

EASPD's written submission
on the draft guidelines on Deinstitutionalization, including in emergencies
of the Committee of the United Nations Convention
on the Rights of Persons with Disabilities
June 2022

1. Executive Summary

A. European Association of Service providers for Persons with Disabilities (EASPD)

EASPD, a European not-for-profit organisation, aims at promoting equal opportunities for persons with disabilities through effective and high-quality service systems across Europe, in line with the principles of the UN Convention on the Rights of Persons with Disabilities. EASPD represents over 20,000 service providers in 41 countries, across Europe and beyond and our members are working in a wide range of activities. Additionally, our members are active in transforming their services to be in line with the UN CRPD, further supporting independent living and supported decision-making for persons with disabilities, also working on employment, education and training, and early childhood intervention. Currently, one of the most important challenges that services are facing is the non-compliant financial and legal frameworks which are neither supportive nor enabling during this transformation.

EASPD also participates to the Conference of State Parties to the United Nations Convention on the Rights of Persons with Disabilities (hereinafter UN CRPD), is member of the European Disability Forum (EDF) and member of the European Commission's Disability Platform.

B. EASPD's Overarching Position on the Draft Guidelines on Deinstitutionalization, including in emergencies of the Committee of the UN CRPD (hereinafter Guidelines)

EASPD welcomes the Guidelines as they provide a **clear vision and recommendations towards States Parties** on realizing the right of persons with disabilities to live independently and be included in the community.

EASPD's work with various national, regional and local authorities in their deinstitutionalization (DI) efforts, has provided us with a very clear understanding that States Parties need support also on a practical level. It is often not only the lack of political will/ commitment that puts a standstill in realizing the right of persons with disabilities in living independently and be included in the

community, but also the lack of know-how to implement such fundamental changes. Currently, European States Parties are far from realizing this right for persons with disabilities. During their DI efforts, we are witnessing that they tend not to follow a holistic approach. For example, they tend to leave outside persons with intellectual and psycho-social disabilities and other support needs, they omit to implement the needed legal reforms or provide adequate resources to further support the DI efforts, among others. Due to these experiences, we believe that **the Guidelines should be accompanied by good practices on DI processes/ practices and on the transformation of services from across the world.** This will further support States Parties in realizing independent living and inclusion in the community for persons with disabilities.

Furthermore, EASPD recognizes the multi-layered process of deinstitutionalization and wants to emphasize the role that service providers can and are already playing in further supporting the DI processes in their respective countries. In our view this role is not adequately represented in the proposed Guidelines. For EASPD, the smart transformation of services to more enabling and empowering forms of care and support, needs to be based on the [principles](#) of participation, inclusion, non-discrimination, equality, choice and control over life and on the right to receive support adequate to individual needs. It is essential that the DI process is inclusive of all people with support needs, even people with higher support needs. [DI strategies and action plans](#) should also include measures to prevent institutionalization. Therefore, DI requires [thoughtful planning to facilitate the transition while ensuring](#) that will not lead to certain individuals being left without the care and support they need.

This in no way aims to defend and protect outdated and institutionalized models of support. It rather aims to recognize the continuous efforts of many service providers to ensure equal opportunities for persons with disabilities by guaranteeing the delivery of high-quality support in line with the principles of the UN CRPD. **The broad diversity of situations and legal contexts across the continent, as well as the diverse ways and models in which each type of service is implemented need to be considered in the assessment of community-based services.** The reality is that there are very few examples of legal frameworks in full compliance with the mandates of the Convention across the world, and that the funding procedures (e.g., public procurement) are restricting services from responding to the evolving needs and wishes of persons with disabilities. These, along with the workforce issues, such as staff shortages, non-attractive job opportunities, low wages, **hinder the process of transformation of services in line with the Convention.**

It is within this basis and the experience of our sector regarding the implementation of the UN CRPD that we are providing the following suggested amendments. We believe that **by integrating the**

challenges and opportunities of service providers in these processes it will further strengthen and support the realization of these Guidelines:

2. EASPD's Suggested Amendments

❖ Suggested amendment on paragraph 14

14. Institutionalization includes all forms of placement and detention **where residents are isolated from the broader community and/or compelled to live together, do not have sufficient control over their lives and over decisions which affect them, and the requirements of the institution tend to take precedence over the residents' individual needs.** (...)

EASPD's motivation for the suggested amendment

The European Expert Group on Deinstitutionalization, in which EASPD is a member too, emphasizes in its [Common European Guidelines on the transition from institutional to community-based care](#) that there are different understandings of what constitutes an institution or institutional care, depending on each country's legal and cultural framework. Therefore, it aims to define institutions by mainly examining the factors, as outlined above on the suggested amendment that further constitute "institutional culture". Size is an important factor as well, as smaller, and more personalized living arrangements are more likely to ensure opportunities for choice, self-determination, and a person-centred approach. However, the small size of accommodations does not in itself guarantee the elimination of institutional culture in the setting.

