficulties to enjoy them in practice.

LESSON SIX: Deinstitutionalisation and legal law capacity reform must be parallel processes.

It is also vital to consider the impact of institutionalisation on legal capacity and decision-making processes. People who have been institutionalised for extensive periods are time, whether formally deprived or not of legal capacity, were not allowed to make decisions for themselves and saw control exercised even over the most basic aspects of their life, such as the clothes they were to wear and the food they were to eat. As a consequence they might need support to augment their decision-making capabilities. The existence of supported decision-making mechanism has therefore to be ensured for all people. Deprivation of legal capacity should never be an option.

CONCLUSION: Deinstitutionalisation is a process – not a goal in itself. Full social inclusion must be the goal.

I would like to emphasise once again the importance of involving people with disabilities in this process, particularly people with disabilities who are institutionalised or have been institutionalised. They are the best to know what they need to be provided with during this process. In our experience it is not uncommon to hear people who live in institutions talking about their fears related to going to live in the community. Nor is it uncommon for people who have been sent to live in the community with no support to manifest their wish to come back to institutions. Involving the people who are the direct target of DI process will help Governments identify the needed services and fully fulfil its obligation to have the right to live independently and be included in the community respected.

SPEAKER TWO:

“Uganda: Peer support, micro-finance and preventing abuse”

Derrick Kizza, Executive Director, Mental Health Uganda

Mental Health Uganda (MHU) is an indigenous, registered, national, membership-based Disabled People’s Organization (DPO) established in response to the overwhelming marginalization, isolation and abuse of rights of people with mental health issues.

We have membership all over the country with close to 20,000 registered members.

We specifically undertake activities in relation to legislation, policy and rights advocacy; community sensitisation and awareness; social research; counselling and peer support; and membership mobilisation.

Peer support and micro-finance

Although MHU is supporting many districts, this presentation will pay much more emphasis to one district- Mpigi.

Mpigi has a district executive committee of 9 members providing leadership to the district association. Membership is extended to users, care givers and, since recently, to psychiatric health workers.

They were supported by MHU secretariat in 2003 to start up a loan and saving scheme run by the executive committee.They lend out money to members who return it with a very small interest rate.

Of the total membership, 46 members have been able to borrow from the loan and savings scheme.

Members often borrow to pay school fees before they harvest from their gardens, engage in farming, small scale trade, and brick making and laying etc.

The executive committee pays visits to the members interested in borrowing and provide advice before lending out the money to the member.

Benefits to the broader membership

With support from the MHU secretariat they lobbied the hospital in Gombe and were given land where they constructed a commercial building for income generation.

In instances when medicines are not available at the hospital, the association contributes money to procure them from the private pharmacies;

Every first Tuesday of the month is a clinic day. Peer counsellors provide counselling to members who come to receive treatment at the health centre. After building trust, more members are saving with the district association.

They have also formed peer counselling groups down to the village level. These groups often visit homes of patients in their locality to provide support to the patient and family. They have been able to increase families' awareness on mental illness, address drug adherence problems, and identify cases of human rights abuse.

Every four months, the association buys basic household materials like salt, soap, and sugar and distributes to some of those members who are not able to borrow from the association.

Existing challenges

The size of loan and saving is small hence does not meet the high demand from the members;

Limited knowledge and awareness on mental health, illness and rights.

Limited access to holistic mental health care. Most of the psychiatric treatment is only limited to dispensation of psychiatric drugs.

Limited access to psychiatric medication for the many users around the country.

Emerging opportunities

The district association has been able to benefit from the district disability grant twice. They have used the money received to boost their loan and saving and also bought 2 big commercial saucepans which they lend out to people preparing social functions.

Annually, MHU organises an annual forum where representatives from all parts of the country come together to learn from each other.

One of the members of the district association is now a member of the district disability union. Over the years, tt has not always been easy to have our members joint the disability union and councils.

SPEAKER THREE:

“Slovakia: Measuring quality in community-based services”

Miroslav Cangár, Forum for Human Rights

Three basic principles governing quality of social care services under Article 19 CRPD

One of the elements of the right to independent living under Article 19 CRPD is the *quality* of provided social care services, with an emphasis on the quality of life of an individual - the service user. The starting point of our understanding of elements of rights enshrined in Article 19 CRPD is that it relates only to what can be understood as *community-based services*. Thus, speaking of the quality of a life of an individual, institutional settings cannot by definition meet this element. **Therefore, when we are discussing the quality of social care services, we mean the quality of community-based social care services.**

Under Article 19 CRPD we have defined three basic and interrelated principles covering the notion of quality. We call them principles, because we understand that the principle is a norm commanding that something must be realised to the highest degree that is actually and legally possible.[1] These principles are 1) Dignity, 2) Capacity and 3) Relationships.

