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Rights of persons with disabilities

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the rights of persons with disabilities, Heba Hagrass, in accordance with Human Rights Council resolution 53/14.

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* A/80/150.

Report of the Special Rapporteur on the rights of persons with disabilities, Heba Hagrass

Care and support for children with disabilities within the family environment and its gendered dimensions

Summary

In the present report, the Special Rapporteur on the rights of persons with disabilities, Heba Hagrass, highlights barriers faced by children with disabilities and their caregivers to the enjoyment of their human rights, in the absence of adequate support services. She unpacks the gendered dimension of unpaid care and support to children with disabilities in the family environment, mostly provided by women. She outlines diverse measures and services to be implemented as part of inclusive and human-rights based care and support systems and makes actionable recommendations to States to protect the right to family life, prevent institutionalization and promote gender equality.

I. Introduction

1. Growing up in a safe and healthy family environment is the best way to guarantee children's well-being, development and lifetime outcomes. Increasingly, policies recognize that the well-being of children and their caregivers are interrelated, while investing in supporting families and caregivers improves equitable social and economic growth.[1]

2. In the present report, the Special Rapporteur focuses on the often-overlooked needs and experiences of children with disabilities and their family caregivers, in particular women (including mothers), and measures required to establish and strengthen care and support systems that protect and promote the human rights of children with disabilities and their caregivers. Parents and caregivers often face multiple and intersecting forms of discrimination and discrimination by association with a person with disabilities, which is a form of disability-based discrimination under article 5 of the Convention of the Rights of Persons with Disabilities.[2]

3. Children with disabilities continue to be disproportionately separated from their families and placed in institutions, despite extensive evidence of harmful impacts such as violence, abuse, neglect and segregation. In Europe and Central Asia, for example, they are 6 to 30 times more likely to be in formal residential care, with this region having the highest rate of child institutionalization worldwide.[3] As expressed in many submissions, persistent institutionalization is the result of lack of services and support, not of the wishes of families and, even less so, of children.[4]

4. To inform her report, the Special Rapporteur issued a call for inputs and received 102 responses[5] from States, organizations of persons with disabilities, associations of persons with disabilities and their families, civil society, service providers and United Nations entities, inter alia. She is thankful to all those who contributed and shared valuable information. The Special Rapporteur is particularly thankful to organizations that conducted surveys among families. In addition, she held a consultation with parents of children with disabilities and youth with disabilities from Moldova in May 2025.[6] The preparation of the report also entailed extensive desk research and document review.

II. Conceptualizing care and support in and for families of children with disabilities

A. Key concepts and terminology

5. Care and support are central to the well-being of all people and societies. Nonetheless, this essential work remains undervalued, unrecognized and largely provided by women and girls owing to social norms and gender stereotypes. Care and support must be understood through social co-responsibility whereby States are the

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[1] See United Nations Children's Fund (UNICEF), "Family-friendly policies: redesigning the workplace of the future", policy brief, 2019.

[2] See Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018) on equality and non-discrimination; CRPD/C/ARE/CO/1; CRPD/C/BEL/CO/1; and CRPD/C/ESP/CO/1.

[3] See UNICEF, "Leveling the playing field for children with disabilities", In Focus (Geneva, October 2024).

[4] See submission from Human Rights Watch.

[5] Inputs received in accessible formats are available at www.ohchr.org/en/calls-for-input/2025/call-inputs-care-and-support-children-disabilities-within-family-environment.

[6] Consultation facilitated by Lumos.

primary duty bearers for respecting, protecting and fulfilling human rights, including through law and policy frameworks, public infrastructure and service delivery.

6. Historically and geographically, there have been diverse and evolving conceptualizations of “care” and “care work.” Most recently, the United Nations system conceptualized it as the “act of caring for oneself, for others and for the planet, and which includes providing support and assistance to those who require it to enable their participation in society with dignity and autonomy”, and centred around key principles including leaving no one behind and human rights.[7] This conceptualization includes the 5R framework on recognizing, reducing, redistributing and rewarding care and representing those providing care, and embodies a holistic approach by defining “care systems” as encompassing legal and policy frameworks, services, financing, social and physical infrastructure, programmes, standards and training, governance and administration and social norms.

7. Care work is often framed as “burden” and “hardship,” which is magnified when referring to caring for children with disabilities. Such narratives perpetuate ableist attitudes perceiving disability as an inherent burden, while not addressing the real issues linked to lack of community-based support services and related gaps in realizing the right to autonomy and independent living and unequal social organization of care and support. They also fail to recognize that persons with disabilities, including parents with disabilities, provide care and support too.

8. Increasingly, the discourse is shifting towards “care and support”, in recognition of the rights and needs of both those providing and requiring care and support.[8] This nuance is essential for persons with disabilities. Historically, the preferences and choices over which type of support they receive and the way in which it is received were neglected, with support needs framed as “care”, leading to disempowerment and control.[9] The term “support” therefore describes assistance provided with control and choice by those requiring it to enable participation in society with dignity and autonomy.[10]

9. The conceptual difference between care and support is important when addressing the needs of children. While infants and younger children depend on care provided by others, with age and evolving capacities, their needs progressively change from care to support. Moreover, children with disabilities might require specific care and support, in addition to the usual child-rearing responsibilities that parents are expected to provide. That is why public services are essential to ensure that the specific needs of children with disabilities are met, for instance in terms of assistive devices, rehabilitation, etc. The Special Rapporteur uses the term “care and support” in the present report, recognizing both the evolving capacities of children and the additional needs of children with disabilities.

10. In the report, the Special Rapporteur focuses on the family environment as the best place for all children to grow up in and where they can establish a stable relationship with a committed adult caregiver. Stable and nurturing relationships can be provided in diverse types of families,[11] and all families should be respected and supported to fulfil their child-rearing responsibilities. Service providers, professional paid caregivers and peers sharing living arrangements, for example in group and “family-like” homes, cannot be a substitute for growing up in a family. Supporting

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[7] United Nations, *Transforming Care Systems in the Context of the Sustainable Development Goals and Our Common Agenda*, United Nations system policy paper (2024).

