**Written Submission on the Draft Guidelines on Deinstitutionalisation, including in Emergencies**

**Feedback and comments from**

**the European Network on Independent Living - ENIL**

**4 July 2022**

**Executive summary**

The European Network on Independent Living – ENIL welcomes the Draft Guidelines on Deinstitutionalisation, including in emergencies. There is a need to further clarify the States Parties’ obligations under Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), in particular when it comes to deinstitutionalisation and how to practically achieve the transition from institutions to living independently and being included in the community for all disabled people. In our submission, we propose general and specific comments, with a view of making the Guidelines more practical and thus more useful to those implementing, promoting and monitoring deinstitutionalisation reforms in Europe.

1. We propose to better explain in the introduction the nature of the document (i.e. that it does not replace the General Comment 5, but should be used in conjunction; that it does not replace the need for national deinstitutionalisation strategies and action plans, but should be used as a basis for the planning etc.). We also propose to better explain how the misuse of funds for the building and renovation of institutions can both be prevented and challenged.
2. There is no specific mention or guidance relating to the prevention of people being institutionalised. A key part of institutional closure is the stopping of placing people in institutions. We suggest to have a separate section in the guidelines about preventative community-based support, including outreach support to people with psycho-social disabilities.
3. We fully support the point made about institutions not being party to leading the closure programme. We propose to add that this should extend to large service/support providers and others with a vested interest in retaining an institutional basis to care and support in the future.
4. We are faced with the misuse of personal funding (i.e. personal or individual budgets and direct payments) for purchasing institutional places and support, thus maintaining the institutional approach as opposed to enabling people to live more independently. There are clauses about the use of state funding in the draft Guidelines; these should be extended to include ‘individually allocated funding’ and barring its use to maintain institutional care.
5. We would like the draft Guidelines to further develop the role of peer support. We note the importance of peer support with regard to issues already raised (funding, preventative support) and to supporting people making decisions about their life, their support and their home. Additionally, peer support can help people have a voice, enabling people to speak up and feel more confident.
6. In the ‘intersectional’ part there is no mention of the challenges and multiple experiences of discrimination facing older disabled people. There needs to be acknowledgement of ‘care homes for older people’ as institutions, and that their closure and the support for older disabled people to live as independently as possible be developed and made available.
7. Supported decision-making and peer support and the difference between capacity to make decisions and legal capacity. There needs to be clearer protection and respect given to the decisions made by a person. This links clearly to peer support as a positive and supportive part of the process.
8. There is a need for stronger statements about eligibility for supports and services to live independently. It is important to highlight that eligibility should be established based on person centred / strengths-based approaches linked to human rights and the right to live independently, rather than or deficit or medicalised approaches (focused on what an individual ‘cannot’ do/is perceived as unable to do).
9. We propose to simplify the text, to make it easier to understand and translate, and to add, wherever possible, specific suggestions on what SHOULD be done, and HOW TO do it as opposed to what not to do. For example, we suggest to explain what a DI strategy/action plan may look like; i.e. what sections should be included, as opposed to just saying it needs to be developed in consultation with disabled people.

**Specific proposals for changes to the text**

**Paragraph 4** – Delete ‘under life-threatening conditions’. As institutionalisation is per se discriminatory, there is no need to focus on the conditions.

Add ‘the impact of the pandemic and recent conflicts’, to acknowledge the impact of the war in Ukraine on thousands of people in institutions.

**Paragraph 5** – Change ‘institutionalisation’ into ‘deinstitutionalisation.

Delete ‘in some cases’. In many countries, DI processes are slow, delayed, or have not started.

**Paragraph 14** – Delete the sentence beginning with ‘Mainstream institutional settings, such as prisons, refugee camps, etc.’ or acknowledge elsewhere in the document that disabled people may be detained or segregated in mainstream settings. However, keeping this sentence here, where ‘institutionalisation’ is defined, may cause confusion between disability-specific institutions and mainstream settings where disabled people may be over represented, but some of which are under criminal justice (or other) systems. There is nothing further in the Guidelines to explain how States should go about closing such places and what to do in case of refugee camps, for example, prayer camps etc. We believe that putting all settings in the same paragraph may undermine our efforts to improve the States’ understanding of what is an institution and to commit to their closure. We do not think it is realistic for DI plans to include mainstream settings and believe that different approaches/strategies would be needed to cover mainstream settings.

