



African Disability Forum, Arab Organization of Persons with Disabilities, ASEAN Disability Forum, Down Syndrome International, European Disability Forum, Inclusion International, International Federation of Hard of Hearing People, International Federation for Spina Bifida and Hydrocephalus, Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families, Pacific Disability Forum, World Blind Union, World Federation of the Deaf, World Federation of the DeafBlind, World Network of Users and Survivors of Psychiatry

## IDA's submission for the CRC Committee's Day of General Discussion on Children's rights and alternative care

June 2021

### I. Introduction

1. IDA welcomes the initiative by the Committee on the Rights of the Child (hereinafter "the CRC Committee") to hold a Day of General Discussion on Children's rights and alternative care. It constitutes a great opportunity to embrace the latest standards on alternative care for children with disabilities, stemming from the UN Convention on the Rights of Persons with Disabilities (CRPD). This submission addresses crucial issues and provides recommendations regarding children with disabilities and children of parents with disabilities.

### II. Overrepresentation of children with disabilities in institutional care

2. It is roughly estimated that 2.7 million children between the ages of 0 and 17 years could be living in institutional care worldwide.<sup>1</sup> Children with disabilities tend to be overrepresented among them and States should collect more accurate data on this regard.<sup>2</sup> Recent estimations indicate that there are 93 million children aged 0-14 years with moderate and high support needs.<sup>3</sup> In some places, "children with disabilities are up to 17 times more likely to live in institutions than other children".<sup>4</sup> More than 290.000 children with disabilities lives in public residential care in 24 countries from Eastern Europe and Central Asia.<sup>5</sup> Yet, these might be *underestimations* due to lack of appropriate data.<sup>6</sup>

3. Drivers of institutionalization of children with disabilities include poverty,<sup>7</sup> stigmatization,<sup>8</sup> discrimination against them and their families,<sup>9</sup> and lack of or poor access to services and supports.<sup>10</sup> Further, the primary role of families remains neglected and unsupported. Families are often constrained to place their children in institutions because education, health, habilitation, and rehabilitation services, among others, are not provided in the community and/or in mainstream settings.

### III. The right to grow up in a family environment in international law

4. International human rights law acknowledges the family as "the natural and fundamental group unit of society" from the outset.<sup>11</sup> Since 1989, the Convention on the Rights of the Child

(CRC) recognizes the family as the natural environment for the growth and well-being of children and that children should grow-up in a family environment<sup>12</sup> and aims at preventing family separation (art. 9), supporting parents (art. 18); and providing *alternative care* to those children “temporarily or permanently deprived of [their] family environment” (art. 20) suggesting different forms deemed appropriate by them (e.g. “foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children”). Throughout its work, this CRC Committee has stressed the importance of prioritizing family-based alternative care and avoiding institutionalizations.<sup>13</sup>

5. In 2006, after more than a decade of research on negative impact of institutionalization on all children,<sup>14</sup> the CRPD came to stress that States “shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting” (art. 23(5)). In its general comment 5 (2017), the CRPD Committee called for de-institutionalization and stressed 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.”<sup>15</sup> Similarly, the Special Rapporteur on the Rights of Persons with Disabilities called for reviewing the UN Guidelines on Alternative Care,<sup>16</sup> and stated that “*any placement* of children in a residential setting outside a family must be considered placement in an institution”.<sup>17</sup>

#### **IV. Support to parents of children with disabilities in performing child-rearing responsibilities to prevent family separation (articles 9 and 18 of the CRC)**

6. The lack of access to inclusive mainstream services by children with disabilities<sup>18</sup> and to disability related support schemes and services pushes parents to place their children with disabilities in institutions.<sup>19</sup> Further, the lack of assistive technologies<sup>20</sup> and of financial assistance for covering disability related costs,<sup>21</sup> poses additional barriers in accessing services. Moreover, where accessible services and supports are to some extent available, parents often face legal and administrative barriers such as eligibility criteria based on the child’s impairment -but not on their needs-, incompatibilities, and inconsistencies in the provision of different types of support, and their exclusion from assistance planning.<sup>22</sup>

7. The upbringing of children with disabilities is challenging in many contexts. Primary caregivers (in particular mothers)<sup>23</sup> are often discriminated by association and/or forced to leave/reduce employment, decreasing their capacity to afford services for their children.<sup>24</sup> Parents also report the dearth of knowledge on disability and of competencies for child behaviour management, independent advocacy and budgeting.<sup>25</sup> Thus, parents are more likely to experience depression, stress, and self-stigmatization.<sup>26 27</sup>

8. Many countries tackle these issues providing family-centred services. For instance, improving childcare competencies of parents through community-based parent training programmes (e.g. tutoring families raising infants with “special health needs”)<sup>28</sup> and peer support<sup>29</sup> has proved effective in supporting families in Ghana,<sup>30</sup> the UK,<sup>31</sup> Russia<sup>32</sup> and Spain.<sup>33</sup> Main outcomes have been reducing stress,<sup>34</sup> caregiver empowerment<sup>35</sup> and increasing capacity for home-based care for children (including with high support needs).<sup>36</sup> Additionally, in Japan,<sup>37</sup> Canada,<sup>38</sup> and Russia,<sup>39</sup> many of the different types of respite care<sup>40</sup> provide relief and rest to caregivers<sup>41</sup> and contribute to the development of children.<sup>42</sup>

9. Supporting families of children with disabilities requires a holistic approach. Providing **accessible mainstream services for children**<sup>43</sup> contributes with an inclusive background. Parents would not become forced to struggle for the inclusion of their children with disabilities, avoiding stress. Such preconditions provide specific family-centred programmes and interventions with more chances of success. Additionally, **accessible targeted services** (e.g.

speech and language therapists,<sup>44</sup> occupational therapists,<sup>45</sup> and physiotherapists, art therapy<sup>46</sup>) are needed for supporting inclusion and assisting children and their parents.

