



November 2020

## Joint recommendations for the European Disability Rights Strategy 2021-30

### 1. Introduction

Persons with disabilities still face obstacles to their inclusion and participation in society on an equal basis with others and are more exposed to violence.<sup>1</sup> Children with disabilities are especially vulnerable to social exclusion, neglect and violence, and are at greater risk of being institutionalised, due to a lack of support services available to the family, and a lack of inclusive education in the community. With the right services in place, family separation can be prevented and many of these children could grow up in birth, extended or foster families: as part of the community.<sup>2</sup>

However, the socio-economic impact of the COVID-19 pandemic, coupled with strained government services, is further testing the capacity of vulnerable families to care for their children. Ultimately the number of children at risk of separation, in need of additional support, or in alternative care is likely to increase. At the same time, the congregate environment in institutional facilities exposes children and workers to a high risk of virus transmission. Children with disabilities and underlying health conditions are especially vulnerable, and in some cases at higher risk of developing complications after contracting the virus.<sup>3</sup> In the context of the current pandemic, it is thus essential to scale up the capacity of quality family-based care, social protection and health systems to enhance family resilience and prevent unnecessary family separation and recourse to residential care.

Lumos and Hope and Homes for Children therefore welcome the upcoming Disability Rights Strategy for 2021-30, and see a renewed strategy as an opportunity to build on the lessons learned from the Disability Rights Strategy 2010-20, foster deinstitutionalisation for children with disabilities and promote inclusive education globally. In this way, the new strategy can play a vital role in accomplishing the full implementation of the UN Convention on the Rights of Persons with Disabilities

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<sup>1</sup> European Commission, Roadmap on Union of Equality: Strategy on the Rights of Persons with Disabilities 2021-2030, <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12603-Union-of-Equality-European-Disability-Rights-Strategy> [accessed 16 October 2020].

<sup>2</sup> Anghela, R., Herczog, M. & Dima, G. (2013). The challenge of reforming child protection in Eastern Europe: The cases of Hungary and Romania. *Psychosocial Intervention*. 22: 239-249. [psychosocial-intervention.elsevier.es/en/the-challenge-reforming-child-protection/articulo/S1132055913700279/#.WRsQvmjys2w](https://doi.org/10.1080/1132055913700279) [accessed 20 October 2020].

<sup>3</sup> Better Care Network, The Alliance for Child Protection in Humanitarian Action, UNICEF (2020). Technical Note: Protection of Children during the Coronavirus Pandemic, p. 3. [https://alliancecpha.org/en/system/tdf/library/attachments/covid-19\\_alternative\\_care\\_technical\\_note\\_final.pdf?file=1&type=node&id=37605](https://alliancecpha.org/en/system/tdf/library/attachments/covid-19_alternative_care_technical_note_final.pdf?file=1&type=node&id=37605) [accessed 21 October 2020].



(UNCPRD; in particular Article 18 and 23), the UN Convention on the Rights of the Child (UNCRC), the Sustainable Development Goals and the European Pillar of Social Rights.

This paper outlines how children with disabilities end up in institutional care and explains how growing up in an institution is particularly harmful to this vulnerable group of children. It presents recommendations on how the European Disability Rights Strategy 2021-30 can best contribute to *all* children's right to family life.

## 2. International and EU policy and legal framework supporting deinstitutionalisation

A number of international and EU policy and legal instruments declare that institutional settings are a breach of human rights, in particular the UNCPRD and the UNCRC.

The UNCRC, ratified by all Member States, affirms that as far as possible, *all* children have a right to live with their families and that parents or other legal guardians have the primary responsibility to protect and care for the child (article 18). The UNCRC and the UN Guidelines for the Alternative Care of Children<sup>4</sup> also call on States to ensure that families have access to services which support them in their caregiving role. Moreover, the UNCRC states that children with disabilities should 'enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community' (Article 23(1)). The UN Committee on the Rights of the Child also expressed its concern at the high number of children with disabilities placed in institutions and has urged States parties, through deinstitutionalisation programmes, to support the ability of such children to live in their family, extended family or foster care.<sup>5</sup>

Over the years the EU has **embedded its commitment to promoting deinstitutionalisation within EU law, policy, and its use of funds.**

