



VALIDITY



JOINT RESPONSE TO THE EUROPEAN COMMISSION ROADMAP FOR THE CHILD GUARANTEE BY THE EUROPEAN NETWORK ON INDEPENDENT LIVING, VALIDITY FOUNDATION AND DISABILITY RIGHTS INTERNATIONAL

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The European Network on Independent Living (ENIL), Disability Rights International (DRI) and the Validity Foundation welcome the opportunity to respond to the European Commission's Roadmap for the new Child Guarantee. As organisations of and for persons with disabilities, we are pleased that children with disabilities, including children in institutions, have been recognised as one of the key target groups of this strategy.

The areas which will be covered - early childhood education and care (ECED), health care, education, nutrition, housing, culture and leisure activities - are of great importance to all children, and much remains to be done to close the gaps in access of children with disabilities to these rights. We have, therefore, outlined below a number of issues requiring attention, and actions that, if included in the Child Guarantee, would help address them. Our submission also focuses on the impact of COVID-19 on children with disabilities, including children in institutions.

The Child Guarantee should have the following objectives in relation to children with disabilities living with their families, and children in institutions:

1. PROVIDE ALL CHILDREN WITH THE RIGHT TO GROW UP IN A FAMILY

All children have the need and the right to live and grow up with a family.¹ The preamble of the Convention on the Rights of the Child (CRC) recognizes that for their "full and harmonious development", all children "should grow up in a family environment." Reflecting the CRC standards, the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out that the best interests of the child are the paramount consideration in all decisions affecting them (Article 7(2)), and places clear obligations on States to protect the right to family life (Article 23) and to live and be included in the community (Article 19). In General Comment No. 5, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) unequivocally states that "[f]or children, the core of the right to be included in the community entails a right to grow up in a family."² The CRPD Committee goes on to explain that: "Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. 'Family-like' institutions are still institutions and are no substitute for care by a family."³

¹ See Eric Rosenthal, "The Right of All Children to Grow Up with a Family under International Law: Implications for Placement in Orphanages, Residential Care, and Group Homes", 25 Buffalo Human Rights Law Review 101 (2019) (describing the development of the right to family under international law and summarizing research findings on the need and ability of all children to grow up in a family).

² U.N. Secretary-General, *General Comment No. 5 (2017) on living independently and being included in the community*, U.N. Doc. CRPD/C/GC/5 (Oct. 27, 2017), para. 37. [hereinafter General Comment No. 5]

³ *Id.*, para. 16(c).

The Child Guarantee must include the following binding guidance⁴ for Member States, and the following actions:

- It must make it clear that **there are no exceptions to the right to grow up in a family for any child, applying the principle of non-discrimination**. The need for care, support services, treatment, socio-economic status or education can never justify violating a child's right to family, and deprivation of family life on the basis of disability amounts to discrimination and must be prohibited by law.
- Where children are living without or deprived of parental care, governments are under the obligation to **create supportive services so that children with and without disabilities have a range of options for living in the community in a family setting**, including extended kinship care, foster care, or adoption, and including the maintenance of the child's sibling relationships. Residential type services, regardless of size, must not be regarded as a 'family environment'.
- Where States fail to meet their legal obligations to create the family-based support systems necessary to implement the right to family for all children, this is a human rights violation. Nevertheless, the **State still has the duty to minimize the physical danger and emotional damage caused by depriving children of the right to family**. States who fail in these obligations must ensure that any placement of a child in a non-family environment is only an exceptional and temporary measure and that urgent steps are taken to restore the opportunity for family life. During any temporary placement, there must be full respect for family or extended family connections that a child has, and steps must be taken to support reintegration into family life and the maintenance of connections with family, extended family, and friends in the community.
- For older **adolescents making the transition to adulthood**, the adolescent may choose to live in a community-based supported living arrangement that is not family-based. Such choice may only be viewed as informed and voluntary, however, if the adolescent is provided support to make an informed decision and after being provided the opportunity to observe, live in, and experience a safe and stable family-based setting with support services appropriate to his or her age, gender, and/or disability.
- In order to monitor progress that Member States are making in ensuring that all children are able to grow up in a family, the **available data must distinguish between different forms of residential care (such as group homes for children, children's villages etc.), and family-based care**.