[8] See Human Rights Council resolution 54/6; General Assembly resolution 77/317; Economic and Social Council resolution 2024/4; and A/HRC/58/43.

[9] A/HRC/34/58, paras. 23–28.

[10] A/HRC/58/43, para. 5.

[11] A/HRC/29/40, para. 23.

families of children with disabilities is crucial to prevent family separation, institutionalization and protect child rights, including freedom from violence, abuse and neglect.

11. Lastly, the Special Rapporteur acknowledges the importance of a life-course approach, multiple and intersecting forms of discrimination and leaving no one behind. Care and support needs evolve throughout childhood and into adulthood and older age, thus requiring continuity and systemic and integrated approaches.

B. Gendered dimensions of care and support for children with disabilities

12. There is a strong gendered dimension in care and support for children with disabilities. Globally, women and girls undertake a disproportionate share of unpaid care and support, often at great cost to their human rights and gender equality.[12] Owing to social expectations around gender roles and traditional families, social norms and economic inequality, care and support responsibilities for children and other family members continue to be perceived as "women's role." Meanwhile, men engage less in caregiving and childcare, in part owing to stereotypical perceptions of such activities as "unmanly."

13. Such dynamics are further exacerbated in families of children with disabilities, where women, including mothers, grandmothers and sisters predominantly assume caregiving responsibilities. All submissions received confirmed that women, and especially mothers, assume the role of the primary caregiver for children with disabilities.

14. Worldwide, women – and in particular mothers – are expected to reduce or stop paid work to provide unpaid care and support for children with disabilities. Other female relatives, in particular grandmothers, are also more likely to be involved. In a survey among families of children with autism in Europe, mothers were the primary caregivers in 68 per cent of the families, parents shared caregiving responsibilities (at varying degrees) in 22 per cent of families, and only 3 per cent identified the father as the main caregiver.[13] Studies on the care economy in Lebanon and Oman also indicate that mothers are the primary caregivers for children with disabilities, and, to balance work and caregiving, they often rely on older women (grandmothers) to share these responsibilities.[14]

15. The gendered division of care and support for children with disabilities is linked to stereotypical gender roles and ideals of motherhood, reinforced by prevailing charity and medicalized attitudes towards disability. Thus, caring for children with disabilities can be expected as a form of self-sacrifice from "perfect" mothers, while impairments are considered a personal tragedy that is best managed privately. Instead of understanding of their needs and the offering of appropriate support, mothers are met with pity and admiration of their "strength" – which reinforces isolation and guilt to seek assistance not only for their children but for themselves. As summarized by one mother, "after a child with disabilities was born my role has been reduced to that of a caregiver in society".[15]

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[12] See A/HRC/59/45.

[13] See submission from Autism Europe.

[14] See submission from the Economic and Social Commission for Western Asia.

[15] See submission from Disability Rights International.

C. International human rights framework

16. The international human rights framework provides specific protections for the human rights of caregivers of children with disabilities, in particular when considering the interconnected rights of persons with disabilities, children and women and girls under the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities and the Convention on the Elimination of All Forms of Discrimination against Women.

17. Children with disabilities have rights equal to those of other children, and States are required to provide inclusive, community-based and supportive services for children with disabilities and their families (Convention on the Rights of Persons with Disabilities, arts. 19 and 23 (3) and Convention on the Rights of the Child, art. 23 (1)), including early intervention, habilitation and rehabilitation, inclusive education, accessible infrastructure, assistive devices and child protection and social services. These services underpin the right to family life and prevention of concealment, abandonment, neglect and segregation of children with disabilities (Convention on the Rights of Persons with Disabilities, art. 23 (3)).

18. The right to full inclusion in society entails the right of children to live and grow up in a family – and not in a residential care setting of any size, with an obligation for States to implement deinstitutionalization.[16] The human rights model of disability underpins all principles and rights enshrined in the Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child. Existing guidance on alternative care under article 20 of the Convention on the Rights of the Child should be interpreted against the higher standards upheld in the Convention on the Rights of Persons with Disabilities.[17]

19. Both the Convention on the Rights of Persons with Disabilities (art. 23 (3)) and the Convention on the Rights of the Child (art. 18) require States to support parents in their caregiving responsibilities, notably through appropriate services that include information and assistance to enable them to understand disability in a positive way and to support children while respecting their best interests and evolving capacities. Children with disabilities have the right to be heard on matters that affect them and their views taken into account in accordance with their age and maturity (Convention on the Rights of Persons with Disabilities, art. 7, and Convention on the Rights of the Child, art. 12).

20. Support to family caregivers should enable them to support family members with disabilities to live independently and include respite care, childcare services and other supportive parenting services, financial support, counselling etc.[18] The Committee on the rights of persons with disabilities recognized that, in some instances, "the rights of persons with disabilities cannot be realized without the protection of family caregivers" and that family caregivers have the right to State assistance when this is needed to protect the rights of family members with

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[16] Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017) on living independently and being included in the community, paras. 16 (c) and 37. See also guidelines on deinstitutionalization, including in emergencies (CRPD/C/5); and joint statement by the Committee on the Rights of Persons with Disabilities and the Committee on the Rights of the Child of 18 March 2022, available at https://www.ohchr.org/sites/default/files/2022-03/CRC-CRPD-joint-statement_18March2022.docx.

[17] See Guidelines for the Alternative Care of Children (General Assembly resolution 64/142). See also A/HRC/40/54, para. 51.

[18] Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017), para. 67.

disabilities.[19] The Committee further highlighted discrimination by association faced by family carers, in particular with regard to employment.