The EU introduced the **ex-ante conditionality on social inclusion 9.1. in the European Structural and Investment Funds Regulations in the 2014-2020 programming period, with a dedicated investment priority on the transition from institutional to community-based care.**<sup>6</sup> This commitment has been further reaffirmed with the introduction of enabling conditions in the draft Common Provisions Regulations (CPR) for the 2021-2027 programming period,<sup>7</sup> and by identifying deinstitutionalisation among the priorities for investments in Cohesion Policy Funding 2021–2027 in the 2019 country reports (annex D).<sup>8</sup> Moreover, in 2018, the European Commission showed high political commitment for deinstitutionalisation globally, by proposing a Regulation establishing the Neighbourhood, Development and International Cooperation Instrument (NDICI) that prioritises the promotion of the

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<sup>4</sup> United Nations (2009) Guidelines for the Alternative Care of Children (2009) A/RES/64/142 [http://www.unicef.org/protection/alternative\\_care\\_Guidelines-English.pdf](http://www.unicef.org/protection/alternative_care_Guidelines-English.pdf) [accessed 27 Jul 2017].

<sup>5</sup> Committee on the Rights of the Child, General Comment 9 (2006) on the rights of children with disabilities, paragraph 47.

<sup>6</sup> [Common Provisions Regulation, Regulation \(EU\) No 1303/2013](#)

<sup>7</sup> [Proposal for a Common Provisions Regulation, COM/2018/375 final](#), Article 11

<sup>8</sup> European Commission (2019) [2019 European Semester: Country Reports](#)



transition from institutional to community-based care for children, both within its geographic and thematic programmes.<sup>9</sup>

In addition, the updated EU Guidelines for the Promotion and Protection of the Rights of the Child (2017)<sup>10</sup> highlight the importance of appropriate alternative care for children that allows them to participate in community life, of preventing family and child separation, and of taking into consideration the child's best interests.<sup>11</sup> More recently, the **EU Action Plan on Human Rights and Democracy 2020-2024**<sup>12</sup> prioritised the development of quality alternative care and the transition from institution-based to quality family- and community-based care for children without parental care. Finally, the European Parliament (EP) has taken a strong position on deinstitutionalisation. In its resolution on children's rights on the occasion of the 30th anniversary of the Convention on the Rights of the Child<sup>13</sup> (November 2019), the EP calls on the Commission **"to use EU funds to support the transition from institutional to community-based services, both inside and outside the EU"**.<sup>14</sup> Most recently, in its resolution of 18 June 2020 on the European Disability Strategy post-2020, the EP called on the Commission to: "adopt a strong position on the fact that the general availability of mainstream community-based services"; promote the "transition from institutional and/or segregating care to community-based support, including personal assistance, and inclusive services (both mainstream and tailor-made), in all EU policy tools and initiatives"; and to "ensure that overall progress in deinstitutionalisation is included as an indicator in the EU social scoreboard"<sup>15</sup>.

### 3. Institutionalisation of children and the specific situation of children with disabilities

Millions of children worldwide live in residential institutions including so-called orphanages that deny their human rights and cannot meet their needs.<sup>16</sup> One million of these children are believed to live in the wider European region.<sup>17</sup>

There are numerous definitions of what the term 'institution'<sup>18</sup> means when referring to children's residential care. A group of experts working on this issue for the European Commission determined

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<sup>9</sup> [Proposal for a regulation on the Neighbourhood, Development and International Cooperation Instrument, COM \(2018\) 460 final](#), Annex II and III

<sup>10</sup> European Union (2017), Guidelines on the Promotion and Protection of the Rights of the Child, p. 19 [accessed 06 Mar 2018].

<sup>11</sup> Ibid, p. 21.

<sup>12</sup> Annex to the joint communication to the European Parliament and the Council. EU Action Plan on Human Rights and Democracy 2020-2024. JOIN (2020) 5 final, p. 3.

<sup>13</sup> (2019/2876(RSP)) [https://www.europarl.europa.eu/doceo/document/TA-9-2019-0066\\_EN.pdf](https://www.europarl.europa.eu/doceo/document/TA-9-2019-0066_EN.pdf).