**Paragraph 18** – Suggest to provide a different example for common errors; in our experience, rather than ‘renovating settings, adding more beds’, it would be more helpful to refer to ‘replacing large institutions with smaller ones’ as the most common error.

**Paragraph 25** – Personal assistance should be defined in more detail, including mentioning that eligibility assessments should be human rights-based; that the PA users should be able to control the recruitment, qualification requirements, hiring, and training of their personal assistants. We consider the point about control over training to be very important. Overall (related to Section b. Support services), it is essential to specify that disabled people should have control over the training of their ‘supporters’ (assessors, assistants, community rehabilitators, ‘home carers’, support persons, support workers, front-line social workers, etc.).

Paragraph 26 – we suggest adding that definitions should be added into policy and legislation.

**Paragraph 34** – Add that this information is best provided in the form of peer support.

**Heading of section IV** – ‘Differentiated approaches’ may be a term that is hard to translate into other languages; suggest to specify in a footnote or an annex what this term means.

**Paragraph 36** – Replace ‘selection processes about who leaves’ with ‘deciding that some people cannot live independently and must stay in the institution is discriminatory’.

Suggest to reword the sentence ‘responsibility for deskilling persons … or ‘weakness’ to persons with disabilities.’, to make sure it is easier to understand and translate into other languages.

**Section on Intersectionality** - A section on older persons with disabilities and their de/institutionalisation and is needed, similar to the separate sections on women and children (paragraphs 40-50). The institutionalisation of old people bleeds into institutionalisation of disabled people due to the intersections between disability and old age, due to the practice of housing disabled younger people in nursing homes, and due to the general normalisation of institutional care that nursing homes perpetuate.

**Paragraph 44** – Explain what the sentence ‘Thus, support for children with disabilities… ‘ means in practice. Suggest to add some examples.

**Paragraph 52** – There is a mention of legislative recognition of the right to live independently, but this is not explained in a subparagraph below. We suggest to add a heading: Right to independent living, explaining that this would include access to support services, such as personal assistance, as a right, and making sure that this right is not positioned within health legislation.

**Paragraph 53** – The phrase ‘affirmative, free, informed expression of consent’ might need further clarification, to support translation into other languages.

**Paragraph 54** – We suggest to add after this paragraph the need to introduce complaints mechanisms, as these are referred to in paragraph 55.

**Paragraph 55** – Suggest to explain what the sentence ‘Release from disability-based detention…’ means in practice. I.e. what should State Parties do to comply with this standard.

**Paragraph 61** – The sentence ‘State Parties should…’ is unclear. We suggest to explain in simpler terms that States should identify how much money is currently going into institutions and make a plan of how they will redirect this to community-based services.

**Paragraph 61** – We suggest to delete ‘because they are segregated …’ States Parties should simply identify services not compliant with the Convention, for whatever reason. Instead of ‘Planning should ensure’, we suggest to start the sentence with ‘The objective of the mapping should be to …’.

**Paragraph 63a** – Add ‘the need for service structures and professions’

**Paragraph 63d** – Replace ‘develop’ with ‘ensure’

We suggest to add a separate paragraph VI, focusing on Funding in this section, bringing together all the points related to funding and adding the missing ones.

**Paragraph 65** – We suggest to add that States Parties must have a plan on how to deal with resistance to the closure of institutions by the management and staff of institutions, trade unions, families and the general public (to deal with the Not In My Back Yard types of protests).

**Paragraph 68** – Add that disabled people should be trained in how to establish Centres for Independent Living (CILs) and their role in supporting independent living, in addition to these receiving public funds.

**Paragraph 71** – Add empowerment as one of the objectives of peer support.

**Paragraph 72** – The last sentence explains what ‘respite care’ is not. However, it would be useful to also explain what a Convention compliant respite care might look like; i.e. what good practices are there.

**Paragraph 74** – Suggest to start this paragraph with ‘With regard to persons experiencing distress or unusual perceptions’ (nb: this is a term that may need clarifying, to support translation), to make the paragraph clearer.

**Paragraph 74** – Suggest to clarify the guidance that ‘disability-related support services’ should ‘link with existing services and networks in the community’. What does this mean in practice? What type of services are welcome, as opposed to those that should be avoided?