21. Under article 5 of the Convention on the Elimination of All Forms of Discrimination against Women, States must recognize and address intersectional discrimination faced by women in their caregiving roles within the family, including when caring for a child with disability. Under article 11.2 (c), States should provide the necessary supporting social services to enable parents to combine family obligations with work responsibilities and participation in public life, in particular by establishing childcare facilities.[20] States must also guarantee the right to social security (art. 11.1 (e)), including non-contributory old-age pensions, for those who spend extensive periods outside the labour market to provide care.[21]

22. There is a growing discourse towards "a right to provide and receive care and to exercise self-care" to be implemented through comprehensive care and support systems that are grounded in human rights and intersectional approaches.[22] The recognition and understanding of intersectional approaches in the design and implementation of care and support systems – underpinned by the synergies in the international human rights framework – is vital to ensure that the needs and rights of both those providing and requiring care and support are fulfilled.

III. Lived experiences of families and children with disabilities

23. Raising a child with disability profoundly affects families and the enjoyment of the human rights of family members, especially in the context of inadequate public support and services and negative societal attitudes. In this chapter, the Special Rapporteur outlines the experiences of caregivers, based on received submissions, including the way in which the gendered division of care and support exacerbates inequalities at the intersection of gender and disability. While she seeks to draw attention to significant difficulties faced by family caregivers and children with disabilities, these do not negate the loving and positive relationships that many parents, siblings, children with disabilities and other family members enjoy.

A. Stigma and exclusion

24. In all geographical regions, families of children with disabilities reported experiencing significant stigma related to disability, in particular when children have intellectual and psychosocial disabilities and extensive and complex support requirements. Mothers, in particular, encounter shame and blame for bearing a child with disability.[23] Such attitudes can be especially strong when mothers are blamed for "causing" impairments because of presumed failings to observe lifestyle recommendations during pregnancy or when they chose to have the child despite risks

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[19] See Views adopted in 2022 by the Committee on the Rights of Persons with Disabilities in *Bellini et al. v. Italy* (CRPD/C/27/D/51/2018).

[20] Not to be interpreted as residential institutions for children with disabilities under the Convention on the Rights of Persons with Disabilities.

[21] See Views adopted in 2019 by the Committee on the Elimination of Discrimination against Women in *Ciobanu v. Republic of Moldova* (CEDAW/C/74/D/104/2016).

[22] Buenos Aires Commitment, paras. 8 and 9. The Inter-American Court of Human Rights has been requested to issue an advisory opinion on the right to care as an autonomous right under article 26 of the American Convention on Human Rights; see https://www.corteidh.or.cr/docs/opiniones/soc_2_2023_en.pdf.

[23] See submissions from Broken Chalk, Face Equality International, Fetal Alcohol Spectrum Disorder – Carers Action Network, Groupement la vie pour tous and Pallium India, inter alia.

of congenital conditions detected during pregnancy. Women are criticized based on sexist and ableist attitudes for failing to meet the societal expectations of a "perfect" mother, as well as for having a child that will require resources and support, leading to emotional distress and guilt.

25. Both children with disabilities and their primary caregivers are affected by stigma and discrimination, resulting in rejection by society and at times by their families. Mothers and children with disabilities are often abandoned by the fathers, either when the impairment is identified or as the long-term implications of the care and support needs become apparent.[24] A study conducted in Rwanda, for example, documented persistent stigma against children with disabilities, who are regularly called abusive names, while the stigma is associated with the entire family of the child.[25]

26. In some cases, children with disabilities have been accused of being cursed and a punishment for their parents, especially mothers who end up being pressured to abandon their children. Cases of medical professionals encouraging parents to institutionalize their children with disabilities, including after birth, have also been reported.[26] This relates to incorrect beliefs that families are not best placed to take care of their child and that specific care and support can be effectively delivered only in institutional settings. Parents tend to be confronted by ableist opinions presenting the parenting of a child with disability as a source of difficulty, disappointment and failure and suggesting the lowering of expectations as to the capacities and future possibilities for their child.[27]

27. Such negative attitudes affect the mental well-being, confidence and sometimes behaviour of family caregivers towards a child with disability. The wish to avoid intrusive and abusive comments and looks leads them to self-isolate and limit social interactions. They report feeling unwelcome in public spaces such as playgrounds and schools or in public transportation. Stigma also exists within families, with severe impacts on children with disabilities, for example when children are hidden away and prevented from accessing disability assessments that would grant them access to social protection or support in education.

B. Gaps in inclusive education and other key childcare services

28. Lack of accessible, adequate and affordable services for children with disabilities was identified as a key issue, with profound effects on the well-being and enjoyment of human rights by both children and caregivers. Families struggle with high costs, long waiting lists, geographical inaccessibility, lack of qualified professionals and fragmented services. Gaps were highlighted concerning early identification and intervention, health services, habilitation and rehabilitation, inclusive education, financial support, assistive devices, accessible environment and transportation and support for independent living as children become adults, in particular, lack of employment opportunities. These gaps are consistent with the

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[24] See submission from Light for the World.

[25] See https://bettercarenetwork.org/sites/default/files/2022-10/kap_study_on_children_with_disabilities_to_send.pdf.

[26] See submission from Hope and Homes for Children.

[27] See submission from Coalición Colombiana por la Implementación de la Convención sobre los Derechos de las Personas con Discapacidad.

inequalities experienced globally by persons with disabilities, including children.[28] Caregivers and children from particularly marginalized communities, such as ethnic minorities or low-income families, experience heightened barriers to access to support and services. For example, children of African descent can face delays and disbelief during disability assessments, which limits access to support and services.[29]

29. Early childhood care and inclusive education are critical for the long-term development and inclusion of children with disabilities and transitioning to independent living once they reach adulthood. They are also crucial for caregivers to give them time for paid employment, self-development, self-care and a social life. While progress has been made in these areas, significant inequalities remain. Data from 34 low- and middle-income countries showed that children with disabilities are 25 per cent less likely to attend early childhood education and 49 per cent more likely to have never attended school compared with other children.[30] Even when legal and policy frameworks on inclusive education are in place, in practice families are denied access because of lack of capacities, qualified staff and accommodations within early childhood care facilities and schools, especially outside urban centres.