<sup>14</sup> [P9\\_TA\(2019\)0066](#), para 43.

<sup>15</sup> [P9\\_TA\(2020\)0156](#), para 33, 35

<sup>16</sup> Desmond, C., et al. (2020) Prevalence and number of children living in institutional care: global, regional, and country estimates. *Lancet Child Adolescent Health*. VOLUME 4, ISSUE 5, P370-377. [https://doi.org/10.1016/S2352-4642\(20\)30022-5](https://doi.org/10.1016/S2352-4642(20)30022-5) [Accessed 02 July 2020]

<sup>17</sup> Ceecis, U. (2011). End placing children under three years in institutions. UNICEF

<sup>18</sup> See for example Eurochild's definition extracted from the UN Guidelines for the Alternative Care of Children: "a residential setting that is not built around the needs of the child nor close to a family situation and display the characteristics typical of



that an institution is any residential setting where an ‘institutional culture’ prevails. Children living in an ‘institutional culture’ are isolated from the broader community and are compelled to live with children to whom they are not related. These children, and their families, do not have control over their lives, or decisions that affect them. Crucially, the requirements of the organisation tend to take precedence over the children’s individual needs.<sup>19</sup>

Research consistently demonstrates that on average more than 80 per cent of children in institutions are not 'orphans',<sup>20</sup> but are placed there due to reasons such as poverty, **disability**, discrimination, a lack of family support services in the community and as a result of migration and trafficking.<sup>21</sup>

### 3.1. The overrepresentation of children with disabilities in institutional care

Children with disabilities are often overrepresented in institutional care.<sup>22</sup> Data from 2007 in Central and Eastern Europe/Commonwealth of Independent States (CES/CIS) countries suggests; that children with actual or perceived disabilities face a greater risk than others of being institutionalized and of staying so for long periods, accounting for 316 per 100,000 children aged 0 - 17.<sup>23</sup> The rate has remained remarkably stable over the last 15 years. This suggests a clear and systematic discrimination towards children with disabilities - that sets them up for a life of vulnerability and abuse. According to UNICEF, across Eastern Europe and Central Asia, children with disabilities are almost seventeen times more likely than other children to be institutionalised<sup>24</sup>. In the context of development, children with disabilities also face discrimination and stigmatisation.

A key factor leading to the overrepresentation of children with disabilities in institutional care is the lack of inclusive and support services in the community.<sup>25</sup> Children with disabilities are more likely to

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institutional culture (depersonalisation, rigidity of routine, block treatment, social distance, dependence, lack of accountability, etc.). Cited in the Common European Guidelines on the Transition from Institutional to Community-based Care. European Expert Group on the Transition from Institutional to Community-based Care, November 2012, <http://www.deinstitutionalisationguide.eu>. In addition, UNICEF when defining an institution considers “whether the children have regular contact and enjoy the protection of their parents or other family or primary caregivers, and whether the majority of children in such facilities are likely to remain there for an indefinite period of time”. Cited in the UNICEF Consultation on Definitions of Formal Care for Children, pp.12–13.

<sup>19</sup> European Expert Group on the Transition from Institutional to Community-based Care (2012), *Common European Guidelines on the Transition from Institutional to Community-based Care*, <https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf> [accessed 14 October 2020].

<sup>20</sup> Csáky, C. (2009) Keeping children out of harmful institutions: why we should be investing in family-based care, *Save the Children*, p. vii

<sup>21</sup> Ibidem; Chiwaula, L. et al. (2014). Drumming together for change: A child’s right to quality care in Sub-Saharan Africa. The Centre for Excellence for looked after children in Scotland (CELCIS).

<sup>22</sup> UN Secretary-General (2019). Status of the Convention on the Rights of the Child. New York, USA: United Nations, p13/17. <https://reliefweb.int/sites/reliefweb.int/files/resources/Status%20of%20the%20Convention%20on%20the%20Rights%20of%20the%20Child%20-%20Report%20of%20the%20Secretary-General%20%28A-74-231%29%20%5BEN%5D.pdf> [accessed 3 Aug 2020].

