

EPR contribution to the call for submissions from the Committee on the Rights of Persons with Disabilities to the Draft Guidelines on Deinstitutionalization, including in emergencies

30th June 2022

EPR is a community of service providers working with people with disabilities committed to high quality service delivery. EPR's mission is to build the capacity of its members to provide sustainable, high quality services through mutual learning and training.

EPR and its members are committed to support the right of persons with disabilities to live independently and be included in the community. By assisting and working with leading service providers across Europe, EPR promotes the sharing of good practices and the development of quality services and community-based support that help to tackle and discriminatory barriers affecting the life of people with disabilities.

In the document below EPR proposes amendments to the draft guidelines to which draw from the experience of its members involved in providing community-based services which aim to contribute to successful deinstitutionalization processes.

Proposals for amendments to the text with comments

Paragraph 15

An institution is defined by certain elements, including obligatory sharing of personal assistants with others and no or limited influence over whom one has to accept personal assistance from; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities in the same environment. Hospitals - where the emphasis is on intensive medical treatment - are outside the scope of what is meant here by an institution

This is to clarify the scope of user choice related to persons providing support services. The funding/service provision model might not allow for choice by a service user of which staff member they wish to provide support to them for every service, without having an impact on whether the service provided exhibits elements of an institutional culture. Any staff member providing support services should ensure a person-centred and individualised approach and ensure none of the elements of an institution are present in their service delivery. Personal assistants should be chosen

by the person with a disability, as specified in the paragraph that follows. Physical medical care may require in-patient treatment for short or long-term.

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Personal assistance services must contain the following elements: individualised, with funding that should be based on individual needs, sufficiently high to guarantee a high-quality personal and socially integrated service, and controlled by the user who should be able to decide to what degree they will manage the service themselves, either as an employer, or to contract the service from a variety of providers. All persons with disabilities should have access to personal assistance, regardless of their requirements for support in exercising their legal capacity. States Parties must be committed to and ensure transparent quality control of personal assistance services, the results of which should be publicly available.

In some countries the public budget available for personal assistants is too low and the waiting lists high. States Parties should not just legislate for personal assistance services but also ensure funding is available to implement it properly for all people who can benefit from it.

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Definitions of community-based support services, including in-home, residential, and other support services, and personal assistance should prevent the emergence of new segregated services during the deinstitutionalization process. 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 fulfilling the criteria outlined in Paragraph 15, and for sheltered workshops that do not fulfil criteria related to article 27 of the UNCRPD referred to in the relevant General Comment, are not community-based services.

As there is a definition in the guidelines these should be the basis for defining services. Elements of sheltered workshops considered to be incompatible with the UNCRPD will be dealt with in the General Comment of the UN Committee on article 27 so there should be a reference to this.

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States Parties should allocate adequate public funds, including those from international cooperation, to set up and ensure the sustainability of inclusive community support systems and inclusive mainstream services, including successfully piloted new services, support systems, staff training and professions.

One reason for institutionalisation is the lack of community-based social services. Publicly-funded mainstream services in some places are non-existent/chronically underdeveloped and underfunded. See also comment on paragraph 64.

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States Parties should closely involve persons with disabilities through their representative organizations, and especially people leaving institutions and survivors of institutionalization, and their representative organizations, in all stages of deinstitutionalization processes, in line with articles 4(3) and 33 and General Comment No. 7. Stakeholders, such as service providers, support staff, policy makers, families, local communities and trade unions, should also be facilitated to bring their experiences and expertise to the processes within a co-production logic.

All actors impacted by the DI process and in the implementation of community-based services will need to be involved to ensure their engagement and effective roll out of new policies and services.

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.

The main point here is stakeholders with financial interests and the enumeration of possible stakeholders could obscure this point.

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...The Committee recognizes that some persons with disabilities may prefer to receive support from a family member, complementing, or as an alternative to, publicly funded services.[...]

Publicly funded: support services also provided by non-state service providers.

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Children placed in institutions based on their actual or perceived disability, poverty, ethnicity or other social affiliation, are likely to develop impairments because of institutional placement. Thus, support, including Early Childhood Intervention, for children with disabilities and families should be included in mainstream supports for all children.