❖ Suggested amendment on paragraph 26

26. Definitions of community-based (...) during the deinstitutionalization process. **Criteria, such as person-centred support and planning, prioritization of needs and wishes of persons with disabilities, active inclusion in the community and mainstream services, localization of the setting in the centre of the community and in non-congregating environments, size of the infrastructure, adequate ratio between support staff and people in need of support, among others, should also be the basis of assessing a service as community-based or the contrary.** For example, group housing – including small group homes-, sheltered workshops, institutions for providing respite care, transit homes, day care centres, or coercive measures such as community treatment orders, **not meeting the criteria mentioned above,** are not community-based services. **Institutional culture may appear in any setting, regardless of the size. Therefore, definitions based on quantitative indicators (i.e., numbers) alone are not sufficient to determine the potential institutional character of a setting.**

EASPD's motivation for the suggested amendment

Community-based support should be identified as those services that enable persons to live independently, make decisions, and be active members of their communities. Characteristics, such as the criteria included

on the suggested amendment should also be determinants for a setting to be considered as community-based service or not. Therefore, EASPD suggests that there is **an emphasis on the Guidelines also on the way community-based services should be delivered and evaluated.**

❖ Suggested amendment on paragraph 33

33. States Parties should (...) and General Comment No. 7. **The decision-making processes should be driven and primarily influenced by persons with disabilities and their representative organizations. Relevant stakeholders, such as services providers, support staff, policy makers, families, local communities' representatives, trade unions, and others, should be part of the consultation processes to share their experiences and expertise around deinstitutionalization and the development of community-based services. Those stakeholders ~~Service providers, charities, professional and religious groups, trades unions, and those~~ with financial or other interests in keeping institutions open, should be prevented from influencing decision-making processes related to deinstitutionalization.**

EASPD's motivation for the suggested amendment

Deinstitutionalization requires the cooperation and involvement of all relevant actors, consequently generating co-ownership. Though a **co-production approach**, all relevant stakeholders can provide their experiences and expertise to further advance the development of a DI strategy and more importantly contribute positively to its execution. This will ensure the development of a solid coalition and build strong, resilient communities. It will also strengthen the relationship between the relevant stakeholders and avoid possible resistance to change from certain ones, thus moving closer to realizing the right to live independently and be included in the community for persons with disabilities.

❖ Suggested amendments on paragraphs 44, 45, 49, 50

44. Children placed in (...) mainstream supports for all children **and preventative measures towards families and children must be available, including Early Childhood Intervention (ECI) services based on the needs of children and families.** Peer support for children and adolescents is essential for full community inclusion.

45. Even short-term placement outside a family causes great suffering and trauma, emotional and physical impairments. **Instead, family-centred ECI happens in the home and in daily environments of the child and has the potential to empower the family and improve the child development of cognitive and social skills, with positive consequence on education and employment later in life.** Preventing institutional placement for children must be a priority. Family-based placements, with financial and other forms of support **including ECI services**, should be created for all children with disabilities.

49. States Parties should develop and ensure access to support services in the community, including **early childhood intervention**, personal assistance and peer support, for children and adolescents with disabilities, **and their families as** necessary. Educational systems (...) institutional settings.

50. To prevent institutionalization of children, accessible information **and support services** should be made available for families and children, **such as support groups for families with children with disabilities and their siblings**. It should be presented in multiple user-friendly formats through **maternity hospitals, childcare settings, such as nurseries and kindergartens**, schools, community centres, (...) an institution.

EASPD's motivation for the suggested amendment

Institutionalization should not be an option for children with disabilities and access to mainstream education and care must be a reality for them. **Early Childhood Intervention (ECI) is key in preventing placement in institutions**, in fostering inclusion in Early Childhood Education and Care/ education and in achieving the child's potential, strengthening the family and its wellbeing.

❖ Suggested amendment on paragraph 52 and suggested addition after paragraph 57

52. (...) and (iv) the right to equality and non-discrimination; **and (v) the right to adequate standard of living and social protection.**

v. Right to adequate standard of living and social protection

(new) 58. In order for the deinstitutionalization process to be effective, States Parties should guarantee adequate and equal access to affordable and quality standard of living.

EASPD's motivation for the suggested amendment

Under article 28 of the Convention, States Parties have an obligation to ensure access by persons with disabilities to assistance to disability-related expenses, public housing programmes, social protection programmes, poverty reduction programmes, retirement benefits and programmes.

❖ Suggested amendment on paragraph 62

62. Existing community-based services (...) adaptability of services. **On the basis of this planning**, services that do not comply with the Convention should be ~~discontinued~~ **evaluated to identify those aspects of the service(s) which fall short of compliance. This should be followed by either transforming them so they do comply or close and then replace them with new services designed to be compliant from the outset.**

EASPD's motivation for the suggested amendment

EASPD believes and is also witnessing through its membership the **smart transformation of services towards quality, empowering and person-centred forms of support, in compliance with the Convention.**

We believe that by directly discontinuing services which do not fully comply with the Convention, without their prior evaluation and without determining their feasibility to transform in UN CRPD-compliant services, diminishes the continuous efforts of service providers to improve. This in no way aims to justify the continuation of all current services or the continuation of institutionalized forms of support. This aims to recognize that there are services, which despite the challenges that they are facing and with no adequate support, are continuously focusing on improving and supporting their beneficiaries to live independently, make their own decisions, and have control over their lives.