10. The CRC Committee has identified measures to prevent the separation of children with disabilities from their parents and fulfil their right to grow up within a family, including supporting family-based care<sup>47</sup> through the development of flexible and qualitative childcare services for all children<sup>48</sup> and improving professional training and qualification programmes.<sup>49</sup> The CRC Committee has encouraged States to provide financial assistance<sup>50</sup> and to subsidize care services<sup>51</sup> for family support. Further, the CRC Committee has highlighted that awareness-raising among families and childcare stakeholders is required to eradicate stigma and promote a positive image of children with disabilities.<sup>52</sup>

11. In light of the COVID-19 pandemic, additional measures supporting families are necessary.<sup>53</sup> Important challenges for parents of children with disabilities are the loss or reduction of many essential services and social engagement opportunities.<sup>54</sup> Developing telehealth services and online parent training has contributed to the well-being of children with disabilities and their families, e.g. in Italy<sup>55</sup> and China.<sup>56</sup>

## **V. The prevention of separation of children from their parents with disabilities**

12. Children of persons with disabilities (especially persons with intellectual disabilities and persons with psychosocial disabilities)<sup>57 58</sup> are at greater risk of being separated from their families. Prejudicial parenting capacity assessments,<sup>59</sup> the denial of legal capacity,<sup>60</sup> and other discriminatory practices<sup>61</sup> violate the parental rights of persons with disabilities and simultaneously the rights of children not to be separated from their families (articles 9(1) CRC and 23(1-4) CRPD). Additionally, although many persons with disabilities could perform their parental responsibilities if provided with adequate support services,<sup>62</sup> service providers often deny their provision to parents with disabilities considering that “support in parenting young children is not regarded as a basic need.”<sup>63</sup>

13. Repealing or eradicating restrictions to legal capacity contrary to Article 12 of the CRPD, in law and practice, becomes essential to ensure that all children of persons with disabilities can fulfil their right to grow up within their family and refrain from discriminating parents in exercising parental rights. Further, States should adopt a comprehensive strategy at the national, regional, and local levels, in both urban and rural areas, on family support measures for parents with disabilities, including providing long- or short-term personal assistance, grants, guidance and parenting skill intervention training,<sup>64 65</sup> and access to assistive devices. Quality support services for parents with disabilities should be enhanced by including adequate mechanisms to engage with users in assessing their support needs<sup>66</sup> and awareness-raising measures on parents with disabilities targeting other relevant actors.<sup>67</sup>

## **VI. Prevention and eradication of institutionalisation: the right to be provided alternative care within a family setting**

14. There is consensus among UN mechanisms, including the CRC and CRPD committees, that the family is the natural environment for the growth and well-being of children, that the child should grow up in a family environment and that institutionalization of children, especially in large institutions, must be eradicated, given that they are inherently harmful and not comparable to a nurturing family environment. This paves the way towards inclusive alternative care systems focused on providing children with that family environment.

15. In practice, children with disabilities continue to be separated from their families and communities and placed in residential institutions, on the grounds of their alleged “best interest” and “better quality of care”. Further, States continue to invest resources in institutions.

The CRC Committee has been concerned at the high number of children with disabilities in institutions<sup>68</sup> and urged States to “set up programmes for de-institutionalization of children with disabilities, re-placing them with their families, extended families or foster care system”.<sup>69</sup> Based on the CRPD, **IDA believes that all forms of institutionalization are incompatible with and do not fulfill the right of children with disabilities to a family environment.**

16. Strong evidence over the years supports the consensus on institutions being harmful for all children, especially for children with disabilities. Institutions are characterized by regimentation, poor social environment, low-quality care, neglect and abuse that adversely affect the development of all children including those with disabilities.<sup>70</sup> Among the negative impacts, the absence of emotional bonds with the attachment figure causes higher prevalence of mental and behavioural challenges among all children, in particular at an early age.<sup>71</sup> Specifically, children with psychosocial disabilities in residential settings often have attachment disorders.<sup>72</sup> Finally, the mortality rate among institutionalized children with disabilities is much greater than the rate among other institutionalized children.<sup>73 74</sup>

#### **A. Preventing and phasing out small scale group homes as a policy alternative**

17. The recent years have shown a worrisome trend developing in many contexts: the dismantling and phasing out of large institutions gives room to new forms of institutionalization, in so called small groups homes (SGH), with fewer children but keeping institutional features, but also in orphanages and residential special schools, and to trans-institutionalization (moving children from one institution to another under the guise of deinstitutionalization).