30. Many children with disabilities continue to be taught in segregated settings and away from families, including in boarding schools. Inadequate inclusive education systems are a key driver of institutionalization, exclusion and family separation. In this context, some caregivers decide to homeschool, which again increases responsibilities undertaken by mothers while denying children with disabilities quality education and separating them from their peers.

C. Poverty, inequality and adequate standard of living

31. When family caregivers need to fill gaps in care and support services for children with disabilities, they are exposed to negative economic impacts and increased risk of poverty. This is, first, connected to difficulties to maintain paid employment, with many caregivers having to significantly reduce working hours or leave their jobs.[31] In Europe, 85 per cent of families of children with autism reported that their incomes have been negatively affected, with 42 per cent of primary caregivers leaving their jobs and 32 per cent scaling back professional commitments.[32] Caregivers face discrimination by association, in particular in employment when employers question their commitments and capacities because of caregiving responsibilities, leading to barriers in recruitment,[33] access to flexible working arrangements and keeping jobs.

32. Second, family members are generally left to cover much of the extra costs related to the disability, such as assistive devices, home adaptations, specific therapies and schooling, accessible transportation, personal assistance and other services. For example, the cost of raising and caring for a child with autism is estimated to be six

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[28] See Alexandre Cote and Lena Morgon Banks, eds., *Global Disability Inclusion Report: Accelerating Disability Inclusion in a Changing and Diverse World*, (UNICEF (on behalf of the Global Disability Inclusion Report steering group), New York, 2025); and United Nations, Disability and Development Report 2024: accelerating the realization of the Sustainable Development Goals by, for and with persons with disabilities".

[29] See submission from Alana Institute.

[30] *Global Disability Inclusion Report* (2025), p. 26.

[31] See submission from the Committee on the Rights of Persons with Disabilities.

[32] See submission from Autism Europe.

[33] See submission from Alana Institute.

times higher than for other children.[34] In some countries, the extra costs surpass the national average income[35] which is clearly impossible for most families to meet. In the Philippines, families with children with disabilities were found to be systematically disadvantaged in accessing basic services compared with other families, with their children needing expenditures 40 to 80 per cent higher than other children. As a result, poverty rates were 50 per cent higher in households with children with disabilities.[36]

33. Financial support available to children with disabilities and caregivers is often largely insufficient to mitigate limited employment opportunities and extra costs related to disability. In all regions, caregivers indicated that disability cash benefits for their children, and carer subsidies, where they exist, are too low to cover actual care and support needs and ensure an adequate standard of living for them and their children. Moreover, eligibility criteria for disability benefits often remain restrictive and medicalized, leaving many children with disabilities left out. All these factors generate social exclusion and marginalization, with an increased risk of institutionalization for children with disabilities.

34. The economic impacts of raising a child with disability are gendered and disproportionately affect women and, in particular, mothers. Owing to social norms, gender pay gaps and women being overrepresented in low-paid jobs, mothers are predominantly the ones to withdraw from the labour market or work fewer hours. This makes them more economically dependent on others and generates vulnerability. In the long term, they have more difficulties saving for retirement and contributing to pensions, especially if adequate non-contributory pensions are not in place. Given the high rate of family separations, women are often left alone to provide financially for their children with disabilities, leading to severe financial strain and higher levels of poverty for them and their children and associated risks such as institutionalization.

D. The invisible work of advocating and organizing access to care and support

35. In addition to reduced incomes, significant extra costs related to disability and provision of care and support, primary caregivers dedicate significant time and energy to advocate, coordinate and organize access to services and support for their children with disabilities. This invisible and unrecognized work is largely undertaken by mothers – to the point that advocacy and activism for a child with disability becomes part of their identity.[37]

36. Barriers to access to services for children with disabilities remain high because of complex, fragmented and hard to navigate administrative systems. This places the onus on caregivers to ensure that the system works together for their children, for example with regard to education, healthcare, rehabilitation and access to assistive technology. Caregivers must often seek out information on the forms of assistance for which they and their children are eligible, prepare and organize documentation and appointments and sometimes dispute decisions related to disability assessments, benefits, healthcare, education, etc. The bureaucratic difficulties of advocating and

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[34] See Sophia Dückert and others, “Multidimensional burden on family caregivers of adults with autism spectrum disorder: a scoping review”, *Review Journal of Autism and Development Disorders* (2023).

[35] See Kenneth R. Katumba and others, “The economic burden incurred by families caring for a young child with developmental disability in Uganda”, PLOS Global Public Health, vol. 3, No. 4 (2023).

[36] See UNICEF Philippines, *Cost of raising Children with Disabilities in the Philippines* (Manila, 2022).

[37] See submission from Complex Care Group.

fighting for the rights of children with disabilities have been consistently highlighted as a source of stress, exhaustion and requiring significant time and energy.[38]

37. Where individualized budgets are available to contract support services for a child with disability, primary caregivers will often oversee the finding and hiring of service providers, including specific therapies, and the managing of contracts and bills. Caregivers often must explain the needs of their children to assessors, social services and school staff, inter alia. The school environment has been highlighted as particularly challenging, with caregivers needing to proactively fight for inclusion and protection from bullying and explain their child's behaviour.

E. Violence, abuse and neglect

38. Globally, nearly one in three children with disabilities experience violence – twice as many as other children.[39] They are exposed to many forms of violence (e.g. infanticide, sexual, physical, verbal, neglect, exploitation, child labour, bullying) in different settings (e.g. institutional care, family, schools, cyberspace).

39. Within families, caregivers experiencing stress and lacking adequate support may engage in harmful practices, often under the guise of discipline or care.[40] Violent forms of discipline are driven by factors such as negative attitudes towards and beliefs about disability; a lack of skills and options for teaching children self-control and acceptable behaviour; and financial pressures. One study showed that children with disabilities are twice as likely to be beaten as a form of discipline and are significantly more likely to experience severe physical punishment as compared with other children, while their caregivers (mothers) tend to believe more that physical punishment is necessary to raise a child properly.[41] The same study also indicates a higher risk of neglect, including lower rates of early stimulation and responsive care or inadequate supervision.