DIGNITY: The respect for human dignity forms part of the very essence of human rights. First principle of quality of any social care service is its conformity with human rights of persons with disabilities. Social care service providers must respect, protect, fulfil and promote *all* human rights of their users. Naturally, starting from negative obligations not to subject an individual to any form of discrimination on any ground or any form of ill-

---

[1] Robert Alexy, Theory of Constitutional Rights, Oxford University Press, 2002.

treatment or a disproportional interference with the right to his or her privacy, and continuing with positive obligations in relation to typically education, employment, rehabilitation, etc.

The principle of dignity stands at the very core of quality of any social care service. It can be implemented especially through the adoption of specific internal standards, their daily application, as well as the effective and continuing evaluation of both these standards and the needs of the service users. Further, an efficient external oversee mechanism must be available.

CAPACITY: There is a moral significance of individuals' capability of achieving the kind of lives they have reason to value.[2] This powerful statement can be further conceptualised by a concept known as a "life plan". It is akin to the concept of personal fulfilment, which is based on the *options* that an individual may have for leading his life, and achieving the goals that she sets for herself. Strictly speaking, those options are the manifestation and guarantee of freedom. An individual can hardly be described as truly free if she does not have options to pursue in life and to carry that life to its natural conclusion. Those options, in themselves, have an important existential value. Hence, their elimination or curtailment objectively abridges freedom and constitutes the loss of a valuable asset, a loss that we cannot disregard.[3]

Thus, the principle of capacity calls for understanding of person's live as one which concerns the full self-actualisation of the person, account of her calling in life, her particular circumstances, potentialities, ambitions, thus permitting her to set for himself, in a reasonable manner, specific goals, and to attain those goals.[4]

---

[2] See, Amartya Sen, The Idea of Justice, Harvard University Press, 2009.

[3] Loayza Tamayo Case, Reparations (art. 63(1) American Convention on Human Rights), Judgment of November 27, 1998, Inter-Am. Ct. H.R. (Ser. C) No. 42 (1998), para. 148.

[4] Ibid., para. 147.

Following this logic, we can conclude that all social care service providers must respect, protect, fulfil and promote *all* activities enabling the person concerned to accomplish, to the most achievable extent, his or her self-actualisation; especially by way of strengthening his or her potentials. Implemented in practice, this means an active person-oriented support on the individual level and an active participation of service users in provision of community based services.

RELATIONSHIPS: The social environment of any service user can be further considered from the perspective of how the person naturally finds himself or herself in interactions and relationships. Starting with the state, then with specific homogenous groups (religious, ethnic, etc.), her local community and relatives and close friends. Three levels can be described, the macro, mezzo and micro level. The macro level refers to the ability to either retain or develop relationships with the wider community as a citizen or with other persons of same or similar cultural, ethnic or religious identity. The mezzo level can be understood from perspective of interactions and relationships with persons or authorities placed inside the circles surrounding the person, e. g. professional relationships with colleagues at workplace, local community in home town, teachers at school, etc. The micro level refers to the intimate circle of the person concerned and encompasses relationships and interactions with family, friends and other close people. All levels must be *good* and the good social environment is one where a person feels free from threat, both physically and psychologically. This environment could be achieved when being in a relationship with persons who are deeply understanding (empathic), accepting (having unconditional positive regard) and genuine (congruent)[5].

Thus, social service providers are under an obligation to respect, protect, fulfil and promote relationships on all three levels defined

---

[5] Carl Rogers, On Becoming a Person: A Therapist's View of Psychotherapy. Houghton Mifflin Harcourt. 1995.

above. Service providers are obligied to support person’s social relationships on individual level with strong focus on the quality of each relationship.

SPEAKER FOUR:

"Deinstitutionalisation of children with disabilities"

Emina Ćerimović, Researcher, Human Rights Watch

I would like to start today's presentation by telling you a story of Julija, a 3-year-old girl with developmental disabilities I met in Serbia in November last year. Julija has a rare genetic condition called Apert Syndrome which results in vision and hearing loss, difficulty breathing and eating, and webbed fingers and toes. I met her in her home, surrounded by her proud and loving parents and grandparents. She was playing with her baby sister, Tijana. She was extremely happy to see me – a stranger, and immediately stretched out her hands towards me giving me a lovely hug I will not forget.

Her parents – Jasmina and Ivica - told me about their struggle to keep Julija at home, with her family, where she belongs. Immediately after her birth, they told me, doctors and nurses in Serbia advised them over and over again to leave Julija in the maternity ward and to place her in an institution for children with disabilities. Doctors and nurses explained it is the best they can do for their child: "Medical nurses would tell us, 'It is better for her to be with children that are like her,'" Jasmina told me.