Additionally, **it is imperative to evaluate support services while taking into consideration the challenges they face, and the contexts under which they operate.** Challenges such as staff shortages, poor working conditions, legal and fiscal policies that are not facilitating to respond to the complex and evolving needs of individuals, pose threats on their resilience and on quickly and adequately realizing their transformation in human-rights based support services.

❖ Suggested amendment on paragraph 63c

(c) Ensure that a wide range of support mechanisms and services exist in the community, **including in rural and insular areas**, and that all persons with disabilities can plan and direct their own support, including persons with high support requirements, and those that use alternatives to verbal communication;

EASPD's motivation for the suggested amendment

EASPD believe that **the development of support mechanisms and services should be also prioritized in rural and insular areas.** The underdevelopment of services in such areas, has a major impact on the lives of persons with disabilities living in those areas, as these people face poor access to welfare services, education, employment, income, and life chances. The need for action on this has been further emphasized in the [EU Strategy for the Rights of Persons with Disabilities 2021-2030](#), as well as in the [Action Plan of the European Pillar of Social Rights](#).

❖ Suggested amendment on paragraph 64

64. States Parties should map (...) with the Convention. **If the transformation of some or all of the existing workforce is considered to be feasible, the workforce must be provided with adequate training and support. This training must follow the principles of the UN CRPD and its implementation on the day-to-day operations of services. States Parties should ensure that services are sufficiently and adequately staffed to respond to the needs and wishes of persons with disabilities. They should work towards the attractiveness of these**

employment opportunities as career options. States parties should establish continuous learning and training opportunities, including supervision and mentoring schemes, as well as staff evaluation processes to ensure that the workforce is providing support to people with disabilities in compliance with the Convention. They workforce should provide services solely under the direction of persons with disabilities, or their family members in respect of children with disabilities, or on the basis of the best interpretation of the person's will and preferences where affirmative consent cannot be realistically attained. States Parties should ensure that clear legal frameworks are in place (e.g., ethical guidelines) to ensure that services are provided in a legally correct environment and that the workforce is protected and adequately prepared to enable people with disabilities to exercise their right in directing their support services. States Parties should ensure that those responsible for human rights violations are not licensed to provide new services.

EASPD's motivation for the suggested amendment

There are significant staff shortages in social care across all EU Member States. The reasons for these shortages are lower than average wages, the lack of attractiveness of jobs in this sector, which are considered to have [poor working conditions, poor career paths and fewer opportunities for training, as well as high working pressure](#). EASPD believes that States Parties should address these challenges, by creating job profiles which are fundamentally more attractive so as to address the shortages in qualified staff and ensure better working conditions. **The [single most important element and challenge in social service provision is staff](#) and the detrimental impact all these challenges can have on the transition to person-centred and community-based forms of care and support (rather than institutional), in line with the UN CRPD, cannot be underestimated.** Additionally, there is a need for clear legal frameworks that will allow social services to operate in legally correct environments. For example, clear deontological/ ethical frameworks outlining the responsibilities of professionals, together with adequate training to enable professionals to further support and empower individuals to make choices and control their lives are essential.

❖ Suggested amendment on paragraph 76

76. Funding models of support services should be flexible and not limited by "supply". **These funding models should rely on partnerships and user-centred funding models, rather than models focusing on buyer-supplier logics.** States Parties should invest in creating and developing a wide range of flexible support services to respond to the demands and wishes of diverse individuals, **including those living in rural and insular areas**, respecting their choice and control, including the option of designing new forms of support. **States Parties should ensure that these services are funded adequately and sufficiently to ensure the continuity of the support provided, especially in the period of transformation.** States Parties should also invest in equipping these services with adequate and well-trained workforce.

EASPD's motivation for the suggested amendment

[The experience from Europe](#) to date suggests that [social services rely to funding models](#) that can have a dramatic (and often adverse) impact on services. For example, in a competitive market (often found in public procurement) where price outweighs quality as a criterion for winning the contract, regular (sometimes even annual) contract renegotiations result in a wholly short-term approach. This can create unstable employment for staff, insecure funding for providers and can lead to impossible demands on the capacity of small local providers to cope with delayed cash flows, re-submission requirements etc. The benefit of pilot projects funded by the EU, for example, and other grants is welcome, but their long-term impact is undermined by the inability (or unwillingness) of states to take over the funding of such innovative schemes. **The evolving needs of people with disabilities and other support needs demand a rather evolving funding model towards social services to support in meeting these needs.** Therefore, it is imperative to identify [alternative funding models](#) that fully consider the needs, wishes of people with disabilities, while ensuring the sustainability of the services.

For more information, please contact, Konstantina Leventi, Senior Policy Officer, EASPD: konstantina.leventi@easpd.eu.