2. ENSURE ACCESS OF ALL CHILDREN WITH DISABILITIES TO INCLUSIVE EDUCATION

An estimated 93 million children worldwide live with disabilities⁵. Like all children, they need quality and inclusive education to develop their skills and realize their full potential. Nearly 50 percent of

⁴ Based on a joint statement by the disability and child rights groups on behalf of children without parental care to the UN, from September 2019. See: https://enil.eu/wp-content/uploads/2019/07/2019-09-12_UNGA-Right-to-Family-Life.pdf

⁵ Source: UNICEF, available at: <https://www.unicef.org/education/inclusive-education#:~:text=Inclusive%20education%20means%20all%20children,speakers%20of%20minority%20languages%20too>

children with disabilities are not in school, compared to only 13 percent of their peers without disabilities⁶.

The CRPD made an important breakthrough in the right to education guaranteed under international law, defining that every child should have access to inclusive education. The CRPD Committee indicates that the goal of education is to ensure children's "full development and sense of dignity and self-worth", as well as to ensure their "full and equal participation... as members of the community". As such, education of all students must take place in an inclusive environment,⁷ implying the obligation to move away from segregated or parallel forms of education or training for children with disabilities. Inclusive education must, therefore, be understood as a process that transforms culture, public policy and practice to create inclusive learning environments for all children, and which is responsive to the diverse needs of individual students, including students with disabilities.

Sustainable Development Goal (SDG) 4 also affirms the obligation to provide inclusive quality and equitable education. The OHCHR Thematic Study of the Rights of Persons with Disabilities to Education (2013) affirms that only inclusive education can provide both quality education and social development for persons with disabilities, and that states must provide guarantees of universality of access and participation, and ensure that the right to non-discrimination in education is legally enforceable.

The Child Guarantee must include the following binding guidance for the Member States, and the following actions:

- Early childhood interventions must guarantee respect for the dignity and autonomy of the child. In line with SDG 4, and the 2030 Agenda for Sustainable Development, Member States must **ensure access to quality early childhood development, care and pre-primary education, together with the provision of support and training to parents and caregivers of young children with disabilities**. If identified and supported early, young children with disabilities are more likely to transition smoothly into pre-primary and primary inclusive education settings. Member States must ensure coordination between all relevant ministries, authorities and bodies as well as OPDs and other NGO partners.⁸
- Educational **institutions and programmes must be accessible to everyone, without discrimination**. The entire education system must be accessible, including buildings, information and communication, comprising ambient or frequency modulation assistive systems, curriculum, education materials, teaching methods, assessment and language and support services.
- Education must focus on the **scope, active participation and achievement of all students**, especially those who, due to various reasons, are excluded or marginalised. It also highlights the obligation to remove barriers that in any way impede access to education,⁹ particularly through guaranteeing access to reasonable accommodations, assistance and specific forms of support necessary to guarantee full participation, maximum development and educational/social attainment.

⁶ Ibid.

⁷ This position is shared by the Committee on the Rights of the Child, General Comment 9. The rights of children with disabilities, CRC/C/GC/9, 27 February 2007.

⁸ U.N. Secretary-General, *General Comment No. 4 (2016) on right to education*, U.N. Doc. CRPD/C/GC/4 (Sept. 2, 2016), para. 65

⁹ U.N. Secretary-General, *General Comment No. 4 (2016) on right to education*, U.N. Doc. CRPD/C/GC/4 (Sept. 2, 2016), para. 9

