**Basic services for children in need – European Child Guarantee**

Contribution to consultation on Child Guarantee, October 2020

Inclusion Europe is the European movement of people with intellectual disabilities and their families fighting for the equal rights and full inclusion in all aspects of life of people with intellectual disabilities. It has 79-member organisations in 39-European countries.

Inclusion Europe welcomes the [Child Guarantee initiative](https://ec.europa.eu/social/main.jsp?catId=1428&langId=en) to ensure that every child in Europe at risk of poverty or social exclusion has access to free healthcare, free education, free early childhood education and care, decent housing and adequate nutrition.

Inclusion Europe also appreciates that the feasibility study took into account children with disabilities and other children with “special needs” as target groups. We however deplore the use of the terminology “special” to speak of children with disabilities. We believe that every child has the same needs of access to education, healthcare, suitable housing. Every child is special in their own way but when it comes to disability, the use of “special” comes with negative connotations.

The EU Child Guarantee is a great opportunity to improve the quality of life of children with disabilities as it will focus on children in poverty and at risk of social exclusion. Children with intellectual disabilities and their families tend to be disproportionately affected by poverty and social exclusion, as they not only face extra costs (healthcare, logistical and human support) reducing their available resources, but also have limited opportunities to secure employment while providing the necessary care.[[1]](#footnote-2) This affects all five-key-policy areas addressed in the EU Child Guarantee.

To contribute to the roadmap, and enable the EU Child Guarantee to “break the cycle of disadvantage and poverty”, Inclusion Europe examined for each area the challenges and what the guarantee needs to ensure to achieve its goal:

* **Preliminary remarks on the lack of harmonisation of the definitions across the EU**

The definition and classification of disability differs across EU member states, leading to different entitlements across EU countries and discrepancies.

Plus, as mentioned in the Target Group Discussion Paper on Children with Disabilities, several definitions of the key policy areas of the EU Child Guarantee vary across the EU. For instance, the definition of ‘free healthcare’ may mean in one country that therapeutic appliances are partially refunded, whereas in another, the entitlement to free healthcare would depend on the annual income of parents. Additionally, in eight member states, co-payments exist for medical prescriptions. Because of these differences, entitlements of children with disabilities to free healthcare vary across Europe and it may even hinder their access to quality services because of the extra-costs.[[2]](#footnote-3)

For this reason, harmonisation of definitions and correct indicators based on robust and disaggregated data need to be established to construct and evaluate polices of the Child Guarantee, to monitor, notice and avoid differences among states that hinder children’s access to quality services or even exclude them from entitlements. Additionally, intersectional policies and indicators should be incorporated, to establish real rights and real access to services for all children with disabilities and their families.

Finally, consultation and participation of children with intellectual disabilities and their families regarding polices affecting them is a necessity.

* **Early Childhood Education and Care**

Early childhood education and care for children with intellectual disabilities and complex support needs is vital to have access to mainstream education, employment, better health, welfare and support for parents and less institutionalisation. However, not every Member State ensures quality family-based early intervention services through health insurance coverage, which increases the finical burden on families and impedes them to afford therapy. In some countries early childhood education and care is only available in rehabilitation centres and institutions, leading to institutionalisation and segregation.[[3]](#footnote-4)

The Child Guarantee must ensure available and accessible early intervention for all children and it must be affordable for their families.

* **Healthcare**

Children with intellectual disabilities are often in poorer health than other children their age due to barriers in accessing quality healthcare as well as specialised care. This is largely due to the extra costs deriving from: medical care; staff having little understanding about intellectual disabilities and thus often failing to diagnose and recognising that a person with intellectual disabilities is unwell; inadequate aftercare or follow-up care; and the lack of accessible services.[[4]](#footnote-5)

The Guarantee must ensure that healthcare coverage includes early childhood education and care, extra expenses of medical care and health checks to prevent and detect malnutrition.

