

Global report on children with developmental disabilities

From the margins to the mainstream



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Foreword

Children and young people with developmental disabilities are a large and growing population. In 2019, there were approximately 317 million children and adolescents with health conditions that contribute to developmental disabilities globally. But across the world, their needs have been neglected in health systems planning and policy provisions for health.

At the same time, children and young people with developmental disabilities continue to experience stigmatization, prejudice, institutionalization and barriers to participation, as well as social, economic, educational and other forms of exclusion. They encounter barriers in accessing health care and receive poorer quality care compared with their peers.

The net effect of these omissions and exclusions is widespread inequalities in health outcomes and increased risk of dying prematurely for children, young people and adults with developmental disabilities.

This global report is a call for action to accelerate changes at individual, family, community and society levels to achieve inclusion and health equity. It makes the case for greater investment to build responsive multisectoral care systems for children and young people with developmental disabilities. Using findings from research and practice and guided by international human rights conventions, this global report provides key insights into the state of knowledge, policy, programming and public monitoring in respect of developmental disabilities.

The Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child provide a solid foundation to guide policy changes to create the conditions for children and young people with developmental disabilities to enjoy

optimal health and participation. Our understanding of approaches to optimizing health and development trajectories for these children and young people is now deeper, thanks to advances in the field of brain science, public health, epidemiology and social studies, experiences from implementation in countries and – significantly – contributions by persons with lived experience.

Midway to the deadline set out in the 2030 Agenda for Sustainable Development, the global community needs to turn words into action. Governments have committed to “leave no one behind”. This vision can only be achieved if the aspirations and needs of children with developmental disabilities are considered as central to all relevant efforts and are brought to the forefront of public health agendas – from the margins to the mainstream. This global report provides a framework for action to accelerate changes in care systems and policy in order to provide inclusive and enabling environments and responsive health care for all children and young people with developmental disabilities. We must augment both implementation and monitoring to build back fairer for persons with developmental disabilities, anchoring investments in universal health coverage and disability inclusion efforts.



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Acronyms and abbreviations

ADHD	Attention deficit hyperactivity disorder
ASD	Autism spectrum disorder
GBD	Global Burden of Disease
ICD-11	International Classification of Diseases, 11th Revision
ICF	International Classification of Functioning, Disability and Health
IHME	Institute for Health Metrics and Evaluation
LMICs	Low- and middle-income countries
mhGAP	Mental health Gap Action Programme
MICS	Multiple indicator cluster survey
SDGs	Sustainable Development Goals
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Children's Fund



1. Prioritizing children and young people with developmental disabilities

Every child and young person has the right to enjoy the highest attainable standard of health and well-being (1, 2). The realization of this right depends on the capacity of governments to ensure safe, healthy, enabling, inclusive environments; universal access to health care and education; and equitable opportunities for participation in all realms of life. Yet, due to the clustering of vulnerabilities and the failure of societies to ensure inclusion, universal health coverage and enabling environments for all, children and young people with developmental disabilities are more likely to experience adversities, such as stigmatization, violence, poverty, school dropout and parental mental illness. They are also more likely to experience poor health and have unmet health care needs, and are deprived of opportunities to thrive (3, 4).

1.1 Aim

The aim of this global report is to increase awareness on the significance of investing in intersectoral approaches to promoting health, well-being and participation and access to quality care for persons with developmental disabilities from a public health and social justice perspective.

It also provides a framework for action to accelerate changes in sociocultural, legal and care systems in order to provide inclusive and enabling environments and responsive care for all children and young people with developmental disabilities. It draws attention to the imperative of strengthening accountabilities.

While it is acknowledged that a life-course perspective is required to design strategies and programmes for persons with developmental disabilities, this global report focuses on children, adolescents and young people under 24 years of age.

The report is written for decision-makers who develop policies and care systems relevant to optimizing the health of children and young people with developmental disabilities and their caregivers. The report's framework for action is relevant to the role of governments, UN agencies, professional organizations and civil society organizations, including persons with disabilities and donors.

1.2 Scope and terminology

Children and young people with developmental disabilities are a heterogeneous group. In this global report, the term "children and young people with developmental disabilities" is used to refer to children and young people with health conditions that affect the developing nervous system and cause impairments in motor, cognitive, language, behaviour and/or sensory functioning. In interaction with various barriers and contextual factors, these impairments may hinder a child's full and effective participation in society on an equal basis with others. The term "children and young people with developmental disabilities" is therefore used as a shortened form of "children and young people with conditions affecting the developing nervous system – and causing impairments in motor, cognitive, language, behaviour and/or sensory functioning – and associated disabilities", terminology that is generally accepted in the field and perceived as non-stigmatizing. In this global report, the term "neurodevelopmental conditions" is used interchangeably with "developmental disabilities".