<sup>23</sup> At home or in a home? Formal care and adoption of children in Eastern Europe and Central Asia, UNICEF, 2010

<sup>24</sup> Children under the age of three in formal care in Eastern Europe and Central Asia: a rights-based regional situation analysis’, UNICEF 2012, p. 45

<sup>25</sup> Ibidem.



live in poverty than their peers<sup>26</sup>, and are extra dependent on access to services (such as health care, education and support services to the family). A lack of those services might mean parents are not able to adequately care for their child. Stigma and discrimination may lead to challenges around preventing the separation of children with disabilities from their families, and placing them in family- and community-based care, which means they more often end up in institutional care and may not benefit from deinstitutionalisation processes at the same rate as other children.<sup>27</sup>

Another key driver of institutionalisation among children with disabilities is a lack of inclusive education. Across the world, a significant proportion of children live in residential special schools.<sup>28</sup> Labelled as having special educational needs, children are arbitrarily separated from their families and sent to residential special schools, often far from their home, due to a lack of inclusive schools in the local community.<sup>29</sup> A study conducted by the Fundamental Rights Agency found that in several countries, such as in Bulgaria, Lithuania and Portugal, educational staff sometimes advise parents of children with disabilities to place them in special schools or institutions, either because of the inability of some mainstream schools to educate and include children with disabilities, or due to pressure coming from parents of children without disabilities.<sup>30</sup>

Moreover, legislation in some countries might lead to an overrepresentation of children with disabilities in institutional care. For example, in Romania, children under two years old are not allowed to be placed in institutional care, but an exception is made for children with disabilities.<sup>31</sup>

The **Committee on the Rights of Persons with Disability** has emphasised its concern about the institutionalisation of children with disabilities and subsequently articulated clear recommendations to many State Parties. The following are examples, taken from selected State Parties where Hope and Homes for Children and Lumos operate:

- **European Union (2015):** “The Committee is concerned about the number of boys and girls with disabilities living in institutions across the European Union who have no access to mainstream, inclusive, quality education.”<sup>32</sup>.
- **Bulgaria (2018)** should “Ensure the full deinstitutionalization of girls and boys with disabilities and their right to live in a safe family environment, including in foster families”<sup>33</sup>

<sup>26</sup> UNICEF (2005). Children and disability in transition in CEE/CIS and Baltic states.

<sup>27</sup> UN Secretary-General. (2019). Op. cit., p. 13/17.

<sup>28</sup> Council of Europe (2017), Fighting school segregation in Europe through inclusive education, [rm.coe.int/fighting-school-segregation-in-europe-through-inclusive-education-a-posi/168073fb65](https://rm.coe.int/fighting-school-segregation-in-europe-through-inclusive-education-a-posi/168073fb65) [accessed 25 June 2020].

<sup>29</sup> Georgette Mulheir (2012), op. cit.

<sup>30</sup> FRA (2015), Violence against children with disabilities: legislation, policies and programmes in the EU, p. 75.

[https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-2015-violence-against-children-with-disabilities\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-violence-against-children-with-disabilities_en.pdf) [accessed 19 October 2020].

<sup>31</sup> Romania, Law no. 272/2004 concerning the protection and promotion of the rights of the child, Art. 64 (1) and (2).

<sup>32</sup> CRPD/C/EU/CO/1

<sup>33</sup> CRPD/C/BGR/CO/1



- **Bosnia and Herzegovina (2019)** should “Accelerate the deinstitutionalization process across the State party, by supporting and facilitating family-based care for children and harmonizing the foster care system at all levels of government”<sup>34</sup>
- **Ukraine (2015):** “The Committee is deeply concerned about the (...) widespread institutionalization of children with disabilities throughout the country. It is particularly concerned about the reports of sexual abuse and exploitation of children with disabilities in institutions and their trafficking abroad. (...) and is particularly alarmed about the reports of deaths of children with disabilities in institutions due to malnutrition related illnesses”. The Committee “recommends strengthening its efforts for deinstitutionalization”.<sup>35</sup>
- **Rwanda should (2019)** “Take measures to enable children with disabilities to live in family settings with appropriate support, including alternative care within the wider family or within the community in a family setting”<sup>36</sup>
- **South Africa (2018):** “The Committee is concerned about (...) the large number of children with disabilities, nearly 600,000, who are out of school or studying in specialized schools or classes, in particular children with psychosocial disabilities, and children with disabilities placed in centres for children or less regulated special service centres, all of which are based on long-term institutionalization, often located far from their families and communities, isolated and lacking properly trained staff”. The Committee recommends Rwanda to “Develop and adopt effective implementation plans for prevention and early intervention programmes in communities to enable early identification of and support for children and adults with disabilities in family and community settings with adequate budget allocations (...), increased public awareness-raising programmes to understand the importance of family and community-based provisions instead of institutionalization”<sup>37</sup>.

