



## EEG Response to the EU Disability Rights Strategy 2021-2030

The European Expert Group on the Transition from Institutional to Community-Based Care (EEG) is a coalition representing children and their families, people with disabilities and their families, homeless people, people experiencing mental health problems, service providers, public authorities and UN organisations. The EEG members come together because we believe the segregation and institutionalisation of all people must end.

Institutional care refers to any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have enough control over their lives and over decisions which affect them; and
- the requirements of the organisation itself tend to take precedence over the residents' individual's needs.

Both the EU and all Member States are bound by the United Nations Convention on the Rights of Persons with Disabilities (CRPD). All EU member states are also bound by the Convention on the Rights of the Child (CRC). For children, the core of the right to live independently and be included in the community entails a right to grow up in a family environment.

### **What the new Disability Strategy says about De-institutionalisation**

On the 3<sup>rd</sup> of March 2021 the European Commission released the new EU Disability Rights Strategy for the period 2021 to 2030. This follows up to the previous ten-year Strategy that was launched in 2010.

The European Commission acknowledges the gravity of the situation of persons with disabilities living in institutions in the EU: "More than 1 million children and adults with disabilities aged less than 65 and more than 2 million aged 65 and over live in institutions." It also reflects on the tragic impact of the COVID-19 pandemic on people living in institutions.

The Strategy states: "Many persons with disabilities, adults and children, are segregated from community life and do not have control over their daily lives, in particular those living in institutions. This is mainly due to the insufficient provision of appropriate community based services, housing and technical aids, as well as to the limited availability of support for families and of personal assistance, including in the area of mental health. The situation is particularly difficult in remote and rural areas. The COVID-19 pandemic highlighted and intensified the challenges faced by persons living in institutions."



The Strategy proposes the following actions:

- **By 2023**, the Commission will issue **guidance recommending improvements for Member States on independent living and inclusion in the community**. Member States should enable persons with disabilities to live in accessible, supported housing in the community, or to continue living at home (including personal assistance schemes).
- **By 2024** the Commission will present a **framework for Social Services of Excellence for persons with disabilities** to improve service delivery and enhance the attractiveness of jobs in this area including through upskilling and reskilling of service providers.
- **In 2022**, the Commission will conduct a **study on social protection and services for persons with disabilities**. This will offer guidance to support Member States in further reforms of social protection focusing on persons with disabilities and disability assessment frameworks, including upon requests through the Technical Support Instrument.
- In 2021 the Commission will issue a **toolkit for inclusion in early childhood education and care**, which includes a specific chapter on children with disabilities and will support Member States to further develop their **teacher education systems** to address shortages of teachers in Special Needs Education and competences of all education professionals to manage diversity in the classroom and develop inclusive education.
- The Commission will continue supporting national, regional and local authorities in their efforts for deinstitutionalisation and independent living, including through the 2021-2027 shared management funds, the Renovation Wave, the Renovation Component of the Recovery and Resilience Plans, and the Technical Support Instrument.

## Reflections and recommendations from the EEG

The EEG welcomes the Commission's recognition of the severity of the situation for people segregated in institutions. We also welcome to see actions proposed to address the issue.

The EEG welcomes that fact that this Strategy appears to be more inclusive than the previous one and now includes a focus on particularly vulnerable groups such as homeless people with disabilities. This is significant given that the situation of this group is particularly urgent from a DI/independent living perspective.

The Committee on the Rights of Persons with Disabilities called on the European Union in its Concluding observations (CRPD/C/EU/CO/1) in 2015 to "develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that



they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached" (para 51).

In this quote, the CRPD Committee explicitly calls on the EU to:

- strengthen the monitoring of the use of EU funds,
- ensure that EU funds are strictly used for the development of support services for persons with disabilities in local communities,
- ensure that EU funds are not used for the redevelopment or expansion of institutions,
- ensure that payments are suspended, withdrawn, and recovered if the obligation to respect fundamental rights is breached.