The underlying health conditions of children and young people with developmental disabilities are heterogeneous in terms of aetiology. What they have in common is that they all cause "early interference", impairment or injury to the developing nervous system during the prenatal period, infancy or childhood, which manifest as delays, regression or loss of developmental competency in motor, cognitive, communication, social or sensory domains. The underlying health conditions include autism, disorders of intellectual development and other conditions listed in the International Classification of Diseases, 11th Revision (ICD-11) (5) under neurodevelopmental disorders (see Box 1.1), and also a much broader group of congenital conditions (such as Down syndrome) or conditions acquired at birth (such as cerebral palsy) or during childhood (6). Annex 1 provides examples of developmental disabilities, their ICD-11 codes and examples of potentially associated limitations in functioning and participation. Developmental disabilities are sometimes described in subcategories according to the nature of the underlying health conditions: developmental disabilities related

to the nervous system, sensory developmental disabilities, metabolic developmental disabilities and degenerative developmental disabilities.

Box 1.1. Neurodevelopmental disorders

Neurodevelopmental disorders (5) are a subset of the larger group of conditions being referred to as “developmental disabilities”. In ICD-11, “neurodevelopmental disorders” are defined as behavioural and cognitive disorders that arise during the development period and result in significant difficulties in the acquisition and execution of specific intellectual, motor, language or social functions. The presumed aetiology of neurodevelopmental disorders is complex and in many cases is unknown.

The ICD-11 category of neurodevelopmental disorders includes the following diagnoses: disorders of intellectual development, developmental speech or language disorders, autism spectrum disorder (ASD), developmental learning disorder, developmental motor coordination disorder, attention deficit hyperactivity disorder (ADHD) and stereotyped movement disorder.

Wide variation is seen in how children and young people with developmental disabilities acquire developmental competences. Their cognitive and neurosensory profiles – i.e. how they learn, carry out daily activities and interact with their environments – vary widely. The diversity is influenced by genetic and biological factors; nurturing; interactions within the home, school and community; sociocultural, political and economic factors; and complex interactions among these internal and external factors. The severity of the impacts on day-to-day functioning also varies widely and evolves over time. Children are often limited in their opportunities for participating in society and usually experience disability throughout adulthood.

1.3 Frameworks and guiding concepts

Recent advances in advocacy, brain science, human rights, disability frameworks and positioning of disability and neurodevelopmental conditions in global development and public health agendas contribute approaches to optimizing the health and well-being of children and young people with developmental disabilities.

A human rights imperative

The health, well-being and participation of children and young people with developmental disabilities have been promoted in international legal documents in the sectors of both disability and child rights, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2) and the United Nations Convention on the Rights of the Child (UNCRC) (1). Yet, children and young people with developmental disabilities experience stigmatization, prejudice, institutionalization, barriers to participation and social, economic, educational and other forms of exclusion. Many of them grow up in conditions of poverty and scarce resources. Ecological instability and environmental threats, war, violence and other types of adversity influence children’s health. These conditions often have cumulative effects. Thus, the more intersecting adversities and layers of marginalization that a child or young person faces, the greater their risk of poor health and well-being.

The diverse human rights approaches to health, well-being and disability have the following tenets in common:

- recognition of the inherent right to respect for human dignity and diversity;
- ensuring non-discrimination and full, equitable participation for all in economic, social, political and other types of freedom;
- the entitlement of children to live with their families and to community inclusion;
- the entitlement of every person to the means necessary to develop and express their own potential;
- the right of children with disabilities to preserve their identities;
- the right to respect for physical and mental integrity; and
- ensuring that every person is autonomous and has the best opportunities to make their own decisions.

With respect to disability, human rights-based approaches include an assurance of the basic rights of all people according to their inherent human worth, rather than their productive value to society or the economy. Duty-bearers must reinforce and extend the protection necessary for groups who are marginalized or at risk of marginalization (7).

A biopsychosocial approach: addressing barriers and improving functioning and health

WHO's International Classification of Functioning, Disability and Health (ICF) (8, 9) recognizes that disability results not only from a person's impairments, but also from the interaction of those impairments with various societal, physical or environmental barriers that may prevent their full participation in society. When the ICF definition is applied to children and young people with developmental disabilities, it reveals the reality of the lived experience of impairment for children and their families and the difficulties individuals may face in carrying out activities. The ICF definition also draws attention to the role of physical or environmental barriers and their impact on the involvement of children and young people in meaningful tasks and participation in society. Improving the functioning and health outcomes of children and young people with developmental disabilities requires a whole-of-society approach, with attention to structural and attitudinal barriers and promotion of inclusive environments in the home, schools, communities and workplaces.

Ecological approach based on brain science: multi-layered actions embedded in the reality of children, young people and their families