18. Available research shows that SGHs retain the main features of institutions (e.g. rules that discourage emotional attachment between staff and children,<sup>75</sup> lack of privacy,<sup>76</sup> absence of conditions for improving social skills,<sup>77</sup> etc.) that adversely affect the development of children, including those with disabilities.<sup>78</sup> A recent meta-analysis shows that “family-like homes” do not ensure the same development level as family settings provide. The mental health and, to less extent, the physical growth of children from SOS Children’s Villages, are delayed compared to their peers in families.<sup>79</sup>

19. SGHs and family-type homes are often considered as a stepping-stone to fulfilling the rights of children with disabilities to a family environment and community living. **This is misleading and experience has proven it wrong.** SGHs continue the reprehensible practice of social exclusion and segregation of children with disabilities, e.g. in India,<sup>80</sup> Serbia<sup>81</sup> and Bulgaria.<sup>82</sup> SGHs’ require important resources, which -being always limited- do not go into developing accessible services and family support measures.<sup>83</sup>

20. Moreover, some children with disabilities, with “emotional and behavioural challenges” are often placed in “therapeutic group homes” alleging availability of better health care. However, therapeutic group homes are “most unlikely to be able to deliver services of sufficient power, intensity and duration”.<sup>84</sup> In the majority of cases, these children can be better served in families than in therapeutic small settings.<sup>85</sup> Indeed, family-based treatment programmes (e.g. multisystemic therapy and multidimensional treatment foster care) have proved their effectiveness in different countries.<sup>86 87</sup>

21. Occasionally, the development of SGHs, even as a stepping-stone (see para. 19), is defended based on the scenario of children finding themselves **suddenly** without parental care and/or abandoned. In this sense, SGHs would be presented as a “last resort measure” to provide some kind of “emergency shelter” to those children. In response, IDA would like to share with the CRC Committee, few points of clarification and reactions:

- a. **Specially for the case of children with disabilities, what might be presented as “temporary” becomes permanent**, initiating paths most likely towards years of institutionalization. Specific

available research shows that some types of disability are “negatively related to *successful exit*” from institutional care (consisting of, e.g., placement with original family, relatives or in a foster family, adoption or transition to adult life and independent living).<sup>88</sup> In particular, “children with developmental disabilities placed in foster care due to abuse and/or neglect are [...] less likely to achieve successful permanency placement with families”.<sup>89</sup> This could be explained by the current state of practice including lack of support and access to mainstream services.

**b. Children with disabilities usually lag behind in de-institutionalization process**, as it has been documented for the case of Serbia,<sup>90</sup> given the lack of support services and inclusive general services.

**c. Nothing at all prevents States developing family-based systems to address sudden situations of individual emergency**, providing a placement in a family setting and support to that foster family. States should strive to fund, put in place and monitor such systems, as some jurisdictions in the USA are undertaking.<sup>91</sup>

**d. No “emergency shelter” placement of a child with disability in a SGH constitutes a way to fulfil the right to be provided with a “family setting” (23(5) CRPD)** and thus neither with the today’s adequate form of “alternative care” (20(b) CRC). This right is only fulfilled when provided within a family setting, as per current international human rights standards, which are consistent with the evidence on the harms of all forms of institutions.

e. States human rights obligations’ arising from the right to grow in a family and be provided adequate alternative care within a family setting require them to:

- i. develop family based alternative care systems, including for cases of emergency (point c).
- ii. stop developing, stop funding, dismantling, and phasing out any other forms of alternative care, which will necessarily fall into institutional features.<sup>92</sup>
- iii. when facing an individual emergency (sudden abandonment or loss of parental care), immediately strive to find a family setting-based solution for the child with disabilities.

f. Whether a national or international court should adjudicate if the State has failed to discharge its obligations on the right to grow in a family and be provided adequate alternative care within a family setting, will depend on the characteristics of every specific legal system and its criteria on responsibility, as well as the circumstances of the case.

## **VII. Inclusive adoption systems: promotion of adoption of children with disabilities without parental care, including through affirmative actions.**

22. Enhancing legislative frameworks, procedures and oversight of adoption is essential to provide a long-term and nurturing family setting to children without parental care for them to develop their fullest potential. Yet, available research shows that children with disabilities do not benefit from adoption as much as other children.<sup>93</sup> Negative attitudes against children with disabilities reduce their chances to be adopted.<sup>94</sup> Potential adoptive parents often hesitate to discuss their plans to adopt children with disabilities due to fears of negative reactions from relatives and the wider community.<sup>95</sup> Some “specialists” may also pre-select “‘adoptable’ children from among those who are legally adoptable” and exclude children with disabilities.<sup>96</sup> Further, lack of adequate/high-quality pre-adoptive services<sup>97 98</sup> and long-term follow-up supports of adoptive families of children with disabilities can result in disrupted adoptions.<sup>99</sup>

23. Challenging that negative background, specific studies on experiences of adoptive parents of children with disabilities reveal that adequate pre-adoptive services contribute to the long-term success of the adoption of a child with disability. For instance, adoptive parents who have been provided with information about a child’s health conditions report a higher level of satisfaction than adopters with little or no previous knowledge.<sup>100</sup> Pre-adoptive phase

also requires information about the adoption process and emotional support from professionals and other adopters (peer support).<sup>101</sup> Furthermore, post-adoptive programmes and resources (e.g. financial subsidies for covering disability-related expenses, in-home supports and crisis intervention, family counselling, respite care) strengthen successful adoption and have a beneficial effect on children with disabilities.<sup>102</sup> Examples demonstrate that successful adoption of children with disabilities leads to positive outcomes for their development and socialization (e.g. India and the UK).<sup>103</sup>

24. Measures are needed to prevent discrimination of children with disabilities during the adoption processes and to strengthen the training and qualification of relevant professionals based on the human rights model of disability.<sup>104</sup> CRPD principles should be reflected in legal and technical standards on the adoption process. Further, should inequalities in benefiting from adoption be verified, specific measures to achieve de facto equality (“affirmative actions”) for children with disabilities should be put in place (article 5(4) CRPD). These could include additional specific subsidies, awareness raising campaigns on promoting a positive image of children with disabilities among potential adopters, expanding volunteer opportunities for future adoptive parents,<sup>105</sup> and specific post-adoption short and long-term assistance.<sup>106</sup>

25. Discriminatory practices against potential adopters with disabilities restrict their equal rights in family life and adoption and deprive children from opportunities to access nurturing family settings within the community. Such practices include the deprivation of legal capacity, assessment of capacities for parenting,<sup>107</sup> and the lack of provision support. Thus, eradicating restrictions to legal capacity, combating discrimination based on disability in adoption procedures and providing short and long-term parenting support services, is key to enable and promote adoptions by persons with disabilities.