With no community support and services available, they made the difficult decision to place their three-month-old baby in an institution for children with disabilities in Serbia's capital, Belgrade, believing they were doing what was best for their child. However, after only two days, her parents noticed a deterioration of Julija's well-being and development: "she was no longer the child she used to be," her mom told me.

After 8 months in the institution with only short visits home, Jasmina and Ivica decided to bring Julija back home. Jasmina described the experience: "When Julija is at home with us, she is one child, and when she is in an institution, she is a different child. She has made much more progress (at home), in terms of her weight and everything else. Her intellectual development, too."

The reason why Julija, her smiley face, and her hug will remain with me for a long time is because I met hundreds of other children with intellectual and developmental disabilities across Serbia, who are separated from their families and live in segregated and large residential institutions with little to no affection. Even though – just like Julija – the majority of them have a living parent, they – unlike Julija – were not smiling or laughing or playing when I met them, but were lying motionless in cribs and beds with no stimulation, education, or play. These are the hallmarks of social isolation.

There is no comprehensive plan on deinstitutionalization of children and adults with disabilities in Serbia. Currently, almost 11,000 persons with disabilities live in Serbian institutions – the majority of them have entered institutions as children. I would ask people with disabilities who lived in institutions I visited how long they have lived there. Over and over again, I would hear "Ever since I was little."

However, there are some promising practices underway on a small scale within Serbia, which we hope will be strengthened and expanded to ensure that children are able to live with their families and thrive in their communities.

One of them is the Family Outreach Service, which provides support to families where there is a risk of separation of children from their families, including families for children with disabilities. The outreach workers visit families and, depending on the needs of the child and the family, provide relevant practical support and assistance in the community. This includes counselling, advocating for the rights of the child and the family with different agencies, bridging the gap between the family and the community, regulating administrative documents necessary for families to receive financial support, obtaining health care, and enrolling children in day care centres and schools.

Selma Catovic, a family outreach worker, explained the main principle of the service: “Our mission is to work with the family, not for them, to empower them, not take care of them.”

Jovana, a single mother of a 12-year-old boy with psychosocial disability, told me how much the support she receives from the family outreach worker means to her: “I was all burned out before she came. I considered sending Mateo [her son] to an institution. Then, we got someone to help us. She is simply there to direct me, to help me look beyond, to provide me with information, to advise me on what to do.

Julija’s parents and many other parents, however, do not have access to any kind of support services in their communities. Services are scarce and where they do exist, they are limited in scope. For example, the family outreach service - which is currently financed by UNICEF and not by the Serbian government- is only being implemented in four major cities in Serbia, with limited financial resources and no long-term sustainability.

For Julija and thousands of other children with disabilities in Serbia, the consequences of the lack of investment in community services is isolation and neglect. More can and should be done.

Thank you.

SPEAKER FIVE:

“Tackling the problem of trans-institutionalisation”

Dragana Ciric Milovanovic, Director, MDRI-Serbia

Although Serbia is considered to be committed to the transformation of its institutions, many wrong steps are being taken, some of them deliberately perpetuating the exclusion of children and adults with disabilities. One of the biggest challenges we noticed is lack of understanding on what community services really are, and Serbia is a very good example how that can be misinterpreted.

During the process of deinstitutionalization Serbia has largely invested in replacing big institutions with smaller ones and with non-residential segregated settings, such as day-care centers, while at the same time closing institutions for children without disabilities by large investments into foster care.

Many day-care centers were opened without further vision about involvement of users in daily activities in the community (ordinary life in the community). These centers were also considered as a replacement for enrolment in schools for children, violating their right to education. Additionally, confirming its almost residential nature, such centers began adding respite care to its services, allowing for clients to stay overnight for a certain period of time.

Small homes for children, although institutions in their nature, did enrol all children in schools but only because it was explicitly one of the requirements set by UNICEF, the organisation who lead the project. However, the biggest challenge remains that children are growing up and will most certainly be returned to institutions for adults after they reach adulthood, as a proper system was not set up to provide successful transition to independent living arrangements.

Misunderstanding of the DI process has been evident on several recent occasions. While repeating Serbia’s commitment to DI, Minister Vulin announced that the ministry’s goal is to make residential institutions self-sustainable by engaging residents in working activities. Additionally, only for the next year, the state allocated massive amounts of money (300 million RSD / 250,000 EUR) for licensing of existing residential institutions, and additional 400 million RSD for development of new services, including opening of new residential homes. All this while talking about developing community services.