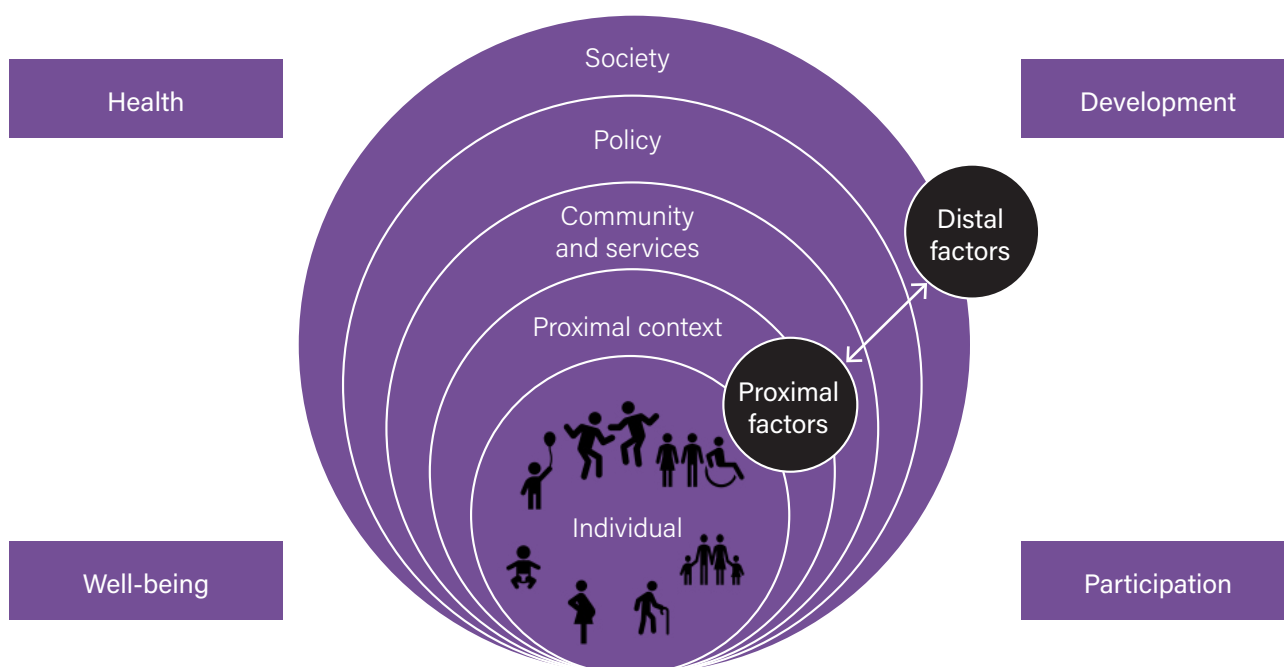
Evidence from neuroscience, genetics, developmental psychology and other fields demonstrates that human brain development is most malleable in the earliest periods of life, from conception until adolescence, and that development can be supported by promoting nurturing interactions within the child's environment. Individuals are most vulnerable to risk during early development, when

they can be set on individual optimal developmental trajectories. Biological, social, political and physical environments have enormous effects on human characteristics during the earliest, most rapid periods of development (10).

The same notion of brain plasticity and conditions of optimal development apply to children with developmental disabilities. In children with developmental disabilities the underlying health conditions are not fixed and finite conditions with unchangeable effects on developmental programming. On the contrary, a range of biological and environmental factors influence development and health trajectories. For optimal development, regardless of functioning, children and young people require certain "inputs" from their environment.

An ecological framework or model acknowledges the embedded nature of human development and demonstrates the various levels at which "inputs" can be made to development. It also recognizes that the relations between children and their environments are bidirectional; as much as an environment may influence a child, a child may influence their environment, particularly at the micro level. As children with developmental disabilities may face barriers in accessing nurturing interactions within families, communities and with peers, tailored responses, such as early interventions to enhance shared engagement and participation must be applied and be sustained during childhood, adolescence and the life-course. An ecological framework for considering children and young people with developmental disabilities situates individual development within concentric circles of influence radiating outwards, including family, community, institutions, policy and the environment (11) (Fig. 1.1).

Fig. 1.1. An ecological framework for considering children and young people with developmental disabilities



Life-course approach: sustained actions during childhood, adolescence and adulthood

Ecological approaches can be usefully augmented by a life-course approach to health, which acknowledges that individuals are exposed to different environments and influences that interplay in health and well-being as they age. There is also recognition that all stages of a person’s life are intricately intertwined with each other, as well as with past and future generations.

The life-course approach aims to ensure people’s well-being at all ages, by promoting healthy behaviours, ensuring access to health services, altering policies, environments and societal norms, and safeguarding the human right to health throughout their lifetime.

A life-course perspective on developmental disabilities means looking at how all the experiences throughout the life of a person with a developmental disability, from preconception onwards, can affect their development and well-being. This includes considering how different experiences interact with each other over time and providing support to individuals with disabilities and their families during major life transitions (12). This perspective goes beyond a single age group and considers the child or young person as an individual moving through

different developmental periods, each period being influenced by events in the preceding period, and each current period laying the foundation for the next phase of life.

A transdiagnostic approach to optimizing health, development, functioning and participation

The ICF provides a framework for understanding health outcomes “transdiagnostically”. In view of the heterogeneity of developmental profiles within diagnostic categories, the huge overlap among diagnoses and the role of environmental barriers, including stigmatization, a “functional”, “non-categorical” approach can be taken to optimizing the health and well-being of children and young people with developmental disabilities. This approach challenges service providers to identify developmental trajectories and targets for intervention to improve development, health, functioning and participation, irrespective of specific diagnosis (13).