## **VIII. Conclusion and recommendations:**

26. IDA stresses that, while acknowledging the complexities and challenges of any deinstitutionalization policy towards inclusion of children with disabilities in the community within family settings, we **oppose all forms of institutionalization and calls on governments and UN mechanisms and agencies to support a CRPD compliant approach to investments in community services and supports which promote the role of families in the realization of the human rights of children with disabilities.**

27. IDA believes the CRC Committee should call States to

- adopt and reinforce measures to provide support to parents of children with disabilities in performing child-rearing responsibilities, notably through:

a. support measures targeted at birth-, extended- and foster-families with children with disabilities, including support services for the different constituencies among children with disabilities and financial assistance for disability-related expenses, while enhancing accessibility and inclusiveness of mainstream services.

b. measures to refrain from and prevent discrimination of children with disabilities and by association against their caregivers.

c. Awareness raising measures targeted to families, relevant professionals, and society at large, on the right of children with disabilities, of the diverse constituencies, and the services and supports available.

- adopt measures to refrain from and prevent disability-based discrimination against all persons with disabilities in the exercise of their parental rights, including legislative reform if required.
- adopt a comprehensive strategy for prevention of institutionalization and for the full de-institutionalization of children with disabilities, with adequate timeframes and benchmarks, in consultation with organizations of persons with disabilities, notably organizations and initiatives of children with disabilities. In particular, States should:
  - a. develop family based alternative care systems inclusive of children with disabilities, including for those cases of individual emergency.
  - b. stop developing, stop funding, dismantle and phase out any other care system based on residential institutions, regardless of their size.
  - c. develop response systems so that, when facing an individual emergency (sudden abandonment or loss of parental care), be able to immediately strive to find a family setting-based solution for the child with disability.
- adopt measures, including legislative reforms if necessary, to ensure adoption systems and procedures are inclusive and not discriminatory of persons with disabilities, both for adults with disabilities as potential parents and children with disabilities to be adopted. "Affirmative actions" favouring adoption of children with disabilities might be required if children with disabilities do not benefit from adoption proportionally, compared to other children.

## **International Disability Alliance (IDA)**

The International Disability Alliance (IDA) is a unique, international network of eight global and six regional organisations of persons with disabilities (OPDs). Each IDA member represents a large number of national OPDs, covering the whole range of disability constituencies. IDA thus represents the collective global voice of persons with disabilities counting among the more than 1 billion persons with disabilities worldwide, the world's largest –and most frequently overlooked– minority group. IDA's mission is to advance the human rights of persons with disabilities as a united voice of OPDs utilising the Convention on the Rights of Persons with Disabilities (CRPD) and other human rights instruments.

For further information, please contact: [jjperezbello@ida-secretariat.org](mailto:jjperezbello@ida-secretariat.org)

International Disability Alliance

150 Route de Ferney

CH-1211 Genève 2

[www.internationaldisabilityalliance.org](http://www.internationaldisabilityalliance.org)