- According to article 24, paragraph 1, of the CRPD States parties must ensure the realization of the right of persons with disabilities to **education through an inclusive education system at all levels**, including pre-schools, primary, secondary and tertiary education, vocational training and lifelong learning, extracurricular and social activities, and for all students, including persons with disabilities, without discrimination and on equal terms with others.
- Quality inclusive education must provide persons with disabilities with **preparation for work life** through the foundation of the knowledge, skills and confidence necessary for participation in the open labour market and in an open, inclusive and accessible work environment (article 27). To ensure smooth transition from childhood to adulthood for children with disabilities, there should be coordination in the implementation of the Child Guarantee, with the Youth Guarantee.
- With regard to international cooperation, and in line with SDG 4 and the Education 2030 Framework for Action, **all bilateral and multilateral cooperation must advance inclusive and equitable quality education and promote lifelong learning opportunities** for all, including support for capacity building, exchange and information sharing and best practices, research, technical and economic assistance, and facilitating access to accessible and assistive technologies. All data and spending of international assistance on education should be disaggregated by impairment. There is a need to strengthen the technical capacity on disability inclusion, intersectionality and CRPD implementation across DG DEVCO, DG ECHO, the EEAS, and the EU Delegations.

3. ENSURE THAT EU FUNDS SUPPORT FAMILY-BASED CARE AND ARE NOT INVESTED IN INSTITUTIONS

In the current European Structural and Investment Funds (ESI Funds) programming period (2014 - 2020), twelve Member States had as one of their priority areas transition from institutional to community-based care. However, while some progress was made in decreasing the number of children in institutions and improving access to family-based care, in many cases, children with disabilities have been moved to other large, or small institutions (also referred to as ‘group homes’ or ‘family-type settings’), rather than placed in family-based care. This is confirmed in the “Report on the transition from institutional care to community-based services in the 27 EU Member States”, published in January 2020, which states that:

“Evidence of increased support for families and increased use of and support for foster families is encouraging, although of course such approaches need to be scaled up and applied much more widely. Those who were most likely to be in larger residential provisions were: 1) children with disabilities, in particular those with intellectual disabilities, autism and those who showed challenging behaviour; and 2) unaccompanied and separated migrant children.”¹⁰

Moreover, in Bulgaria, Disability Rights International (DRI)¹¹ found that the availability of ESI Funds for group homes was “one of the major motivating forces” which encouraged municipal authorities to build the new facilities. Considering that the bigger the facilities, the more funding was available, this

¹⁰ Šiška, Jan and Beadle-Brown, Julie, 2020. *Report on the transition from institutional care to community-based services in 27 EU Member States*, European Expert Group on the Transition from Institutional to Community-based Care. Available from: <https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf> (referred as “the Šiška study”).

¹¹ Disability Rights International, 2019. *A Dead End for Children – Bulgaria’s Group Homes*. Available from: <https://www.driadvocacy.org/wp-content/uploads/Bulgaria-final-web.pdf>

acted as an incentive to build institutions for as many children as possible; typically with 14 beds, but some municipalities also clustered several group homes together. The report went on to state that municipalities competed with one another, in order to use as much EU funding as possible while it was available. In addition, “since some funding came from an EU project to assist less developed areas, remote locations had an incentive to build group homes and worry later about how to bring in children from other parts of the country.”

The Child Guarantee must include the following binding guidance for the Member States, and the following actions:

- It should make it clear that **investing EU Funds in any projects that institutionalise or segregate children with disabilities is a violation of the CRPD and the CRC, as well as the EU Fundamental Rights Charter**. This includes large institutions, family-type homes, children’s villages and special schools for children with disabilities, and covers infrastructural investments, but also investments in human resources. The prohibition should apply to all EU funding streams and programmes, including those aimed at the neighbourhood countries and international cooperation.
- It follows that the use of **EU Funds should be strictly limited to projects that fully comply with the CRPD, in particular Article 19, as explained in the General Comment No. 5, but also other articles**. Member States should closely coordinate the use of the European Social Fund (ESF) and the European Regional Development Fund (ERDF), in order to develop a range of services that support the children’s right to grow up in a family. The European Commission must suspend investments or otherwise sanction Member States which continue using EU Funds to build or renovate institutions of any kind.
- The European Commission should **closely monitor implementation of EU Funds within the current programming, and plans for 2021 – 2027**, in order to prevent projects that fail to comply with the CRPD from going ahead. Member States should ensure close consultations with and involvement of persons with disabilities, through their representative organisations, in all stages of EU Funds use.