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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, as necessary. Educational systems should be inclusive and services to support inclusive education should be ensured. States Parties should include children with disabilities in mainstream schools, and prevent and avoid placement in segregated education, which undermines community inclusion and leads to increased pressure to place children in institutional settings. States parties must ensure teachers in mainstream schools are equipped to support children with disabilities and have enough staff to do so.

Reference to high quality ECI should be made, as a key instrument to provide timely support to children and prevent institutionalisation. Support services are needed for successful inclusive education, especially in the transition phase. See comment para 104

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States Parties should:

- (a) Identify gaps in support for persons with disabilities and the need for new service structures to be developed;
- (b) Consult with organizations of persons with disabilities and service providers to develop, introduce, and evaluate pilot projects;

While persons with disabilities are the main stakeholders, if new services and service structures are to be successfully developed it is essential to include those that will be providing the services in the process.

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States Parties should map the workforce, including demographic and employment trends, and the impact these may have on deinstitutionalization. States Parties should establish priorities for improvement, assessing the feasibility of transformation of the existing workforce to the provision of services to persons with disabilities that comply with the Convention. They should plan new curricula and training and provide sufficient resources to enable upskilling and reskilling of the workforce. They should provide services solely under the direction of persons with disabilities, or their family members in respect of children with disabilities. States Parties should ensure that those responsible for human rights violations are not licensed to provide new services.

To be successful, the transformation of the existing workforce should include reworking training and education curricula for support staff, since community-based settings need different skills, tools etc, and therefore types of studies, content of studies and apprenticeships.

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States Parties should recognize the existence of informal support and ensure communities and families are trained and supported so they can provide support that is respectful of the choices, will and preferences of persons with disabilities and so that they fully engage in deinstitutionalisation. Where persons with disabilities do not wish to be supported by their families or communities, they should have access to other options.

Families can be afraid community-based services may not meet relatives' needs and thus be wary of the DI process, so in addition to ensuring quality support services, education and support for families is important so that they understand and can fully engage in the DI.

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Funding models of support services should be flexible and not limited by "supply". States Parties should invest in the creation, development and long-term funding of a wide range of flexible support services to respond to the demands and wishes of diverse individuals, respecting their choice and control, including the option of designing new forms of support.

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States Parties should ensure sufficient and long-term funding for and the provision of provide different types of individualized and person-centred support services, such as support persons, support workers, direct support professionals, and/or personal assistance.

Services are provided by state and non-state actors. To ensure individualised support services it is necessary to address the shortage of support staff in some parts of Europe, especially in rural areas and territories with low populations, through sufficient and long-term funding to attract and retain staff and provide quality services.

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Access to all mainstream services and provision for basic requirements, should be planned for and ensured in preparation for deinstitutionalization, and when choosing a place to live in the community, settling down in the community and thereafter. States Parties must ensure that community-based services have the right infrastructure and support in place for all persons with disabilities, including those with high support needs. Access to community resources including an adequate standard of living and social protection should be ensured. State Parties should ensure that structures, support services and the local community are fully enabled and engaged to support the inclusion of all persons leaving institutions in the community.

There are persons with disabilities with high support needs who require specialist services, expertise and arrangements in community settings. It is thus essential to ensure such settings have all means necessary to support all people leaving institutions, and that the community itself is empowered to be supportive, to ensure people can be fully included in the community. Mainstreaming without proper support to the new arrangement can end up backfiring, such as what was seen with the move to inclusive education in, for example, The Netherlands and Germany where some mainstream settings were not able to provide the needed support and many learners ended up back in special schools.

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...States Parties should ensure that persons with disabilities leaving institutions, including children, can access information in accessible formats, become aware of educational opportunities and resources required to continue or complete their education, and can pursue studies pursuant to their will and preferences. State parties should also ensure that the workforce in mainstream services such as education receive the needed training and upskilling to ensure they can support people with different disabilities and support needs, and that sufficient staff is available to provide the support.

Educators are often aware of the importance of inclusive education, but may not be equipped to work inclusively because they lack the tools or skills. Some degrees or training does not include disability-related content, and sometimes staff capacity to support all those learners that need it is not there. Investing in the workforce, including their training and knowledge is key to achieve inclusion in these settings.