- 
- <sup>1</sup> See Petrowski, N., Cappa, C., & Gross, P. (2017). Estimating the number of children in formal alternative care: Challenges and results. *Child abuse & neglect*, 70, 388-398. In 30 European countries, there would be approximately 1 million children living in public care facilities (see European Expert Group on the Transition from Institutional to Community-based Care, *Common European Guidelines On The Transition From Institutional To Community based Care*, 33)
- <sup>2</sup> See *European Committee of Social Rights, European Roma Rights Centre (ERRC) and Mental Disability Advocacy Centre (MDAC) v. Czech Republic*, para. 172, requiring the State to collect accurate data when "it is generally acknowledged that a particular group of children is or could be faced with disproportionate care risks in comparison with the majority of population "
- <sup>3</sup> *Promoting rights and community living for children with psychosocial disabilities*, report, WHO, 2015, p.21.
- <sup>4</sup> Jones H. Deinstitutionalization for children with disabilities: technical guidelines for UNICEF's engagement national reform efforts, *UNICEF, Europe and Central Asia*, 2019, p. 5.
- <sup>5</sup> UNICEF transformative Monitoring for Enhancing Equality, *Children in Residential Care* (2014) <<https://urlz.fr/94aL>> accessed 1st March 2019.
- <sup>6</sup> *Promoting rights and community living for children with psychosocial disabilities*, report, WHO, 2015, p.21.
- <sup>7</sup> *Promoting rights and community living for children with psychosocial disabilities*, report, WHO, 2015, p. 24.
- <sup>8</sup> Green, S. E. (2004). The impact of stigma on maternal attitudes toward placement of children with disabilities in residential care facilities. *Social Science & Medicine*, 59(4), 799-812.
- <sup>9</sup> Browne K. The risk of harm to young children in institutional care. *London: Save the Children UK*; 2009.
- <sup>10</sup> Mitchell, G. (2014). Children with disabilities in child and family welfare services. *Children Australia*, 39(2), 107 – 118.
- <sup>11</sup> See Universal Declaration of Human Rights, article 16(3), among other provisions.
- <sup>12</sup> UN Convention on the Rights of the Child, *preamble*, para. 6.
- <sup>13</sup> Reiterated recently in [CRC/C/LUX/CO/5-6](#), para. 21(b): "Phase out institutionalization and facilitate family-based care for children wherever possible, and strengthen the system of foster care for children who cannot stay with their families, with a view to reducing the institutionalization of children"
- <sup>14</sup> See below section V.
- <sup>15</sup> CRPD Committee, general comment no. 5 on Article 19 (Living independently and being included in the community), [CRPD/C/GC/5](#), para. 16.
- <sup>16</sup> Catalina Devandas Aguilar, 40<sup>th</sup> session of HRC Annual meeting on the Rights of the child (2019).
- <sup>17</sup> UN Special Rapporteur on the Rights of Persons with Disabilities, *Ending the Deprivation of Liberty on the basis of Disability* (2019) [A/HRC/40/54](#). For this submission, such is the criterion to identify institutional care.
- <sup>18</sup> For instance, in Kyrgyzstan, many children with disabilities attended the specialist boarding school because of the dearth of inclusive educational services. *Insisting on Inclusion Institutionalization and Barriers to Education for Children with Disabilities in Kyrgyzstan*, Human Rights Watch, 2020.
- <sup>19</sup> Jones H. Deinstitutionalization for children with disabilities: technical guidelines for UNICEF's engagement national reform efforts, *UNICEF, Europe and Central Asia*, 2019.
- <sup>20</sup> *GOAL AREA 5: Every child has an equitable chance in life, Global Annual Results Report, UNICEF*, 2019, p.71.
- <sup>21</sup> Mkabile, S., & Swartz, L. (2020). 'I Waited for It until Forever': Community Barriers to Accessing Intellectual Disability Services for Children and Their Families in Cape Town, South Africa. *International journal of environmental research and public health*, 17(22), 8504, 1 – 13.
- <sup>22</sup> Ingólfssdóttir, J. G., Egilson, S. T., & Traustadóttir, R. (2018). Family-centred services for young children with intellectual disabilities and their families: Theory, policy and practice. *Journal of Intellectual Disabilities*, 22(4), 361-377.
- <sup>23</sup> Pervasive traditional roles based on gender continue to assign mothers the role of care for their children with disabilities. Recently, the CEDAW Committee has concluded that the Moldovan social security system discriminates against mothers of children with disabilities by paying no social insurance pension for the caregiving period, and ensuring no social alternatives for care provision: "Those women are socially excluded, along with their children, because there are no social alternatives for care provision, and when those women reach retirement age, they do not receive sufficient resources to cover their basic needs." (see [CEDAW/C/74/D/104/2016](#), para 3.2.)

- <sup>24</sup> Lease, K. (2018). A Reasonable Solution for Working Parents: Expanding Reasonable Accommodation under the Americans with Disabilities Act to Parents of Children with Disabilities. *Wm. & Mary J. Race Gender & Soc. Just.*, 25, 709 – 729
- <sup>25</sup> Brown, J. (2007). Fostering children with disabilities: A concept map of parent needs. *Children and Youth Services Review*, 29(9), 1235-1248.
- <sup>26</sup> Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS one*, 14(7), 1 – 18.
- <sup>27</sup> Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 48, 44 – 52.
- <sup>28</sup> Vasilyeva, V. S., Druzhinina, L. A., Lapshina, L. M., Osipova, L. B., & Reznikova, E. V. (2018). Tutoring in a family raising an infant with special health needs. *Espacios: Education*, 39(02), 1 – 11.
- <sup>29</sup> Heys, M., Lakhanpaul, M., Allaham, S., Manikam, L., Owugha, J., Oulton, K., ... & Kuper, H. (2020). Community-based family and carer-support programmes for children with disabilities. *Paediatrics and Child Health*, 30(5), 180-185.
- <sup>30</sup> Zuurmond, M., O'Banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., ... & Polack, S. (2018). Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS one*, 13(9), 1 – 17.
- <sup>31</sup> Bray, L., Carter, B., Sanders, C., Blake, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*, 100(8), 1537-1543.
- <sup>32</sup> Vasilyeva, V. S., Druzhinina, L. A., Lapshina, L. M., Osipova, L. B., & Reznikova, E. V. (2018). Tutoring in a family raising an infant with special health needs. *Espacios: Education*, 39(02), 1 – 11.
- <sup>33</sup> Chocarro González, L., Rigal Andrés, M., de la Torre-Montero, J. C., Barceló Escario, M., & Martino Alba, R. (2021). Effectiveness of a Family-Caregiver Training Program in Home-Based *Pediatric Palliative Care*. *Children*, 8(3), 1 – 14.
- <sup>34</sup> Bray, L., Carter, B., Sanders, C., Blake, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*, 100(8), 1537-1543.
- <sup>35</sup> Zuurmond, M., O'Banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., ... & Polack, S. (2018). Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS one*, 13(9), 1 – 17.
- <sup>36</sup> Chocarro González, L., Rigal Andrés, M., de la Torre-Montero, J. C., Barceló Escario, M., & Martino Alba, R. (2021). Effectiveness of a Family-Caregiver Training Program in Home-Based *Pediatric Palliative Care*. *Children*, 8(3), 1 – 14.
- <sup>37</sup> Otsuki, N., Fukui, S., & Sakaguchi, Y. (2020). Measuring the Benefits of Respite Care use by Children with Disabilities and Their Families. *Journal of pediatric nursing*, 53, e14-e20.
- <sup>38</sup> [Respite Care in Canada: Brief, 2012, Canadian Healthcare Association.](#)
- <sup>39</sup> Cantwell N, Davidson J, Elsley S, Milligan I, Quinn N. Moving forward: implementing the United Nations guidelines for the alternative care of children. *Glasgow: Centre for Excellence for looked after children in Scotland*; 2013, p. 54
- <sup>40</sup> E.g. home-based respite services, host families.
- <sup>41</sup> Otsuki, N., Fukui, S., & Sakaguchi, Y. (2020). Measuring the Benefits of Respite Care use by Children with Disabilities and Their Families. *Journal of pediatric nursing*, 53, e14-e20.
- <sup>42</sup> *Promoting rights and community living for children with psychosocial disabilities*, World Health Organization, 2015, p.67
- <sup>43</sup> Notably inclusive education, healthcare, and rehabilitation services
- <sup>44</sup> Law, J., Dennis, J. A., & Charlton, J. J. (2017). Speech and language therapy interventions for children with primary speech and/or language disorders. *The Cochrane Database of Systematic Reviews*, 2017(1).
- <sup>45</sup> See Echsel, A., Price, L., Josephsson, S., & Schulze, C. (2019) "Together on the Way": Occupational Therapy in Mainstream Education—A Narrative Study of Emerging Practice in Switzerland, *Occupational therapy international*, 1 – 10.
- <sup>46</sup> See UK case: Hackett, S. S., Ashby, L., Parker, K., Goody, S., & Power, N. (2017). UK art therapy practice-based guidelines for children and adults with learning disabilities. *International Journal of Art Therapy*, 22(2), 84-94.
- <sup>47</sup> [CRC/C/RWA/CO/5-6](#), para. 29 (a)
- <sup>48</sup> [CRC/C/BEL/CO/5-6](#), para.27
- <sup>49</sup> [CRC/C/BEL/CO/5-6](#), para.27
- <sup>50</sup> [CRC/C/HUN/CO/6](#), para. 30 (a)