4. ENSURE ACCESS OF CHILDREN WITH DISABILITIES TO INDEPENDENT LIVING, INCLUDING PERSONAL ASSISTANCE

For children with disabilities and their families, to have full access to independent living, as set out in Article 19 of the CRPD, mainstream services such as education, health, housing and transport must be accessible. Children with disabilities and their families need a full range of options of support, so that they can choose what works best for them and their family’s needs. Support should not negatively affect a family’s functioning, but support a child with disabilities to enjoy the right to family life. It is important that there is readily available information about services and support available to children, including children with disabilities. Providing children with disabilities and their families with access to support and mainstream services will help Member States realise principle 11 of the Social Pillar, on the equality of opportunities for children from disadvantaged backgrounds.

Personal assistance, as a key tool for independent living, should be available to children with disabilities and their families. At the moment, this is not the case. According to ENIL’s Independent

Living Survey¹², which covered 44 countries in the EU and the wider Council of Europe area, in 25 countries children with disabilities and their families are not eligible for personal assistance.

Personal assistance is beneficial, because it enables parents of children with disabilities to retain employment. It also makes it easier for them to care for other siblings, have time to rest (thus avoiding the need for respite care services) or enjoy sports, cultural and other activities together as a family. Personal assistance does not and should not replace parents; therefore, personal assistants should have clear boundaries and guidance from parents.

In addition to personal assistance and other support services, families should have access to technical aids and equipment such as wheelchairs, hearing aids, communication aids. Communication support should also be available, such as training in sign-language, so that children with disabilities can be fully included in the family. While timely support and continuity in support are key for all persons with disabilities, they are particularly important for children. Given how quickly things change in the life of a child, and how key being able to have access to services such as education can be to a child's development, continuity in support is essential. No child's potential should be stunted by not getting the support they need to access the same opportunities as their non-disabled peers.

The Child Guarantee must include the following binding guidance for the Member States, and the following actions:

- **The right to live independently and being included in the community, set out in Article 19 of the CRPD, applies to all persons with disabilities, including children.** Member States must take into account the needs of children with disabilities and their families when developing strategies and plans for implementation of Article 19, as well as in deinstitutionalisation strategies.
- The European Commission should **promote access to personal assistance for children with disabilities and their families**, as a means of ensuring that children are supported to grow up in a family and to prevent institutionalisation. Equally, when planning for the closure of institutions and the return of children to family care, families should have the option to access personal assistance for their child(ren).
- Member States should be **encouraged to use the European Social Fund (ESF+) to pilot, or expand personal assistance for children with disabilities and their families. ERDF should be used to improve access of children with disabilities to technical aids and equipment, as well as for housing adaptations** to make family apartments and houses fully accessible, and to prevent children from being placed in institutions because of inaccessible homes.

5. PRIORITISE CHILDREN WITH DISABILITIES IN DEINSTITUTIONALISATION REFORMS

Even in countries where deinstitutionalisation reform is ongoing, children with disabilities have been left behind, especially children with more complex support needs. For example, in Serbia which has one of the lowest institutionalisation rates for children in Europe, 75% of children in residential care are children with disabilities. Most of these children face life-long institutionalisation, lacking access to community-based services, including education, consistent with their right to, inter alia, family life, community living, freedom of association, protection from violence and access to justice.

¹² The Independent Living survey was open between July and September 2020, and targeted persons with disabilities and their representative organisations in Europe. Results will be published on 10th December 2020.

Institutionalised children face discrimination in access to healthcare and are often denied medical treatments that would improve their quality of life. In Bulgaria and Romania, we can still find children with untreated conditions such as hydrocephalus, where such treatment could be lifesaving.

Poverty is one of the main factors of institutionalisation of children and it is often linked to disability. Today, many parents are still forced to give up their children because of such social marginalization, as well as poverty or disability.¹³ According to the Child Guarantee Roadmap, the proportion of children suffering from severe housing deprivation is more than 20% in Romania and more than 15% in Bulgaria and Poland which are, at the same time, countries with the highest rates of institutionalisation of children. Therefore, appropriate housing is important for prevention of family separation and is instrumental in family reunification.