* **Quality Education**

Every child has the right to quality education and inclusion at school. Yet across Europe, countless children with intellectual disabilities still do not have access to education in inclusive environments, are put aside in segregated educational settings and some do not have access to education at all.

Segregating children with disabilities and complex support needs and not providing them with the same opportunities to self-realisation, will ultimately affect their socio-economic status later, such as access to employment.[[5]](#footnote-6)

Because education policies fall under shared national and regional competencies, the access to education is very inhomogeneous in Europe.[[6]](#footnote-7) In 2020 the ECHR recognised in G.L v. Italy [[7]](#footnote-8) that children with support needs cannot be discriminated in accessing primary education on the basis of disability.

This right to quality education for all needs to be recognised under the child guarantee, taking into account principles of the CRPD and sustainable development goal 4.

* **Decent Housing**

Children with disabilities worldwide are 17 times more likely to be placed in institutional care than their peers.[[8]](#footnote-9) In the EU, efforts to facilitate the transition to family-based care often do not reach children with disabilities. In fact, legislative frameworks and funds of several Member States continue to favour institutions. Yet, institutionalisation tremendously damages children’s health and development.[[9]](#footnote-10) To end the segregation and institutionalisation of children with intellectual disabilities and complex support needs, inclusive and affordable childcare is the right and only way forward, and it is essential that these efforts include children with disabilities.

The Child Guarantee must contribute to end institutionalisation of children with intellectual disabilities through targeted EU policies and traceable funding.

* **Nutrition**

Families with a child with disabilities tend to be disproportionally affected by poverty and unequal distribution of resources, which can impact their access to adequate nutrition. This is particularly worrying concerning children with disabilities that have dietary needs (a factor that can also contribute to poverty among the family). Research has shown that children with disabilities often do not benefit from services aimed at reducing malnutrition in the same way as those without disabilities.[[10]](#footnote-11)Thus, only through specific targets, can malnutrition among children with disabilities be reduced.

* **Culture and Leisure activities**

Children with intellectual disabilities and complex support needs often face barriers and exclusion in accessing culture and leisure activities on an equal ground with others and cannot enjoy the same activities alongside non-disabled peers. Frequently, the only accessible activities take place in segregated settings.

1. Joseph Rowntree Foundation, ‘Disability, Long Term Conditions and Poverty’, July 2014.  [↑](#footnote-ref-2)
2. Feasibility study for a Child Guarantee, 2019,

<https://ec.europa.eu/social/main.jsp?langId=en&catId=1428&moreDocuments=yes> [↑](#footnote-ref-3)
3. Every child should get the support they need, Inclusion Europe, 2019, <https://www.inclusion-europe.eu/every-child-should-get-the-support-they-need/> [↑](#footnote-ref-4)
4. Disability and Health, WHO, January 2018, <https://www.who.int/news-room/fact-sheets/detail/disability-and-health> [↑](#footnote-ref-5)
5. Inclusion at School a right for every Child, Inclusion Europe, <https://www.inclusion-europe.eu/education/> [↑](#footnote-ref-6)
6. .Exploratory study on the inclusion of pupils with complex support needs in mainstream schools, Inclusion Europe, 2018,

<https://www.inclusion-europe.eu/wp-content/uploads/2018/08/IE_CSN_Education_Report_Final.pdf> [↑](#footnote-ref-7)
7. CEDH, G.L. v Italie, requête n°59751/15, 10 septembre 2020 <https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-204322%22]}> [↑](#footnote-ref-8)
8. Children with disabilities, UNICEF, <https://www.unicef.org/eca/children-disabilities> [↑](#footnote-ref-9)
9. Children with disabilities deserve a life outside institutions, Inclusion Europe, 2019, <https://www.inclusion-europe.eu/children-with-disabilities-deserve-a-life-outside-institutions/> [↑](#footnote-ref-10)
10. World Report on Disability, WHO, 2011,

<https://www.who.int/disabilities/world_report/2011/report/en/> [↑](#footnote-ref-11)