HUMAN RIGHTS WATCH FORUM Human Rights MDRI-S mdac mental disability advocacy centre

SPEAKER SIX

“Minimum State obligations under Article 19 – law, policy, practice”

Steven Allen, Campaigns Director, Mental Disability Advocacy Centre

Article 12 of the Convention on legal capacity may be regarded as representing the paradigm shift of recognising persons with disabilities as subjects of right – not merely as objects to manage or treat. On the other hand, Article 19 points towards the wider social, economic and political shifts required for persons with disabilities to take their rightful position in our societies. At its heart is choice – about where and with whom to live.

I want to start by saying that, to understand the obligations of States, we must understand that the right to independent living in the community is anathema to any form of social segregation, isolation or institutionalisation. This also goes for isolation and segregation *in the family*.

But Article 19 goes far beyond the physical location of a person. Indeed, it is based on the principles of equality and non-discrimination –persons with disabilities should have the same right to choose where and with whom they live, on an equal basis with others. Yet, why do we still see States arguing that congregate living settings are relevant services for persons with disabilities under Article 19?

Under the Convention, States must “recognise” the right to independent living in the community. What does this mean? Every Government has key and immediate obligations under Article 19 CRPD.

In our view, immediate State obligations must include:

- an immediate end to Government support for schemes which facilitate segregation or isolation;

- gaining a clear understanding of the diversity of persons with disabilities in their societies – ensuring that no person is left behind regardless of their age, impairment, support needs, or any other factor;
- development and publication, with DPOs and civil society, of a comprehensive social inclusion strategy for all persons with disabilities;
- the strategy should not be purely focused on the creation of specialised services for persons with disabilities – indeed, such strategies must draw on the services that already exist, including those provided by the private sector, traditional and peer support networks;
- laying out specific timelines by which real change will be evidences. National action plans must have annual targets and our view is that deinstitutionalisation processes should be limited to a maximum of five years.

Importantly, we must guard against the old cultures of isolation and segregation. You have heard today that even in some new social services being developed for persons with disabilities, the old practices keep emerging. ‘Group homes’ and ‘living centres’ can very easily develop cultures of institutionalisation. When Governments talk about new services, we should all ask – does this really increase inclusion?

It is important to note that Article 19 is not just about technical processes such as deinstitutionalisation. It is crucial that Governments recognise its goal is full inclusion and this necessarily entails a number of linked actions. These include tackling discrimination and stereotypes too often faced by persons with disabilities.

Governments also should take stock of the community resources that already exist in their countries. They should do everything they can to support peer support networks, families and communities to become more inclusive. We look forward to your reflections and questions.

HUMAN RIGHTS WATCH
FORUM Human Rights
MDRI-S
mdac mental disability advocacy centre

Statement by **Jonas Ruškus**, CRPD Committee Member

I am deeply confident that an Independent living and Being included in the community is a fundamental precondition for a decent life for a person with disability.

But there is something much more than this.

Community living together with persons with disabilities is beneficial or I even could say a healer for all, including persons without disabilities, community and the whole society.

Independent and community way of living is a place of transformation towards more human society, while person with disability is an agent of transformation.

When I say transformation, I mean demolition of walls between persons with and without disabilities, I mean change of focus from impairment to capacities, I mean also equality in everyday practice and shared decision making, I mean the shift from alienation towards friendship.This statement is not utopic; it is based on my long-term personal experience of living together with persons with psychosocial and intellectual disabilities within the community of l’Arche.

The mission of community of l’Arche is to make known the gifts of people with intellectual disabilities and working together toward a more human society.

For a person with intellectual disabilities, L’Arche is a place to live independently, or in a household with others, as well as a place of work and a place of activity;

it is a place of support and guidance that adapts as well as possible to the needs of each individual;

it is also a place of commitment, to share daily life with the support assistants and other members of the community.

And I can assure you: it works!

Community of l'Arche, created by Jean Vanier in France more than 50 years ago, today counts 149 communities and 20 projects in 38 countries worldwide, from India and Japan to Honduras and Mexico, two communities in my home country Lithuania including.

I am back now to my statement before about independent and community based living as a transformation for all.

Independent and community based living prepare the ground for each person with disability to be an active citizen to carve out their own unique role in society and to pilot fresh ways of including members with intellectual disabilities in the decision making processes.

Mutual relationship is a ground for transformations, fostering the growth and development of each person.

Transformative relation is not a service relation, is not aid relation, but first it is discovering of each other, going beyond of stereotypes.

I call it Chemistry of transformation: when a Person with disability living within the community becomes, through mutual relationship, an agent of transformation and takes us towards a right to live within diversity, reciprocity and peace.