40. Primary caregivers, especially mothers, can also be particularly vulnerable to violence and abuse, owing to a higher likelihood of financial dependence on others, poverty, isolation, stigma related to bearing a child with disability and general marginalization. They, and other family members such as siblings, can also be exposed to physically violent outbursts from children with disabilities who might struggle with self-regulation and emotional control.

F. Impacts on physical and mental health

41. The cumulative effects of stigma, isolation, financial difficulties, significant care and support responsibilities and energy spent on advocating and organizing access to support and services leaves a heavy physical and emotional toll on caregivers, in particular mothers. Many primary caregivers experience high and sustained levels of stress, anxiety, depression, burnout, fatigue, guilt, denial and fear, while lacking access to adequate mental health support. This is compounded by a sense of being left alone to navigate complex and fragmented care and support systems.

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[38] See submissions from Inclusion International and Ieder(in).

[39] Zuyi Fang and others, "Global estimates of violence against children with disabilities: an updated systematic review and meta-analysis", *Lancet Child & Adolescent Health*, vol. 6, No. 5 (2022), pp. 313–323.

[40] See submission from International Disability Alliance.

[41] See UNICEF, *Seen, Counted, Included: Using Data to Shed Light on the Well-being of Children with Disabilities* (New York, 2021).

42. The physical health of caregivers is also impacted, for example with less time for self-care, making medical appointments for themselves and strain and injuries from physical tasks such as lifting and moving children who need such support. Sleep deprivation, no clear respite periods and being alert to the needs of their children around the clock further contributes to negative physical and mental health impacts, including as caregivers and their children age.[42] Ageing parents face anxiety over fear of how their (often adult) children will be supported once they are no longer alive or able to provide support themselves.[43]

43. Emerging research on parent caregivers of children with disabilities, predominantly mothers, further points to a high prevalence of feelings that life is "not worth living" and suicidal thoughts which significantly exceeded that in the rest of the population. That said, the caregivers were less likely to act on suicidal thoughts which could potentially trigger thoughts of homicide-suicide, in which caregivers consider ending their own life and the life of the person that they care for and support.[44] While cases of such homicide-suicides have been reported by media, serious research on this topic is lacking.

IV. Support for families of children with disabilities and promising practice

44. Children with disabilities and their family members have the right to enjoy family life without being isolated and pushed to the brink because of lack of support and assistance. Diverse forms of support can be provided to caregivers and children within a framework of inclusive, transformative and resilient care and support systems.

A. Data collection and understanding the needs of family caregivers

45. Measuring and understanding the care and support provided by family caregivers, including its gendered dimension, remains difficult as time-use and care surveys generally lack disability-specific questions concerning those providing or receiving care and support. Understanding the division of responsibilities within the family – including as compared with other families – has not been the focus of such surveys. The International Classification of Activities for Time-Use Statistics, for example, does not "distinguish between caring for children with disabilities and caring for other children, since all children require care and supervision".[45]

46. Similarly, there is a dearth of studies about the types of activities provided by caregivers of children with disabilities and the barriers that they encounter.[46] The impacts and needs of families and primary caregivers are therefore not well understood and adequately reflected in public policies. In Kenya, the 2023 support needs assessment report for persons with disabilities and their primary caregivers provided evidence on both the met and unmet support needs of both. Almost all

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[42] Submission from European Disability Forum.

[43] Submission from Inclusion Europe.

[44] Siobhan T. O'Dwyer and others, "Suicidal thoughts and behaviors in parents caring for children with disabilities and long-term illnesses", *Archives of Suicide Research*, vol. 29, No. 2 (2024).

[45] The 2016 International Classification of Activities for Time-Use Statistics was endorsed by the Statistical Commission and provides important input for monitoring progress towards achieving Sustainable Development Goals, including target 5.4 on unpaid care and domestic work. Information on children with disabilities may be collected through relevant questions in the background questionnaire for the time-use survey.

[46] Submission from Mexico.

caregivers (92.2 per cent) indicated that they required financial support.[47] In Europe, a 2017 study showed that children with disabilities were the third most common group receiving care and support from family carers, after adults with disabilities and older persons with support needs. Out of all family carers, 31 per cent said that there was no one to help them fulfil their role, and many mentioned having to unwillingly give up their jobs.[48]

47. More data are also needed to understand and analyse the experiences and needs of children with disabilities. One study on the human rights priorities and experiences of children with disabilities in East and Southern Africa represents a positive example, with questions covering life at home and family relations. Notably, many children indicated emotional support, love and affection from families as the key reason for their happiness, which underscored the importance of a nurturing home environment.[49]

B. Law and policy frameworks and participatory approaches

48. Support for families and caregivers can be formulated and implemented through different legal and policy frameworks, including on early childhood, children and adolescents, persons with disabilities, education, health, employment, child protection, social protection, etc. National strategies on carers represent another type of framework for promoting their well-being and rights, including the redistribution of care and support and participation in employment and education. For example, the New Zealand Carers Strategy and Action Plan 2019–2023 was introduced to alleviate some of the unmet needs of family caregivers.[50]

49. Integrated and comprehensive care and support systems are important for breaking silos between services and integrating intersectional approaches to protect the right of those providing and requiring care and support. Examples of national practices include the pioneering integrated national care system adopted by Uruguay in 2015, recently followed by similar systems in other countries in Latin America and the Caribbean.[51] Kenya is also developing a national care policy to address unpaid and paid care work disproportionately provided by women and girls.[52]

50. To be effective and human-rights compliant, national care and support systems must be developed, implemented and monitored in close and meaningful consultation with persons with disabilities, including children with disabilities and their family caregivers. The participation of children with disabilities is particularly low, with limited data on this topic.[53] Children with disabilities and their caregivers face barriers to participation and to the meaningful inclusion of their views, for example, as their voices are not sufficiently represented among wider caregiver coalitions.[54]

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[47] See https://www.knbs.or.ke/wp-content/uploads/2024/08/Support-Needs-Assesment-report-for-persons-with-disabilities-and-their-primary-caregivers.pdf.