### 3.2. The harms of institutional care for children with disabilities

Over 80 years of research from across the world has demonstrated the different types of harm caused by institutionalisation to children who, deprived of loving parental care, can suffer life-long physical and psychological negative effects.<sup>38</sup> Children who grow up in institutions can experience substantial developmental delays and deviations, such as delays in physical growth, brain development, cognitive

<sup>34</sup> CRC/C/BIH/CO/2-4

<sup>35</sup> CRPD/C/UKR/CO/1

<sup>36</sup> CRPD/C/RWA/CO/1

<sup>37</sup> CRPD/C/ZAF/CO/1, para 12-13

<sup>38</sup> Berens & Nelson (2015). The science of early adversity: is there a role for large institutions in the care of vulnerable children? The Lancet. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)61131-4/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61131-4/abstract) [Accessed 16 September 2016]



development and attention.<sup>39</sup> Long-term effects of living in institutions can include disability, irreversible psychological damage, increased rates of mental illness, involvement in criminal behaviour, and suicide.<sup>40</sup>

Institutionalisation can be particularly harmful to children with disabilities, for whom close, consistent and sustained adult engagement to support them to develop to their full potential is even more important<sup>41</sup>, and which they do not get in institutional care where individualised treatment and attention is hardly possible.

Moreover, violence and neglect can more easily be hidden in institutions, which are often segregated from the community, and which often lack well-functioning monitoring mechanisms.<sup>42</sup> Children with disabilities are at increased risk of falling victim to this system: they reportedly suffer more neglect and abuse than other institutionalised children.<sup>43</sup> For example, a Dutch study found that children with mild intellectual disabilities in institutional care are at higher risk of sexual abuse. The study estimated sexual abuse among children with mild intellectual disabilities to be as high as 9.7 per 1,000 children, compared to 3 per 1,000 children in regular youth care institutions and 0,3 per 1,000 children in the general population.<sup>44</sup> Girls with disabilities face double discrimination, and can be extra vulnerable in institutional settings. For example, girls with disabilities face a greater risk of being victims of forced sterilisation when living in institutions.<sup>45</sup>

Lastly, due to poor deinstitutionalisation processes which do not benefit children with disabilities at the same rate as other children without parental care, some children with disabilities move from one institution to another. This lack of care stability can lead to negative outcomes for these children, affecting their ability to establish emotional attachments and hampering their personal development.<sup>46</sup>

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<sup>39</sup> Marinus H van Ijzendoorn, Bakermans-Kranenburg, J., et al. (2020) "Institutionalisation and deinstitutionalisation of children 1: a systematic and integrative review of evidence regarding effects on development", *The Lancet Psychiatry*, DOI: [https://doi.org/10.1016/S2215-0366\(19\)30399-2](https://doi.org/10.1016/S2215-0366(19)30399-2).

<sup>40</sup> Georgette Mulheir (2012), Deinstitutionalisation – A Human Rights Priority for Children with Disabilities, *The Equal Rights Review*, vol IX, pp. 117-137, [https://www.equalrightstrust.org/ertdocumentbank/err9\\_mulheir.pdf](https://www.equalrightstrust.org/ertdocumentbank/err9_mulheir.pdf) [accessed 19 August 2020].