The Child Guarantee must include the following binding guidance for the Member States, and the following actions:

- It should encourage Member States to adopt **comprehensive deinstitutionalisation strategies (covering all persons with disabilities, including children)**, in line with Article 19 and the General Comment 5, and in close consultation with persons with disabilities and their representative organisations.
- As stated above, It should make it clear that **investing EU Funds in any projects that institutionalise or segregate children with disabilities is a violation of the CRPD and the CRC, as well as the EU Fundamental Rights Charter.**
- It should promote the use of ERDF to **improve access of families of children with disabilities to adequate housing**, in the community.
- Exercise of the **right to education and the right to live in a family environment are closely linked** and are jointly necessary preconditions for guaranteeing the optimal development of all children, including children with disabilities, thus requiring a comprehensive and multisectoral approach. The EU should ensure that Funds are used to support inclusive environments, rather than special or segregated schools.
- The introduction of inclusive education in the local community must take place alongside a **strategic commitment to the ending institutionalisation of persons with disabilities**. The EU and its Member States should recognise the role that exercising the right to inclusive education will play in building the strengths, skills and competencies necessary for all persons with disabilities to enjoy, benefit from and contribute to their local communities.

6. ENSURE PARTICIPATION OF CHILDREN WITH DISABILITIES IN DECISIONS THAT CONCERN THEM

Article 7 of CRPD asserts that, in all actions, the best interests of the child shall be a primary consideration. The best interests is a concept aimed at ensuring the full and effective enjoyment by

¹³ Galina Markova of the Know-How-Foundation added to this critique in an interview with DRI, saying that service providers and reformers “don’t know how to work with parents.” Interview with DRI, February 18, 2019. A small percentage of children separated from families are taken because of abuse by parents. National Scientific Council on the Developing Child, The Science of Neglect: The Persistent Absence of Responsive Care Disrupts the Developing Brain: Working Paper 12 (2012), posted at <https://developingchild.harvard.edu/resources/the-science-of-neglect-the-persistent-absence-of-responsive-care-disrupts-the-developing-brain/> (last visited June 18, 2018).

the child of all human rights and the child's holistic development.¹⁴ Article 7 further asserts that children with disabilities have the right to express their views and the latter be given due weight on all matters affecting them, according to their age and maturity on an equal basis with other children, and that they must be provided with disability and age-appropriate assistance. Guaranteeing the right of children to participate in their education must be applied equally to children with disabilities – in their own learning and individualized education plans, within the classroom pedagogy, through schools councils, in the development of school policies and systems, and in the development of wider educational policy.¹⁵

The Child Guarantee must include the following binding guidance for the Member States, and the following actions:

- All programmes affecting children with disabilities need to ensure their participation on an equal basis with other children, respect the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities.

7. PRIORITISE THE NEEDS OF CHILDREN WITH DISABILITIES, INCLUDING THOSE IN INSTITUTIONS, DURING COVID RESPONSE AND RECOVERY

As the Roadmap rightly states, the Child Guarantee will be “particularly relevant in the context of the socio-economic consequences of COVID-19” and “will help mitigate its negative effects”. This is key, because indeed, the pandemic had a significant impact on children with disabilities and their families in Europe, and world-wide.

According to the Covid-19 Disability Rights Monitor (DRM) global report¹⁶, children with disabilities were disproportionately affected by the measures taken by governments during the pandemic and experienced multiple forms of discrimination on the basis of disability and age. Forty three percent (623) of the COVID-19 DRM survey respondents who knew about the situation of children said that their government took no measures to protect the health and safety of children with disabilities in institutions or in the community. The written testimonies revealed that many essential supplies and services were unavailable to children in the community and in institutions. Respondents from around the world reported that children did not have access to food and medicine. Moreover, children with disabilities did not have access to essential healthcare, respite care, rehabilitation, or education.