Furthermore, in its Inquiry Report on Hungary (CRPD/C/HUN/IR/1), the CRPD Committee called on one of the Member States of the EU, *inter alia*, to

- prevent any further placement of persons with disabilities in any institutional settings by halting programmes that develop institutions, and provide reparations for persons with disabilities seeking redress for their institutionalization (para 114(a));
- amend the current strategy of moving persons with disabilities from large-scale institutions into small-scale institutions (supported housing) by removing all elements of institutionalization (para 114(b)).

It should also be noted that institutionalisation affects more people than just people with disabilities. It would therefore be useful to use the focus on DI in the Strategy as a lever to reach out to other groups as well, and not have all efforts for DI channeled through the Disability Rights Strategy exclusively.

The EEG urges the European Commission and the EU Member States to consider the following in their implementation of the strategy:

- 1) **The guidance recommending improvements for Member States on independent living and inclusion in the community** should first and foremost be guided and based on the experience of people who lived or still live in institutions, and those at risk of being placed there. The EEG is ready to support their participation via our members who directly represent them. It should also be supported by their families and organisations that work with and represent them, as well as service providers. The guidance needs to be very clear on the urgent need to divest from institutional care throughout all EU Member States, as well as in other countries that receive investment from EU funds. We also stress the importance of being clear on what institutional



care is in these recommendations, as well as community-based services (such as supported housing), to avoid any confusion at the national level. The definition of institutional care should fall in line with [that agreed on by all members of the EEG](#) and the General Comment 5 on Article 19 CRPD. We would also underline that the guidance should make use of the [checklist developed by the EEG and Hope and Homes for Children in cooperation with the European Commission](#), and that this be promoted as a tool for determining when EU funding is and is not going towards supporting institutional care.

- 2) The new **framework for Social Services of Excellence for persons with disabilities** must only include community-based services that are designed around the rights, requirements and wishes of service users. It should highlight how service provision that emphasises the empowerment of persons with disabilities and puts them in the driving seat of how services are provided can also improve the job satisfaction of service providers. It should have a focus on training that raises awareness of human rights in relation to persons with disabilities and children. The framework should also address the reality of informal carers, taking into account the gender gap in informal care, and how to achieve informal and family carers' social recognition and access to different social rights such as respite, financial compensation, pension rights, and work-life balance measures. This should go hand in hand with the development of services, such as respite care and preventative services, for the temporarily relief of informal carers and the reconciliation of work and family life.
- 3) The guidance on reforms as part of the **study on social protection and services for persons with disabilities** should emphasise the importance of disability assessment resulting in enough financial support to allow for a life of dignity in the community, and to avoid the risk of poverty. A review of what is considered adequate financial support to persons with disabilities must be combined with reforms of mainstream services used by all citizens, in a way that ensures they can be accessed, to the greatest extent possible, by persons with disabilities without the need to resort to specialised services that can be costly and difficult to access. It is also important to highlight that accessible and inclusive mainstream services such as education, employment and recruitment support, cultural and leisure-time sectors are key to further facilitate the transition to community-based services (DI). The study should also look into issues such as the extra cost of living of persons with disabilities and their families in different EU Member States and regions, the need to improve compatibility of disability entitlements with other forms of income such as paid work, and recommend that Member States abolish the practice known as the “price of love”, whereby persons with disabilities lose financial support on the basis of the income of their spouse. Another issue, worth



looking into, is the impact of the digitalisation of service provision, as there is a need to ensure that safeguards are put in place to avoid this leading to further isolation and social exclusion.

- 4) In their implementation of the EU Disability Rights Strategy, EU institutions and Member States should also ensure increased support for children with disabilities, and their families and caregivers, from their earliest years. Realising the rights of children with disabilities must include a focus on early childhood development, through integrated, accessible and inclusive services and support, including social protection, access to quality healthcare and early childhood education and care and healthy nutrition.
- 5) The continued **support of DI through the use of EU funds** must be met with stronger and stricter system of monitoring and accountability. This can be assisted by stricter compliance with the recommendations made by the CRPD Committee during EU Member States' reviews, as well as promoting the use of the [EEG and Hope and Homes for Children Checklist](#) among Commission desk officers and national managing authorities covering the shared-management funds. Every effort must be made to ensure we do not see investment in existing institutions under the guise of improving energy efficiency, nor investment in new care systems which, even if in smaller settings and with newer infrastructure, remain institutional in nature.

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