Strength-based approaches in which diversity is valued

Some of the young people who are included in the group “young people with developmental disabilities” identify themselves as “neurodiverse”. Neurodiversity

reflects the idea that people experience and interact with the world around them in many different ways; there is no one “right” way of thinking, learning or behaving, and differences are not viewed as deficits. The approach is based on the premise that variation in neurodevelopmental profiles and functioning is inherent to the collective human experience. The word “neurodiversity” has been used in the context of ASD and other developmental conditions, such as ADHD and learning disabilities.

This perspective challenges the traditional classification of neurodevelopmental disorders, which focuses primarily on deficits, diseases and impairments. The neurodiversity movement emerged during the 1990s to increase the acceptance and inclusion of all people with their neurological differences and to promote self-advocacy. The perspective of neurodiversity can stimulate researchers, clinicians and policy-makers to use practices that fully embrace strengths-based and participatory approaches, address structures of exclusion and promote equality (14).

A public health approach centred in universal health coverage

The treatment and care gap for children with developmental disabilities demonstrates that universal health coverage is far from being achieved. Children and young people with developmental disabilities may have complex care needs and often have multiple concomitant conditions (15). While they represent a population that is more likely to use health care services, due to their underlying impairments, their higher risks of multiple or complex impairments and concomitant conditions often lead to exclusion or underserving. Children and young people with developmental disabilities experience significant barriers to accessing mainstream health care and specialized services. Because of this confluence of factors, they have poorer well-being and health-related quality of life than the general population, higher incidences of noncommunicable conditions such as obesity and diabetes, high rates of abuse of psychotropic medications and lower life expectancy (16, 17).

Even in well-resourced, high-income contexts, risks in the environment, barriers to participation and inclusion, including costs, inequitable access to care and unmet health-care needs, can work in synergy with impairments to the detriment of children and young people with developmental disabilities and their families. As most children and young people with developmental disabilities live in resource-limited or

low-income contexts, the impact on their quality of life and the lives of their caregivers can be considerable. Interventions that improve the health, well-being and functioning of children with developmental disabilities reduce the lifetime cost of care for them and should therefore be priorities (18, 19). Strong, inclusive public health systems could ensure that children and young people and their families have equitable access to health promotive, preventive and care services according to their needs and preferences, and are not driven into iterative cycles of poverty and risk for suboptimal health.

Sustainable, equitable strategies to prevent and treat coexisting health conditions and to promote development, well-being and functioning are central to achievement of this goal. The global public health commitments of universal access to health care will not be achieved without the full and meaningful inclusion of children and young people with developmental disabilities.

1.4 Landscape, commitments and context of the report

The UNCRPD (2) and the UNCRC (1) provide part of the legal framework which contributes to the policy changes that create the conditions for children and young people with developmental disabilities to enjoy optimal health and inclusion. Several resolutions of the World Health Assembly have been instrumental in focusing international attention on the long-neglected needs of persons with developmental disabilities and in solidifying countries’ commitments. They include the resolution on autism (WHA 67.8) (20), the WHO Comprehensive Mental Health Action Plan 2013–2030 (21) and the resolutions on disability and rehabilitation (WHA 58.23) (22), on the highest attainable standard of health of persons with disabilities (WHA 74.8) (23) and on epilepsy and other neurological conditions (WHA 73.10) (24).

Within the international child health agenda, the Global Strategy for Women’s, Children’s and Adolescent Health (25, 26) and the 2018 Nurturing Care Framework for Early Childhood Development: A framework for helping children survive and thrive to transform health and human potential (27) provide additional impetus to develop appropriate strategies for optimizing the health and development of children with developmental disabilities. Further, the agenda of the Global Strategy – survive, thrive and transform – situates the provision of child health care in the context of intersectoral social actions to promote enabling environments for young people.

The above commitments and strategies are situated in the context of the Sustainable Development Goals (SDGs), in which disability is a cross-cutting issue and early childhood development and mental health are priorities. The emphasis on inclusion of care for mental and neurological conditions in universal health coverage, also in the context of the COVID-19 pandemic, has set the stage for meaningful action to address pressing global challenges, including

developmental disabilities. The pledge to support early childhood development for inclusive education under SDG 4.2 is an important step for children with developmental disabilities to be accorded priority in the global development agenda till 2030 (28, 29). Such international attention provides promising opportunities for leveraging global work towards substantive changes in policies, practices and social norms.

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2. Developmental disabilities in focus

Developmental disabilities are common in children, as shown by the estimates cited in this chapter, which also provides a brief overview of the risks contributing to developmental disabilities and their programmatic implications. It is important to understand the circumstances of children and young people with developmental disabilities, and this chapter ends with an overview of the health inequalities faced by people with developmental disabilities.

2.1 Global prevalence of developmental disabilities

The prevalence of developmental disability can be estimated in various ways. In this chapter, data from three different methods are provided: epidemiological studies from the peer-reviewed literature, data from the Global Burden of Disease (GBD) Study of the Institute for Health Metrics and Evaluation (IHME) and data from the child functioning module of the multiple indicator cluster surveys (MICS) used by the United Nations Children's Fund (UNICEF). There are important limitations and complexities that need to be considered when describing the epidemiology of developmental disabilities. These are discussed in Box 2.1.