[48] COFACE Families Europe, *Who Cares? Study on the Challenges and Needs of Family Carers in Europe* (Brussels, 2017).

[49] Able Child Africa Network, *Amplifying the Voices of Children with Disabilities* (2025).

[50] See https://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/carers-strategy-action-plan-2019-2023.pdf.

[51] See for example, Law No. 19.353 of Uruguay (2015); Law No. 15.069 of Brazil (2024); the National Support and Care Policy for 2025–2030 and the related action plan in Chile; and the National Care Policy of Colombia (CONPES 4143 of 2025), inter alia.

[52] See www.mygov.go.ke/unpaid-care-work-addressed-kenyas-national-policy-update.

[53] Submission from International Disability and Development Consortium.

[54] Submission from Inclusion Canada.

C. Integrated social protection systems and services

51. Social protection is an essential component of care and support systems, in particular to prevent and address the higher risk of poverty faced by households with persons with disabilities and redistribute unpaid care work. Globally, coverage by child and disability benefits varies significantly. Overall, 38.9 per cent of persons with disabilities receive a disability benefit – these schemes tend to focus on the working-age population and less on covering children with disabilities.[55] Moreover, the adequacy of financial benefits for persons with disabilities, as well as for children and their caregivers, is often insufficient to meet the extra costs related to disability and ensure an adequate standard of living.

52. In some regions, regular disability-targeted benefits to children with disabilities are prevalent, for example in Eastern Europe and Central Asia.[56] These should complement mainstream schemes such as child grants, as the objective is to offset disability-related extra costs faced by families. The continued use of assessments based exclusively on impairments rather than support needs remains a challenge, as they do not respond to individual needs and exclude children who cannot access disability assessments for multiple reasons (see A/HRC/54/36).

53. Cash transfers can be complemented by other benefits for children and caregivers, such as the free or reduced cost of public transportation, healthcare, assistive devices and other services, as well as tax exemptions. Integrated and comprehensive approaches combining cash benefits with services respond more effectively to the needs of children with disabilities and their caregivers. In Sweden, for example, families of children with disabilities can benefit from additional cost allowances, housing allowances and home adaptations or pension points to protect caregivers with reduced working hours.[57]

54. Integrated social protection systems are underpinned by effective and well-resourced case management and referral systems that help families navigate and access benefits and services that they need. In Armenia, integrated social centres bringing together multiple benefits and services, together with a case management system, have been introduced to support caregivers and children, including children with disabilities, based on their specific needs.[58]

55. Several countries reported providing financial allowances to caregivers[59] to compensate for reduced working hours or no employment due to caregiving, and in addition to child disability benefits intended to account for extra costs related to disability. However, eligibility for carer allowances can be limited based on the overall household income, putting women at a disadvantage as their spouses are more likely to maintain employment and higher incomes, and they are not adequately compensated for often round-the-clock care and support provided to their children. Eligibility for such allowances should not be considered incompatible with employment,[60] especially if set at minimum wage levels, to avoid negative impacts on the economic independence of women. Other support options should be available, as being paid to care reinforces gendered roles and monetizes the person requiring care and support, leading to bad family dynamics.

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[55] International Labour Organization, *World Social Protection Report 2024–26* (Geneva, 2024).

[56] UNICEF, "Inclusive social protection systems for children with disabilities in Europe and Central Asia", social protection regional issue brief 3 (2023).

[57] Submission from DHB Sweden.

[58] UNICEF, "Inclusive social protection systems for children with Disabilities in Europe and Central Asia", (2023).

[59] Inputs from Bosnia and Herzegovina, Czechia and Germany.

[60] Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017), para. 89.

56. In some countries, parents can choose to either receive care allowances themselves or hire a personal assistant for their child. Personal assistants can support children with self-care, communication and medical needs, or at school. However, when allowances are too small and not based on the needs of the child, families might not be able to recruit on the open labour market. Low pay and lack of qualified staff, especially for children with intellectual and psychosocial disabilities, also make recruitment difficult. Ensuring fair wages is also critical to recognize and reward paid care work, which has been historically low paid and mostly undertaken by women.

57. The standards under the Convention on the Rights of Persons with Disabilities concerning personal assistance as a tool for independent living[61] need to be considered, in particular, the control and choice of the person with disabilities. Children with disabilities should be involved in the choices and decisions over support through personal assistance, progressively preparing them for more responsibilities as they grow up. Adolescents with disabilities might prefer adult assistants closer in age to them, rather than their parents, as this can support their transition to adulthood and independence. Studies also show very positive impacts on families, as well as economic arguments for personal assistance for children with disabilities.[62]

D. Time for parenting and time for caregivers

58. Paid maternity, paternity and parental leave are crucial for the health and well-being and mothers, children and other family members and for promoting gender equality and sharing caregiving roles between parents. Extended periods of paid parental leave give parents of infants with identified impairments more time to adjust, bond and become familiar with the needs of their child. Paid paternity leave and flexible and shared parental leaves, where fathers are encouraged to take on caregiving, further helps to change traditional gendered roles and allow both parents to become familiar with the specific needs of their child.

59. Flexible working arrangements and additional time off for caregiving are important tools for balancing caregiving and work. In Estonia, parents of a child with disability may take one day of paid leave per month.[63] In France, parents of children with disabilities can benefit from flexible working arrangements and temporary unpaid care leave of up to 310 days in a three-year period during which employment is protected. During the leave, parents can receive a daily allowance to compensate for lost income.[64]

60. Respite care allowing caregivers to take a break to rest and focus on their needs was identified as a key support service for caregivers, in particular mothers. It can be provided in external facilities and programmes or home based, when others, including paid professionals, temporarily step in. In general, families face barriers in accessing respite care owing to long waiting lists and lack of available places, inadequate quality and shortages of specialized workers and significant out-of-pocket costs. In New Zealand, the Carer Support Subsidy can be claimed by caregivers that provide more than four hours unpaid care and support daily to a person with disabilities to pay for a support worker or activities enabling the carer to take a break.[65] In Colombia, the city of Bogotá operates centres (*Manzanas del Cuidado*) with services

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[61] Ibid., para. 16 (d).