When it comes to eligibility assessment, the text reads that ‘States Parties should not use medical criteria when developing new needs assessment tools, and medical professionals should not be involved. Instead, a person-centred process should be used, identifying the range of supports a person may need to live independently and be included in the community.’ We suggest specifying that eligibility assessments should also be human rights-based, streamlined, prioritising self-assessment, and ensuring access to peer advocacy and support in the process.

**Paragraph 78** – Suggest to explain what the safeguards mentioned in this paragraph might mean in practice; the same goes for an ethical regulatory framework. Does it mean adopting a quality framework or something else?

**Paragraph 79** – This is the only paragraph dealing with older persons. We suggest adding a heading dedicated to Older persons, the same way as is done for children and women with disabilities. This is something that is not expanded on in the General Comment 5, so would benefit from additional explanation. In particular, we suggest providing some concrete ideas of what support services might benefit older people, rather than just saying this shouldn’t be in an institution.

**Paragraph 82** – It is unclear what the difference is between the terms ‘support persons, support workers and direct support professionals’. A footnote or a glossary, or further explanation, is needed if we want the States to develop different types of support, and to ease translation into other languages.

**Paragraph 84** – Suggest to explain what ‘repairing the harms caused by institutionalisation’ may look like in practice.

**Paragraph 85** – This paragraph implies that funding for independent living should be provided ‘wherever the service is not provided for free by the State’. However, even when services are provided for free, people should receive funding to be able to choose the service they want. We would also want to discourage services being privatised, as that means services may be expensive or of poor quality.

**Paragraph 86** – Explain that States should discourage disabled people from using personal budgets/direct payments for purchasing institutional care services. This can be done through providing financial incentives – for example, by giving higher budgets to those that want to purchase community supports, providing support with using budgets and managing support, providing support with administration, awareness raising and peer support. At the same time, any financial (or other) incentives that favour institutional provision or may lead disabled people to using their personal budgets for paying for a place in an institution should be discontinued as a matter of priority.

**Paragraph 87** – Explain what ‘additional support’ for families means, and what it might look like in practice.

**Paragraph 90** – There is a danger that this may be interpreted as ‘all mainstream services must be accessible’ in preparation for DI. Suggest rephrasing to make it clear that this needs to be done in parallel, and not to delay the process of DI.

**Paragraph 91** – Explain that no person should be left behind in the process of DI, and which groups tend to be overlooked. Suggest that the process should start with those with the highest support needs, in line with lessons learnt from those countries that closed most institutions. Once support services are developed for those with the highest needs, those with lower support needs can also benefit (which is not the case vice versa).

**Paragraph 92** – It is unclear what ‘self-initiated action in the community’ means.

Also, in respect to the last sentence on support to families whose family members were institutionalised, it is important to make clear this might not always be the case.

**Paragraph 93** – Implies that not everyone should have a transition plan, only if they want it, whereas paragraph 91 states everyone should have a transition plan. It is important to make this clearer; also stating what should be included in such plan.

**Paragraph 93c** – It is unclear what being provided with full disclosure about the ending of institutionalisation means. Suggest to explain better, in simpler terms.

**Paragraph 93e** – Explain that this should not take place within an institution.

**Paragraph 96** – Explain what ‘as harmless as possible’ means.

**Paragraph 98** – Suggest to replace ‘every stage of mainstreaming persons into communities’ with a term that is easier to translate and understand. In general, the term ‘mainstreaming’ translates poorly into many languages.

**Paragraph 108** – Explain what ‘all disability-based institutionalisations should be revoked’ means in practice. What actions should be taken by the States Parties to achieve this?

**Paragraph 111** – Explain what ‘other barriers to inclusion’ means, in the context of funding priorities.

**Paragraph 122** – Add explicitly that data should also be collected about church-run institutions, as these are often excluded from any statistics.

**Paragraph 123** – Reflecting on the definition of institutionalisation from these draft Guidelines, would this also include mainstream settings?

**Paragraph 138** – This is one of the two mentions of complaints mechanisms. We suggest to make this point clearer in the Guidelines and to explain what such complaint mechanisms might look like. This should be linked to monitoring of funding flows and explaining why this is important and who should be in charge of doing this.

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