Epidemiological estimates of developmental disability from the peer-reviewed literature

Recent studies that provide estimates of the prevalence of developmental disabilities in geographically defined populations can help describe the status of knowledge about the epidemiology of these conditions. A review of peer-reviewed literature from January 2000 up to March 2021 identified 43 publications reporting on 129 surveys conducted in 1980–2018 and spanning 84 countries located across five continents (7–44). This review is strictly based on household surveys that report the frequency of developmental disabilities (broadly defined and not limited to a single disorder or type of disability) in populations. Additional details on the methods and findings of the review of peer-reviewed literature are provided in Annex 2.

The overall prevalence of developmental disabilities in children and adolescents ranges widely from one study to another, from < 3% to > 30%. Differences in

Box 2.1. Complexities and limitations in the epidemiology of developmental disabilities

Description of the global epidemiology of developmental disabilities is complicated by a number of considerations. These include: (i) the relations between incidence, prevalence, identification and survival; (ii) the multiplicity of health conditions included under the umbrella of developmental disability; (iii) the frequent overlap or co-occurrence of different types of developmental disability in individuals; (iv) the multidimensional nature of disability; and (v) variation and limitations of existing data sources and methods for estimating incidence and prevalence.

Incidence, prevalence, identification and survival. Most epidemiological studies of developmental disabilities involve estimates of prevalence; however, increases in the estimated prevalence of developmental disabilities may indicate better identification and/or be due to people with developmental conditions living longer. As such, the incidence of developmental disabilities may remain the same, but increases in detection or longevity will increase prevalence over time.

Umbrella category. Developmental disabilities cover a range of different conditions resulting from various underlying impairments and contributing factors. The major diagnostic categories or types of developmental disabilities are summarized in Table 2.1. The list is not exhaustive but conveys the wide range of conditions that fall into this broad category. Epidemiological studies of developmental disabilities apply different inclusion criteria to determine what conditions are considered under the umbrella category; hence comparability of prevalence estimates can be problematic.

Co-occurring conditions. Individuals with developmental disabilities often experience the co-occurrence of multiple disabling health conditions and multiple types of limitations in functioning. For example, studies have shown that the average frequency of epilepsy among individuals with intellectual disability is approximately 23%, which is more than 20 times the frequency in the general population (45). More than one third of children with intellectual disability have one or more co-occurring conditions, such as cerebral palsy, autism, epilepsy, hearing impairment or vision impairment (46–49). The co-occurrence of other conditions makes it difficult to define the total prevalence of developmental disability in specific populations, although certain analytical techniques are designed to overcome the difficulty.

Multidimensional nature of disability. For individuals with developmental disabilities, their levels of functioning are

often more important to them than medical classifications, such as diagnostic categories. Epidemiological studies of developmental disabilities, however, often focus on diagnostic categories and rarely provide information on the multiple ICF dimensions of disability, particularly the domains of participation and environmental and personal factors (50).

Data sources and methods of estimation. The availability and sources of data for estimating the prevalence of developmental disabilities vary widely by country. They include national surveys, administrative data from health-care systems and schools, registries, birth cohort studies and non-national cross-sectional studies. National surveys and administrative data are particularly useful for generating robust national, regional and global estimates of the prevalence of developmental disabilities (46, 48, 51). For example, since 2017, UNICEF’s MICS have included a module on child functioning (52–54), which provides a population-level estimate of the number and proportion of children with functional difficulties. The module is to be administered by the primary caregiver to children and adolescents aged 2–17 years and allows assessment of difficulties in various domains of functioning. For children aged 2–4 years, the domains measured are mobility, regulation of behaviour, hearing, communication and comprehension, playing, seeing, learning and fine motor skills. For children aged 5–17 years, the domains are self-care, memory, coping with change, anxiety, attention, concentration, relationships and affect; the category “playing” is not assessed. UNICEF’s MICS module on child functioning does not provide data for children under the age of 2 years, which limits capacity to assess the service needs for early childhood development interventions.

For most of the world’s population, particularly those living in low- and middle-income countries (LMICs), data for estimating the prevalence of developmental disabilities are extremely limited, resulting in major gaps in understanding the prevalence of developmental disabilities globally (55). The GBD study compensates for some of these data limitations by including modelling to estimate prevalence. The GBD also provides estimates of years lived with disabilities and disability-adjusted life years, which are based on a combination of the estimated prevalence of specific disorders and disability weights associated with those disorders (56, 57). Although there is concern about data limitations in the GBD datasets and about the validity of disability weights, these data provide estimates that can be used for advocacy and are often the only estimates of prevalence globally and for many of the world’s regions.