[62] Submission from the European Network for Independent Living.

[63] See https://eeca.unfpa.org/sites/default/files/pub-pdf/public_policies_best_practices_-_sweden_estonia_and_slovenia_.pdf.

[64] Submission from European Association of Service Providers for Persons with Disabilities.

[65] See www.disabilitysupport.govt.nz/carers/what-is-carer-support.

such as counselling, education and sports for caregivers, while support staff provide care and support to children with disabilities.[66]

E. Inclusive childcare services and education throughout childhood

61. The availability and quality of prenatal and postnatal care varies greatly across regions and countries. Everywhere, however, attitudes and language used by medical professionals during pregnancy and birth shape the experiences of mothers and families and often remain vectors for ableism, sexism and stigma. Parents shared experiences of medical professionals lacking empathy and not sufficiently explaining the situation or being provided with outdated, incorrect and biased information that reinforced negative assumptions around disability. As a result, parents are often left to navigate and learn about care pathways and support options on their own.

62. Given persisting ableist attitudes among medical professionals and advances in technology, it is important for genetic testing to be provided with full respect for the rights of persons with disabilities and their equality as members of society.[67] When impairments are detected, parents should be given timely, comprehensive and accurate information, not only a medical diagnosis and health implications but also information about existing support, early intervention services and connection with other families and organizations to enable them to gain an understanding from those with similar experiences.

63. Early identification and intervention based on multidisciplinary approaches are critical to maximize the functional development and social inclusion of children with disabilities in the long term. For families, early identification and intervention make for better understanding and capacity to respond to the child’s needs and a much-needed space for emotional support, guidance and training.

64. Similarly to other services, the accessibility and adequacy of early identification and intervention vary geographically, with a greater concentration of such services in urban centres, long waiting lists, excessive bureaucracy, lack of trained specialists and high costs among the main barriers. In some cases, early intervention services are outdated and push families towards rehabilitative models outside mainstream settings, thus giving rise to exclusion. In low-income countries, these services are limited or entirely absent, especially for families who cannot afford private healthcare.

65. Early intervention can play an important role in preventing institutionalization and keeping families together. In Moldova, the National Plan for the Development of Early Intervention Services 2023–2027 underpins the roll-out of regional early intervention centres, which should cover nearly all the country by 2027 and are free of charge. Based on an innovative and holistic model of early childhood intervention services, multidisciplinary teams develop individual plans for children with disabilities, while families and caregivers also benefit from parenting and peer-to-peer support. Families report excellent progress made by their children and are more confident in the care and support that they provide. Moreover, the economic costs for early intervention services also appear to be much lower than placing children in residential institutions.[68]

66. Children with disabilities continue to face exclusion and barriers to access to mainstream education, including early childhood, primary, secondary and vocational education. Inclusive education policies and projects are increasing in number but are

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[66] Submission from Coalición Colombiana para la implementación de la Convención sobre los Derechos de las Personas con Discapacidad.

[67] See A/HRC/43/41.

[68] Submission from Lumos and consultations with parents from Moldova.

often underresourced and cannot meet the support needs of children with disabilities, especially those with high and complex support needs.

67. Other public childcare services, such as summer schools, activity camps, extracurricular activities and day care, remain difficult to access for children with disabilities and their families. This means further challenges to balance work and care, additional time and costs required to find alternatives, as well as fewer opportunities for children with disabilities to socialize and develop different skills.[69]

68. Caregivers identified significant gaps in support and services aligned with the principles of independent living during the transition to adulthood. Instead, services available for children are phased out and are not replaced by adequate support for education, employment, housing, supported decision-making or rehabilitations, etc. Rather, parents are expected to continue to provide most of the support required. Again, the risk of institutionalization rises, especially as parents and children age. Some positive examples from high-income countries were reported, such as, in Finland, individualized life planning, vocational training, employment services, accessible housing and home modifications and integrated health and social services.[70]

F. Peer-to-peer and skills support

69. Connecting with other families of children with disabilities is a powerful community-based tool for sharing experiences, information, emotional support and practical advice. The importance of peer-to-peer support was recognized globally, especially as it can provide more accessible and empathetic support than through formal structures. Furthermore, it can be a driving factor behind a more positive and inclusive vision adopted by families for their children with disabilities.[71] For example, mentoring can be particularly transformative for parents of infants and small children. For more experienced caregivers, peer-to-peer support enables them to have their experiences and skills recognized and valued.

70. Much peer-to-peer support is organized through family associations and the non-profit sector, sometimes with public funding contributing to sustain their activities. Associations of parents and families are also instrumental in advocating for the rights of their family members, including children with disabilities and caregivers. They should be publicly supported, including through training and funding for running costs, to facilitate their meaningful participation in public decision-making.

71. Primary caregivers also face challenges in obtaining the skills to provide care and support to children with disabilities, including how to promote their autonomy and human rights. Some caregivers acquire a broad range of specific task skills, such as administering medication, implementing rehabilitation techniques, supporting communication, managing behavioural challenges, navigating bureaucracy and self-advocacy. Many develop these skills without structured training and mentoring.[72] Successful community-based initiatives to promote caregiver skills include the Ubuntu Hub, which brings together professionals, families and research organizations to empower families of children with developmental disabilities and provide peer psychosocial support. In Mozambique, for example, the programme assisted

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[69] Submission from Plena Inclusión.

[70] Submission from Inclusion International.

[71] See examples from Latin America and sub-Saharan Africa, available at https://inclusion-international.org/resource/families-in-action-case-studies-of-family-mobilisation-around-the-world/.