- 
- <sup>51</sup> [CRC/C/BEL/CO/5-6](#), para.27
- <sup>52</sup> [CRC/C/TUV/CO/2-5](#), para. 38 (f), [CRC/C/GIN/CO/3-6](#), para.33, [CRC/C/PSE/CO/1](#), para. 49 (b).
- <sup>53</sup> See, for instance, Degli Espinosa, F., Metko, A., Raimondi, M., Impenna, M., & Scognamiglio, E. (2020). A model of support for families of children with autism living in the COVID-19 lockdown: Lessons from Italy. *Behavior Analysis in Practice*, 13, 550-558.
- <sup>54</sup> Neece, C., McIntyre, L. L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 64(10), 739-749.
- <sup>55</sup> Provenzi, L., Grumi, S., Gardani, A., Aramini, V., Dargenio, E., Naboni, C., ... & Engaging with Families through On-line Rehabilitation for Children during the Emergency (EnFORCE) Group. (2021). Italian parents welcomed a telehealth family-centred rehabilitation programme for children with disability during COVID-19 lockdown. *Acta Paediatrica*, 110(1), 194-196.
- <sup>56</sup> McDevitt, S. E. (2021). While quarantined: An online parent education and training model for families of children with autism in China. *Research in Developmental Disabilities*, 1 – 19.
- <sup>57</sup> In the USA, parents with intellectual and development disabilities were 2.19 times more likely to experience the termination of parental rights than remaining parents. See LaLiberte, T., Piescher, K., Mickelson, N., & Lee, M. H. (2017). Child protection services and parents with intellectual and developmental disabilities. *Journal of applied research in intellectual disabilities*, 30(3), 521-532.
- <sup>58</sup> Parents with intellectual disabilities were involved in 20 – 25% of all custody cases. See Tøssebro, J., Midjo, T., Paulsen, V., & Berg, B. (2017). Prevalence, trends and custody among children of parents with intellectual disabilities in Norway. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 533-542.
- <sup>59</sup> See Aunos, M., & Pacheco, L. (2020). Able or unable: How do professionals determine the parenting capacity of mothers with intellectual disabilities. *Journal of Public Child Welfare*, 1-27.
- <sup>60</sup> See [ECHR Case of Kocherov and Sergejeva v. Russia \(2016\)](#)
- <sup>61</sup> In Belarus, there is the [“List of illnesses in which persons cannot fulfill their parental duties”\(Adopted by the Resolution of the Ministry of health of the Republic of Belarus from 30.03.2010 N 36\)](#). Although the List was created to release parents with disabilities from reimbursement of living expenses for their children who are in out-of-home placement ([Article 93 of the Code of Marriage and Family](#)), civil society reports cases of taking children away from parents with disabilities based only on reference to this List. See [Zero Report](#) (2016), para. 141.
- <sup>62</sup> Completing the program “Improving Parenting Achievements Together” is associated with a 91% reduction in the odds of out-of-home placement for children of parents with intellectual disabilities 1 year after concluding the program. See Augsberger, A., Zeitlin, W., Rao, T., Weisberg, D., & Toraf, N. (2021). Examining a child welfare parenting intervention for parents with intellectual disabilities. *Research on Social Work Practice*, 31(1), 65-74, p. 71.
- <sup>63</sup> Bergman, A. S., Melin Emilsson, U., & Järkestig Berggren, U. (2020). Persons with certain functional impairments apply for parenting support: a study of personal assistance assessments in Sweden. *Nordic Social Work Research*, 1-13, p.10.
- <sup>64</sup> See [CRPD/C/ZAF/CO/1](#), para. 35 (c), [CRPD/C/AUS/CO/2-3](#), para. 44 (b), [Good practice guidance on working with parents with a learning disability \(2007\)](#), *Working Together with Parents Network, University of Bristol updated*, 2016.
- <sup>65</sup> Glazemakers, I., & Deboutte, D. (2013). Modifying the ‘Positive Parenting Program’ for parents with intellectual disabilities. *Journal of Intellectual Disability Research*, 57(7), 616-626.
- <sup>66</sup> Azar, S. T., Maggi, M. C., & Proctor, S. N. (2013). Practices changes in the child protection system to address the needs of parents with cognitive disabilities. *Journal of public child welfare*, 7(5), 610-632, p. 615.
- <sup>67</sup> Gur, A., & Stein, M. A. (2020). Social worker attitudes toward parents with intellectual disabilities in Israel. *Disability and rehabilitation*, 42(13), 1803-1813., p. 1806.
- <sup>68</sup> [CRC/C/GC/9](#), para. 47
- <sup>69</sup> [CRC/C/GC/9](#), para. 49
- <sup>70</sup> *Promoting rights and community living for children with psychosocial disabilities, report, WHO*, 2015.
- <sup>71</sup> Vorría, P., Papaligoura, Z., Dunn, J., Van IJendoorn, M. H., Steele, H., Kontopoulou, A., & Sarafidou, Y. (2003). Early experiences and attachment relationships of Greek infants raised in residential group care. *Journal of Child Psychology and Psychiatry*, 44(8), 1208-1220.
- <sup>72</sup> *Promoting rights and community living for children with psychosocial disabilities, report, 2015. WHO*, p.40.
- <sup>73</sup> According to research conducted in 33 European countries, “for children under three leaving institutions, 28% of those children with disabilities had died in comparison to 0.29% of children in social care institutions”. See *Mapping the number and characteristics of children under three in institutions*