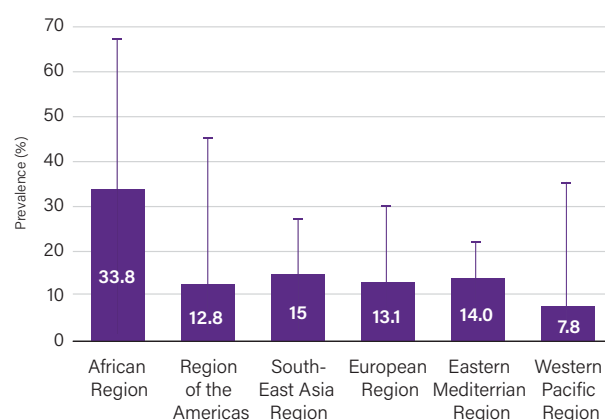
age groups, data collection methods, operational definition for developmental disabilities and choice of assessment tools can help explain the wide range in estimates. When considering the studies that reported prevalence for a broad age span, including both younger children and adolescents, the median of prevalence estimates is 7.2% (ranging from 2.0% to 25.0%). The prevalence is higher among children (< 10 years), at 18.3% (ranging from 0.9% to 67.3%). Only two studies provide prevalence estimates specifically for adolescents (age range: 14–18 years), with prevalence estimates of 3.2% and 12.8% respectively.

Developmental disabilities are more prevalent among boys than girls, with a median male-to-female prevalence ratio of 1.5 (range 0.9–2.0).

There are wider variations in prevalence within than between regions. Fig. 2.1 shows the estimated prevalence of developmental disabilities in children and adolescents in the six WHO regions, as reported in the peer-reviewed literature (1–44).

The median of prevalence estimates of developmental disabilities in children and adolescents identified from review of peer-reviewed literature across WHO regions varies from 7.8% (ranging from 1.6% to 35.2%) in the Western Pacific Region to 12.8% (ranging from 1.5% to 44.0%) in the Region of the Americas, 13.1% (ranging from 3.0% to 30.0%) in the European Region, 14.0% (ranging from 8.4% to 21.0%) in the Eastern Mediterranean Region, 15.0% (ranging from 0.8% to 27.3%) in the South-East Asia region and 33.8% (ranging from 0.9% to 67.3%) in the African Region.

Fig. 2.1. Estimated median prevalence (and range) of developmental disabilities in children and adolescents in the six WHO regions, based on the peer-reviewed literature



The substantial heterogeneity in criteria and methods used to estimate prevalence of developmental disabilities across studies and the limited geographic coverage of data are important limitations for regional and global estimates of the prevalence of developmental disabilities in children based on reviews of peer-reviewed literature. An umbrella review of systematic reviews and meta-analyses of specific developmental disabilities based on the ICD codes showed prevalence estimates ranging from approximately 0.2–0.3% for cerebral palsy to approximately 13% for sensory impairments (58).

Epidemiological estimates of developmental disability from the Global Burden of Disease (GBD) study

While individual prevalence studies and peer-reviewed meta-analyses provide one set of estimates of prevalence, the IHME uses data synthesis and

mathematical modelling to produce GBD estimates of the prevalence of specific conditions by age group, gender and location, prevalence being defined as the total number of cases in the population (Global Health Data Exchange database). Further details of the data sources and modelling strategy can be found in a publication describing the 2019 GBD Study (59). For this global report, GBD researchers computed prevalence estimates with multiplicative equations that assume independent probabilities of the co-occurrence of specific conditions that contribute to developmental disability in childhood. Table 2.1 provides the conditions which were chosen by experts as best representing the WHO case definition for “conditions contributing to developmental disabilities”.

Fig. 2.2 shows the global prevalence of conditions that contribute to developmental disability by gender and age group, for 2019. Overall, the prevalence of these conditions ranged from 7.5% among children

Table 2.1. Conditions included in the category of “conditions contributing to developmental disabilities” for the purpose of calculating prevalence estimates based on 2019 GBD data

Category	Condition
Congenital	Congenital birth defects
	Down syndrome
	Klinefelter syndrome
	Neural tube defects
	Other chromosomal abnormalities
Infectious diseases that affect the brain	Cysticercosis
	Encephalitis
	Malaria
	Meningitis
	Rabies
	Syphilis
	Tetanus
Zika virus disease	
Neonatal	Haemolytic disease and other neonatal jaundice
	Neonatal encephalopathy due to birth asphyxia and trauma
	Neonatal preterm birth
Neurodevelopmental	ADHD
	ASD
	Cerebral palsy
	Epilepsy
	Fetal alcohol syndrome
	Idiopathic developmental intellectual disability
Injuries	Spinal cord injuries
	Traumatic brain injuries
Sensory disorders	Hearing loss
	Vision loss

Fig. 2.2. Global prevalence of conditions that contribute to developmental disability based on 2019 GBD data, by gender and age group