[72] Submission from Jerome le Jeune foundation.

caregivers in identifying risks of developmental delays and in communicating and playing with children.[73]

V. Conclusion and recommendations

72. **The enjoyment of human rights by family caregivers and by children with disabilities is intrinsically connected. Children with disabilities have the right to grow up in a stable family environment to guarantee their well-being, development and inclusion in the community. This right has been historically undermined by lack of adequate, accessible and affordable care and support services, coupled with resources directed to institutional care that segregates and separates children with disabilities from their families. As a result, caregivers provide unpaid care and support to children with disabilities under stark inequalities, systematic gaps in community-based services and social protection and immense pressure. They also experience discrimination by association, in particular in employment and access to social protection.**

73. **Owing to persistent gender stereotypes, cultural norms and stigma, mothers in particular face deep structural inequalities while providing care and support to children with disabilities, leaving them and their children particularly vulnerable to poverty, isolation, violence, abuse and neglect. Female caregivers also experience significant mental health strain while juggling long-term and sometimes highly specific care and support responsibilities, navigating complex, fragmented and bureaucratic social welfare and health systems and advocating for the rights of their children, especially for inclusive education.**

74. **The rights, needs and voices of caregivers and of children with disabilities have remained largely unheard and invisible in relevant legal and policy frameworks. With the emerging focus on establishing inclusive, human rights-based and resilient care and support systems, there is an opportunity to meaningfully consult, formulate and implement policies that effectively protect the right of children with disabilities to family life, including adequate support for their families. Such steps are critical to preventing the institutionalization and segregation of children with disabilities and to recognize, reduce and redistribute unpaid care and support work largely provided by women.**

75. **In this respect, the Special Rapporteur makes the following recommendations to States:**

Evidence-based laws, policies and services to protect the rights of children with disabilities and their caregivers and promote inclusion in the community

(a) **Take urgent and concrete action to develop and implement laws, policies and comprehensive community-based services for adults and children with disabilities in line with the requirements under the Convention on the Rights of Persons with Disabilities, and redirect resources from institutional care and implement time-bound plans for deinstitutionalization;**

(b) **Create inclusive and accessible mechanisms for meaningfully and systematically consulting children with disabilities and their caregivers in the design, implementation, monitoring and evaluation of relevant law and policy frameworks, in particular on care, children and youth, families, gender equality, healthcare, education and social protection;**

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[73] See www.ubuntu-hub.org/what-families-in-northern-mozambique-learned-in-the-ubuntu-programme/?utm_source.

(c) **Regularly collect and analyse data about the experiences and needs of children with disabilities and their caregivers, including as part of surveys on time-use, disability and family support. All data should be disaggregated at least by disability status, gender and age for both caregivers and those requiring care and support;**

(d) **Carry out awareness-raising activities to combat stigma and misconceptions around disability, including during childhood and adolescence, targeting diverse settings such as education, media, culture and sports, recreational spaces, toys and books inter alia;**

(e) **Explicitly recognize in national law that discrimination by association is a form of disability-based discrimination, and establish protections against multiple and intersectional discrimination;**

Recognize, reduce and redistribute unpaid care and support and promote gender equality

(f) **Design and implement policies that promote gender equality in caregiving, such as shared parental and care leaves, automatically crediting time spent providing unpaid care and support towards adequate old-age pensions and addressing traditional and gendered roles around caregiving;**

(g) **Provide adequate financial support to unpaid caregivers without proscribing employment and other income-generating activities, and ensure access to flexible work arrangements;**

(h) **Fund and expand quality community-based respite care services and mental health support for caregivers of children with disabilities;**

Integrated, adequate and accessible social protection and support services

(i) **Urgently remove administrative barriers and make social protection and support services integrated and well-coordinated, with efficient case management, referrals and clear information easily available to caregivers and children with disabilities;**

(j) **Assess and ensure the adequacy and accessibility of existing social protection schemes for families of children with disabilities, in particular regarding extra costs related to disability;**

(k) **Strengthen and integrate social protection systems with targeted and diverse support services, including housing and home modifications, quality assistive devices and mobility and accessible transportation;**

Rights-based and inclusive support and services throughout childhood

(l) **Strengthen access to and availability of prenatal and postnatal care in mainstream health, and develop clear protocols for communication, information and referrals to multidisciplinary services when impairments are identified;**

(m) **Provide training on the human rights of children with disabilities and their caregivers, and non-directive, respectful, and timely communication to medical professionals, in particular in gynaecology, obstetrics and paediatrics;**

(n) **Design and deliver programmes to guide and support caregivers regarding their rights and the rights of children with disabilities, understanding and navigating support systems, including dispute-resolution and redress mechanisms and opportunities to benefit from free legal aid and advice, information and skills related to specific impairments and counselling;**

(o) **Establish and strengthen the availability, quality and accessibility of early identification and intervention services both in urban and rural areas, including through measures to train and retain qualified specialists;**

(p) **Increase investments to implement quality inclusive education for all children starting at the preschool level, grounded in robust legal and policy frameworks that are in compliance with international human rights standards, and provide clear frameworks for reasonable accommodations, accessible infrastructure and individualized support measures;**

(q) **Recognize the right to inclusive early childhood care and education and free pre-primary education for all children through a new optional protocol to the Convention on the Rights of the Child to be considered pursuant to Human Rights Council resolution 56/5;**

(r) **Make extracurricular activities, summer camps, and other childcare services funded by public authorities, accessible and welcoming to children with disabilities;**

(s) **Promote and financially support peer-to-peer groups, associations of family members and organizations of persons with disabilities to foster community-based support, counselling, the sharing of experience and skills and advocacy;**

(t) **Provide a range of human support models, including personal assistants, to children with disabilities based on functional needs assessments;**

(u) **Ensure continuity of support services throughout childhood and onward, especially during the transition to adulthood, prioritizing community-based services that promote independent living, legal safeguards to protect the right to legal capacity and supported decision-making, individualized transition plans with guidance and support on education, employment, housing, social protection and supported decision-making.**