<sup>41</sup> EveryChild and Better Care Network. (2012). Enabling reform. Why supporting children with disabilities must be at the heart of successful childcare reform. New York: Better Care Network. [http://bettercarenetwork.org/sites/default/files/Enabling%20Reform%20-%20Why%20Supporting%20Children%20with%20Disabilities%20Must%20Be%20at%20the%20Heart%20of%20Successful%20Child%20Care%20Reform\\_0.pdf](http://bettercarenetwork.org/sites/default/files/Enabling%20Reform%20-%20Why%20Supporting%20Children%20with%20Disabilities%20Must%20Be%20at%20the%20Heart%20of%20Successful%20Child%20Care%20Reform_0.pdf) [accessed 19 May 2017].

<sup>42</sup> FRA (2015), op. cit., p. 15.

<sup>43</sup> UN, ROE OHCHR (2011), p. 19.

<sup>44</sup> Alink, L., Euser, S., Tharner, A., Van Ijzendoorn, R., Bakermans-Kranenburg, M. (2012), Prevalence of sexual abuse among children with a Mild Intellectual Disability in the Dutch Youth Care in 2008–2010, Universiteit Leiden, Leiden, July 2012.

<sup>45</sup> United Nations General Assembly (2006) Report of the Independent Expert for the United Nations Study on Violence Against Children. A/61/299 P.16. <https://www.unicef.org/violencestudy/1.%20World%20Report%20on%20Violence%20against%20Children.pdf> [accessed 20 Jan 2017].

<sup>46</sup> UN Secretary-General (2019), op. cit., p. 13/17.



#### 4. Recommendations for the European Disability Rights Strategy 2021-30

As described hereabove, in order for the European Disability Rights Strategy 2021-30 to adequately contribute to the goal of reaching full inclusion of persons with disabilities, it is absolutely necessary that children do not grow up segregated in institutions, but in the community in loving and caring families. Following the EU's acknowledgement of the harm caused by institutionalisation and its commitment to support the shift from institutional to family- and community-based care, Lumos and Hope and Homes for Children propose the following recommendations for the European Disability Rights Strategy 2021-2030:

- **Renew the commitment to the transition from institutional to family- and community-based care and extend this commitment to the EU's external action.** Lumos and Hope and Homes for children are pleased that the current Disability Strategy, which is coming to an end in 2020, promoted the transition from institutional to community-based care in EU Member States through the use of the European Structural and Investment Funds. However, in order to achieve policy coherence and to deliver on *all* children's right to family life globally, the new Strategy should prioritise prevention policies and deinstitutionalisation for all children, including children with disabilities, in the EU's external action as well, namely in the context of pre-accession, and its relation with third countries. This should be done by supporting families of origin and ensuring access to mainstream services such as health care and education for all children. It should also include the prioritisation of family-based alternative care provision such as kinship and foster care.
- **Specifically recognise the institutionalisation of children as a harmful practice, and highlight the specific risks for children with disabilities.** Lumos and Hope and Homes for children are pleased that the current Disability Strategy, which is coming to an end in 2020, reiterates that EU internal funding should be used for awareness raising of the situation of people, and in particular children, with disabilities living in institutions. However, in order to reflect the gravity of the issue, the new Strategy should explicitly recognise the institutionalisation of children, including children with disabilities, as a harmful practice (acknowledging the increased risk of violence and sexual abuse). Moreover, the Strategy should be aligned with other relevant EU policy frameworks such as the European Child Guarantee and the EU Strategy on the Rights of the Child.
- **Ensure the views and opinions of children and young people with disabilities, including those living in institutions or who have lived in institutions (care leavers) are included in the design, the implementation and evaluation of the Disability Strategy 2021-30.** Children with disabilities know best what their needs are. It is therefore absolutely necessary to collect their views and include the perspectives of the harder to reach children as well. Children with disabilities should be involved throughout the whole policy cycle of design, implementation and evaluation of the strategy.