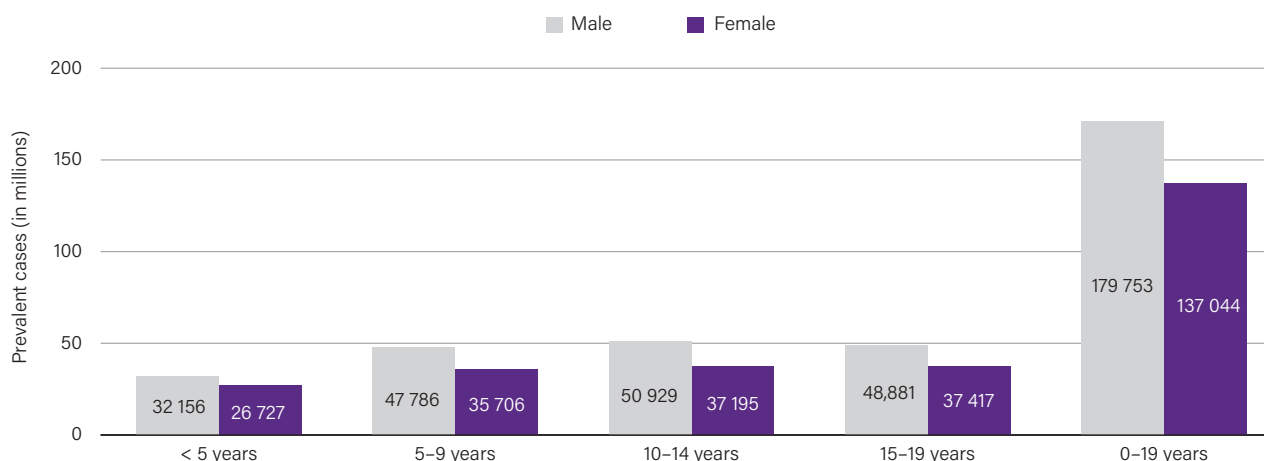


Table 2.2. Prevalence (%) of conditions that contribute to developmental disability, by age group, based on 2019 GBD data

Condition category	Under 5 years	5 to 9 years	10 to 14 years	15 to 19 years
Congenital	0.9%	0.3%	0.3%	0.3%
Infectious diseases	0.1%	0.2%	0.2%	0.2%
Injuries	0.02%	0.1%	0.2%	0.3%
Neonatal conditions	1.4%	1.0%	1.0%	1.0%
Neuro- developmental	4.1%	6.3%	7.0%	6.3%
Sensory disorders	1.3%	5.4%	5.8%	6.6%

under 5 years to 13.9% for those aged 15–19 years. The prevalence among males ranged from 7.9% (< 5 years) to 15.4% (15–19 years) and that among females from 7.1% (< 5 years) to 12.4% (15–19 years).

In 2019, there were 316.8 million cases of developmental conditions in children and adolescents globally. The number of prevalent cases was higher for males (179.7 million) than for females (137 million). Among males, the number of prevalent cases ranged from 32.2 million (< 5 years) to 50.9 million (10–14 years) and 48.8 million (15–19 years). For females, the numbers ranged from 26.7 million (< 5 years) to 37.4 million (15–19 years).

Table 2.2 lists the prevalence of conditions that contribute to developmental disability by six broad categories and age groups. Neurodevelopmental condi-

tions accounted for the highest estimated prevalence in children < 15 years of age, ranging from 4.1% (< 5 years) to 7.0% (10–14 years). Sensory disorders associated with impairment of the nervous system, including vision and hearing loss, also accounted for some of the higher estimates in children aged \geq 5 years.

Fig. 2.3 shows the estimates for the five most prevalent conditions among those that contribute to developmental disabilities: hearing loss, idiopathic developmental intellectual disability, ADHD, cerebral palsy and vision loss. The prevalence of hearing loss ranged from 0.7% (< 5 years) to 5.3% (15–19 years). The prevalence of idiopathic developmental intellectual disability was the highest for 5–9-year-olds, at 2.0%, and for 10–14-year-olds, also at 2.0%. The prevalence of ADHD ranged from 0.2% (< 5 years) to 2.3% (15–19 years). The prevalence

of ADHD was highest for 10–14-year-olds, at 2.9%. The prevalence of cerebral palsy was highest in the 0–5-year age group at 1.6% and lowest in the 15–19 age group at 1.9%. The prevalence of vision loss ranged from 0.5% (< 5 years) to 1.5% (15–19 years). The data used to draw Fig. 2.3 and disaggregated for males and females are provided in Annex 3.

The GBD study 2019 (59) provides data on prevalence by World Bank income group for certain conditions that contribute to developmental disability. The prevalence of four neurodevelopmental and congenital conditions is shown in Table 2.3 by income group. The prevalence of ADHD, ASD and Down syndrome was higher in high- and upper-middle-income countries than in lower-income countries, whereas the prevalence of idiopathic developmental intellectual disability was higher in lower-middle-

income and low-income countries than in higher-income countries. While data on these conditions disaggregated by World Bank income group are useful, it should be noted that the estimates are based mainly on data sources in high-income countries because of the lack of sufficient data from middle- and low-income countries (55).

Table 2.4 shows the prevalence of conditions that contribute to developmental disabilities by WHO region, gender and age group, based on the 2019 GBD study. The prevalence is reported to be highest in the South-East Asia Region (14.8%) and lowest in the European Region (5.1%). The prevalence is higher in males than females in all regions and age groups. For both males and females, the prevalence of developmental disabilities is higher in older than younger age groups.