The majority (55%) of the survey respondents said that their government had taken no measures to support families of children with disabilities during the pandemic. In most cases, governments did not take disability-specific measures and did not take child-specific measures. For instance, a respondent from the UK said that “children were not included in any of the definitions of ‘vulnerable’ to COVID 19 - only adults.” Hence, children with disabilities have been in a situation of compounded vulnerability.

Children living in poverty and children living in rural or remote areas relied on NGOs and charities to deliver essential supplies such as food and medication. However, there were reports that NGOs could not deliver essential, potentially life-saving supplies to children with disabilities. Furthermore, there were reports that children who relied on schools or disability services for food and medication could not access them during the pandemic.

¹⁴ CRC, General Comment No.14, CRC/C/GC/14, May 2013

¹⁵ CRC General Comment No.12 CRC

¹⁶ COVID-19 Disability Rights Monitor Coordinating Group, 2020. *Disability rights during the pandemic – A global report on findings of the COVID-19 Disability Rights Monitor*. Available at: <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>

Children with disabilities around the world did not have access to education and other essential services. The COVID-19 DRM survey received reports that children with disabilities were excluded from remote schooling. For instance, respondents from Malawi and Moldova described how children with disabilities were excluded from remote learning because they did not have access to technology.

Families who were instructed to stay at home with their child with a disability reported that they did not receive any guidance or financial support from the government. For instance, an Irish family member explained that “families of those children are relying heavily on charities to support them and each other. We have literally been left to fend for ourselves.”

The Child Guarantee must include the following binding guidance for the Member States, and the following actions:

- It must ensure that **React-EU and the Recovery and Resilience Facility are used to address the impact of COVID-19 on children with disabilities and their families**. Moreover, EU funds should support “emergency deinstitutionalisation”, by accelerating the development of family- and community-based services that would allow for the (re)integration of children with disabilities into families, and prevent future placements of children with disabilities in institutions.
- In this respect, it is important to **closely monitor investments from React-EU and the Recovery and Resilience Facility**, to prevent them going into institutions and other segregating settings for children with disabilities.
- It must ensure that the **“Team Europe” global response to COVID-19, as well as all future “Team Europe” joint programming and implementation, is inclusive of children with disabilities**. For example, the EU can help facilitate access of children with disabilities around the world to the COVID-19 vaccine.
- The EU and its Member should adopt **inclusive Disaster Risk Reduction strategies for comprehensive school safety and security in emergencies**, which are sensitive to learners with disabilities. Learners with disabilities must not be denied access to educational establishments on the basis that their evacuation in emergency situations would be impossible, and reasonable accommodation must be provided.¹⁷ During the COVID-19 pandemic, States must **prioritise ensuring equal access to education for all children**, conducting individualised needs assessments of children with disabilities and ensuring that individualised supports, accommodations and pedagogical approaches are implemented than enable equal participation in education.

ABOUT THE SUBMITTING ORGANISATIONS:

The European Network on Independent Living (ENIL) is an international network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross-disability and self-determination. **Website:** www.enil.eu.

¹⁷ U.N. Secretary-General, *General Comment No. 4 (2016) on right to education*, U.N. Doc. CRPD/C/GC/4 (Sept. 2, 2016), para. 14

Disability Rights International (DRI) is a human rights advocacy organization dedicated to the protection and full community inclusion of children and adults with disabilities worldwide. DRI documents human rights violations, educates and engages the public through media campaigns, trains and supports activists working to bring change, and conducts strategic litigation to enforce the rights of people with disabilities. DRI's Worldwide Campaign to End the Institutionalization of Children is dedicated to promoting the recognition and enforcement of the right of all children to live and grow up with a family and not in any form of institution, orphanage, or group home. DRI is an organization led by people with disabilities and their families. **Website:** www.driadvocacy.org.

The Validity Foundation – Mental Disability Advocacy Centre is an international non-governmental human rights organisation which uses legal strategies to promote, protect and defend the human rights of persons with intellectual disabilities persons with psychosocial disabilities in Europe and Africa. Validity holds special consultative status with ECOSOC and participatory status at the Council of Europe. **Website:** www.validity.ngo.