---

across Europe at risk of harm (No. EUR/03/5048375). 2004. Copenhagen: WHO Regional Office for Europe. p.22.

<sup>74</sup> Other negative impacts exist, including to physical health, such as increased obesity (see, e.g., Trout, A. L., Lambert, M. C., Nelson, T. D., Epstein, M. H., & Thompson, R. W. (2014). Prevalence of weight problems among youth with high-incidence disabilities in residential care. *Behavioral Disorders*, 39(3), 165-174).

<sup>75</sup> In Norwegian group homes for children with intellectual disabilities, the “problems” of child’s attachment behaviour are addressed by limiting everyday contacts between the staff member and the child for a period. Fylkesnes, I. (2020). Institutional talk and practices: A journey into small group-homes for intellectually disabled children. *Disability & Society*, 1-22, p. 12

<sup>76</sup> Some children with intellectual disabilities express dislike when they are publicly told, “Go and wash your face!” or “Should we go to the toilet?” Fylkesnes, I. (2020). Institutional talk and practices: A journey into small group-homes for intellectually disabled children. *Disability & Society*, 1-22, p.12.

<sup>77</sup> Rosenthal, E. (2019). A Dead End for Children: Bulgaria's Group Homes. Available at SSRN 3664732, p. V

<sup>78</sup> Rosenthal, E. (2019). A Dead End for Children: Bulgaria's Group Homes. Available at SSRN 3664732,

<sup>79</sup> See an IJzendoorn, M. H., & Bakermans-Kranenburg, M. (2021). ‘Tear down your institutions’. Empirical and evolutionary perspectives on institutional care in SOS Children’s Villages.

<sup>80</sup> In India, although children and staff of “inclusive” group home for “girls with and without disabilities” describe a favorable microclimate within the home girls have only occasional “field trips” in the community which require “a lot of planning, time, and resources”. Forber-Pratt, A. J., & Lyew, D. A. (2019). A Model Case: Specialized Group Home for Girls with Disabilities in India. *Child and Adolescent Social Work Journal*, 1-13

<sup>81</sup> In some group homes, children and young persons with physical disabilities are confined to the building without access to elevators on the weekends. See “*It is My Dream to Leave This Place*” *Children with Disabilities in Serbian Institution*, Human Rights Watch, 2016, pp. 21-25.

<sup>82</sup> Rosenthal, E. (2019). A Dead End for Children: Bulgaria's Group Homes. Available at SSRN 3664732.

<sup>83</sup> Jones H. Deinstitutionalization for children with disabilities: technical guidelines for UNICEF’s engagement national reform efforts, *UNICEF, Europe and Central Asia*, 2019, p. 31.

<sup>84</sup> Ainsworth, F., & Hansen, P. (2018). Group homes for children and young people: The problem not the solution. *Children Australia*, 43(1), 42 – 46, p. 45.

<sup>85</sup> Dozier, M., Kaufman, J., Kobak, R., O’Connor, T. G., Sagi-Schwartz, A., Scott, S., ... & Zeanah, C. H. (2014). Consensus statement on group care for children and adolescents: A statement of policy of the American Orthopsychiatric Association. *American Journal of Orthopsychiatry*, 84(3), 219 – 225, p. 222.

<sup>86</sup> Henggeler, S. W., & Sheidow, A. J. (2012). Empirically supported family-based treatments for conduct disorder and delinquency in adolescents. *Journal of marital and family therapy*, 38(1), 30-58.