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- **Encourage Member States to develop, and ensure access to, specialised services for children with disabilities and their families, including foster care families, based on their needs, in addition to mainstream services.** Children with disabilities and their families often do not have access to the services needed to support their needs, without it becoming a financial burden to the family. Access to services for these children and their families should be supported among others through the European Child Guarantee. It should include, but not be limited to, legal assistance for the exercise of certain rights, training to support independent living skills, accessible housing and housing adaptations, technical aids and assistive technologies (e.g. wheelchairs, social alarms, hearing and visual aids, communication aids etc.), psychological support, personal assistance, day care centres, resource centres, parental support for sharing experiences, training for parents or educational assistance, inclusive education and early childhood education and care. Member States should pay special attention to the new challenges brought by the COVID-19 pandemic to achieving inclusive education, and make sure children with disabilities have access to the right tools and means to keep on being educated during the pandemic.
- **Encourage the use of EU funds to support the transition from institutional to family and community based care and the prevention of separation of children from their families, namely the European Social Fund Plus, the European Regional Development Fund, the Instrument for Pre-Accession III and the Neighbourhood, Development and International Cooperation Instrument.** At the same time, the Strategy should ensure a strong commitment that no EU funds are used to support institutional care settings.
- **Encourage Member States to design and implement targeted measures to fight discrimination and stigma in the society, in particular in education and early childhood education and care.** Discrimination and stigma may lead to increased institutionalisation and also fewer alternative care places for children with disabilities. It negatively affects their inclusion in society. For example, it might be the reason for a child with a disability to leave a mainstream school due to pressure from other parents. Therefore, it is of utmost important that states develop action plans and measures to fight discrimination.
- **Call on Member States to ensure all children regardless of disability have access to the same standards of care through legislation and practice.** Disparities in national legislation, as well as discriminatory practice, can lead to an overrepresentation of children with disabilities in institutional care, and might also 'normalise' institutional care for this group of vulnerable children. The Disability Rights Strategy 2021-2030 should therefore issue a recommendation to Member States to ensure the same standards of care for all children deprived of parental care in legislation and in practice.



- **Have a robust implementation and monitoring framework.** A worrying outcome of the evaluation of the Disability Rights Strategy 2010-20 is that there has been a lack of a monitoring framework. In order for the new Disability Rights Strategy to be more effective, to make sure that policy is translated into practice, and that progress is measured, robust implementation and monitoring mechanisms are key. Measures fostering deinstitutionalisation for children with disabilities need to be planned out and committed to in the Strategy, and their implementation and progress needs to be monitored. The measures in the implementation and monitoring framework should be coordinated with other EU strategies and initiatives which target children with disabilities.
- **Address the need for children living in institutions and otherwise outside households to be represented in disaggregated data.** For donors and governments to protect the lives of vulnerable children and meet their human rights obligations, they need to know the scale and the scope of the problem. However, at present there is very limited data about children living in institutions, and consequently there is also no data on children with disabilities living in institutions. The new Agenda therefore needs to focus on improving data collection by Eurostat<sup>47</sup>, as well as encourage Member States and partner countries to close existing data gaps, develop national and global baselines, and invest in accessible, timely and reliable disaggregated data. Quality data collection is also indispensable for an effective monitoring framework.

### About Lumos and Hope and Homes for Children

**Lumos** is an international NGO, founded by the author J.K. Rowling, fighting to tackle the causes of family separation and transform systems of care that take children away from their families and communities. We're committed to ending the institutionalisation of children, so every child enjoys the right to grow up in a loving family where they can thrive. Lumos is a founding member of the European Expert Group on the Transition from Institutional to Community Based Care (EEG), sits on the EU Civil Society Platform against trafficking in human beings, is a member of the Child Rights Action Group (CRAG) and of the EU Alliance for Investing in Children. Lumos is registered in the EU transparency register (N° 849607914394-57).

**Hope and Homes for Children** is an international NGO founded in 1994. Our mission is to be the catalyst for the global elimination of institutional care for children. We work across five regions to design robust child protection systems effective in preventing children's separation from their families and providing quality alternative care in the best interest of all children. Hope and Homes for Children

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<sup>47</sup> Eurostat states that "children living in collective households and in institutions are generally excluded from the target population" of the EU Statistics on Income and Living Conditions survey. See: [https://ec.europa.eu/eurostat/statistics-explained/index.php/EU\\_statistics\\_on\\_income\\_and\\_living\\_conditions\\_\(EU-SILC\)\\_methodology\\_-\\_childcare\\_arrangements](https://ec.europa.eu/eurostat/statistics-explained/index.php/EU_statistics_on_income_and_living_conditions_(EU-SILC)_methodology_-_childcare_arrangements)



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