<sup>87</sup> Kaslow, N. J., Broth, M. R., Smith, C. O., & Collins, M. H. (2012). Family-based interventions for child and adolescent disorders. *Journal of marital and family therapy*, 38(1), 82-100.

<sup>88</sup> Becker, M. A., Jordan, N., & Larsen, R. (2007). Predictors of successful permanency planning and length of stay in foster care: The role of race, diagnosis and place of residence. *Children and Youth Services Review*, 29(8), 1102-1113. See pp. 1108 -1109: “Being diagnosed with a mental disorder, being diagnosed with a developmental disability, having a therapeutic foster care placement, or having an involuntary psychiatric examination was *negatively related to successful exit*.”

<sup>89</sup> Becker, M. A., Jordan, N., & Larsen, R. (2007). Predictors of successful permanency planning and length of stay in foster care: The role of race, diagnosis and place of residence. *Children and Youth Services Review*, 29(8), 1102-1113, p. 1104.

<sup>90</sup> Human Rights Watch, *It is My Dream to Leave This Place*” *Children with Disabilities in Serbian Institution*, 2016, pp. 21-25.

<sup>91</sup> See [How can we ensure a child's first placement is with a family?](#) Jurisdictional scan, 2018, Casey Family Programs. Several States in the USA have been moving towards this kind of systems, “motivated by a desire to reduce trauma for the child [resulting of their first placement], as well as concerns related to the quality of care provided, the length of time children were remaining in receiving centers, and the safety of younger or more vulnerable children when placed alongside older youth with high behavioral health needs” (p. 2).

<sup>92</sup> See *European Committee of Social Rights, European Roma Rights Centre (ERRC) and Mental Disability Advocacy Centre (MDAC) v. Czech Republic*, paras. 157-175.

---

<sup>93</sup> For instance, In Northern Ireland, only 33% of “children with disabilities and special needs” were adopted within three years of last entering care, in comparison with 60% of other children (year ending 31 March 2020). [Children Adopted from Care in Northern Ireland](#), 2020, Report, Information Analysis Directorate, p. 15.

<sup>94</sup> A majority of US adults assume that behavioral issues (63%) or mental (59%) and physical (52%) disabilities of a child adversely affect the probability of being adopted. See *2017 US adoption attitudes survey: Conducted by Harris Poll on behalf of the Dave Thomas Foundation for Adoption*, 2017, p. 69.

<sup>95</sup> Good, G. A. (2016). Adoption of children with disabilities: An exploration of the issues for adoptive families. *Early Child Development and Care*, 186(4), 642-661, p. 652.

<sup>96</sup> Adoption from Viet Nam Findings and recommendations of an assessment, 2009, final report, p. 23

<sup>97</sup> Wind, L. H., Brooks, D., & Barth, R. P. (2005). Adoption preparation: Differences between adoptive families of children with and without special need. *Adoption Quarterly*, 8(4), 37–41.

<sup>98</sup> Adopters report that preparation programmes overemphasised adversarial aspects of upbringing a child with “special needs”. See Denby, R. W., Alford, K. A., & Ayala, J. (2011). The journey to adopt a child who has special needs: Parents’ perspectives. *Children and Youth Services Review*, 33, 1543–1554.

<sup>99</sup> Good, G. A. (2016). Adoption of children with disabilities: An exploration of the issues for adoptive families. *Early Child Development and Care*, 186(4), 642-661.

<sup>100</sup> Perry, C. L., & Henry, M. J. (2009). Family and professional considerations for adoptive parents of children with special needs. *Marriage & Family Review*, 45(5), 538-565, p. 554

<sup>101</sup> Woodman-Worrell, A., & Higgins, M. (2019). Successful adoption for disabled children or children with mental health conditions: a systematic review. *Practice*, 31(5), 311-328.

<sup>102</sup> [Grant, M., & Thomas, C. \(2013\) The adoption of disabled children: Briefing Paper, BAAF](#)

<sup>103</sup> “Fostered/ adoptive parents report an increased frequency of positive social behaviours in these children [children with mental, physical and emotional health and behaviour challenges], approximately after one year after their adoption”. See Khetawat, D. (2020). Cognitive, Behavioural and Emotional Benefits of Deinstitutionalisation for Children with Disabilities: A Comparative Study of the United Kingdom and India. *Institutionalised Children Explorations and Beyond*, 7(1), 83-88, p.86.

<sup>104</sup> [Escaffi P. A., Delano González N., Delano Gonzalez P., Bustos Cardenas, A. \(2019\) Research on Adoption of Children with Disabilities: Chilean Experience. Legal and Psychosocial Analysis, Research Report, p.4.](#)

<sup>105</sup> Prior volunteer experience (e.g. taking an institutionalized child with disabilities home for a short time) has proven to contribute to the adoption of children with disabilities. See Mozzi, G. D., & Nuernberg, A. H. (2016). Adoption of children with disabilities: a study with adoptive parents. *Paidéia (Ribeirão Preto)*, 26(63), 101-109.

<sup>106</sup> Woodman-Worrell, A., & Higgins, M. (2019). Successful adoption for disabled children or children with mental health conditions: a systematic review. *Practice*, 31(5), 311-328.

<sup>107</sup> “The legislation contains a provision about limiting access to the Group I and II persons with disabilities to act as an adoptive parent”. See [The Coalition Public Initial Report on the Republic of Belarus “Compliance with Its Obligations Adopted for the Purpose of Implementing the Convention on the Rights of Persons with Disabilities”](#), 2020, Minsk, p.37.