Fig. 2.3. Prevalence of selected conditions that contribute to developmental disability, by age group, based on 2019 GBD data

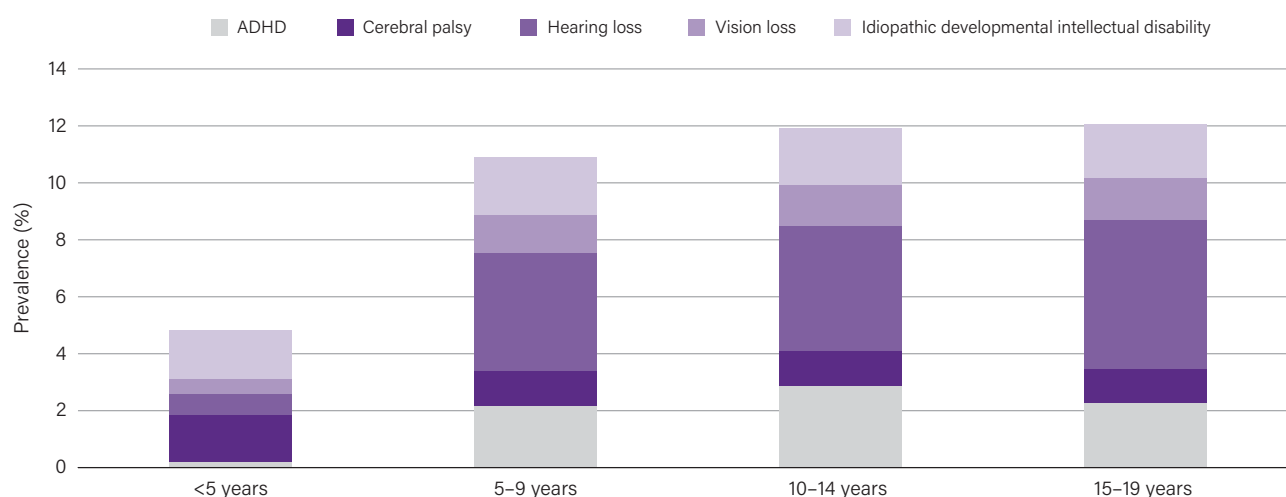


Table 2.3. Prevalence of selected conditions by World Bank 2019 income group¹ based on 2019 GBD data

Conditions	World Bank high-income	World Bank upper-middle-income	World Bank lower-middle-income	World Bank Low-income	Global
ADHD	2.8%	2.8%	1.3%	1.0%	1.8%
ASD	0.6%	0.4%	0.4%	0.4%	0.4%
Down syndrome	0.1%	0.0%	0.0%	0.0%	0.0%
Idiopathic developmental intellectual disability	0.4%	0.6%	3.2%	1.6%	2.0%

¹ Prevalence estimates for select conditions available in the GBD database by World Bank income group are reported here. These prevalence estimates are generated using UN World Population Prospects (WPP) 2019 population weights, available here: <https://population.un.org/wpp/Download/Standard/Population/>

Table 2.4. Prevalence of conditions that contribute to developmental disabilities by WHO region, gender and age group (0–19 years),² based on 2019 GBD data

WHO Region		< 5 years	5–9 years	10–14 years	15–19 years	0–19 years
African Region						
Both		8.6%	12.1%	13.1%	13.6%	11.6%
Female		8.2%	10.9%	11.8%	12.6%	10.6%
Male		9.1%	13.2%	14.3%	14.6%	12.5%
Region of the Americas						
Both		5.0%	8.5%	9.4%	9.6%	8.1%
Female		4.7%	7.4%	8.2%	8.6%	7.2%
Male		5.3%	9.5%	10.6%	10.5%	9.0%
South-East Asia Region						
Both		11.3%	15.2%	16.2%	16.6%	14.9%
Female		11.0%	14.2%	15.0%	15.6%	14.0%
Male		11.6%	16.2%	17.3%	17.4%	15.7%
European Region						
Both		3.4%	5.3%	5.8%	5.9%	5.1%
Female		3.1%	4.6%	4.9%	5.1%	4.4%
Male		3.7%	6.0%	6.6%	6.7%	5.7%
Eastern Mediterranean Region						
Both		9.3%	12.7%	14.1%	14.0%	12.4%
Female		8.6%	11.2%	12.3%	12.5%	11.0%
Male		10.0%	14.1%	15.9%	15.5%	13.7%
Western Pacific Region						
Both		6.3%	10.3%	11.4%	11.6%	9.9%
Female		5.6%	8.3%	9.0%	9.7%	8.2%
Male		6.9%	12.1%	13.5%	13.4%	11.5%

2 Prevalence estimates are produced using UN WPP 2019 population weights for each age and gender group available. These are available here: <https://population.un.org/wpp/Download/Standard/Population/>

Data from the MICS child functioning module

While most efforts to estimate the proportion of children and young people with developmental disabilities are based on the prevalence of specific conditions, an alternative approach is to use estimates of the prevalence of types of difficulties in functioning. The MICS child functioning module can be used to assess children's functioning in a range of domains in large population surveys. Global estimates of the prevalence of difficulties in functioning among children from MICS and other health surveys, most since 2017, indicate that 240 million children between the ages of 0 and 17 years, or one in 10 children, have a disability (15).

Figs 2.4 and 2.5 show that the most frequent functional difficulties depend on the age group; however, psychosocial difficulties predominate at all ages.

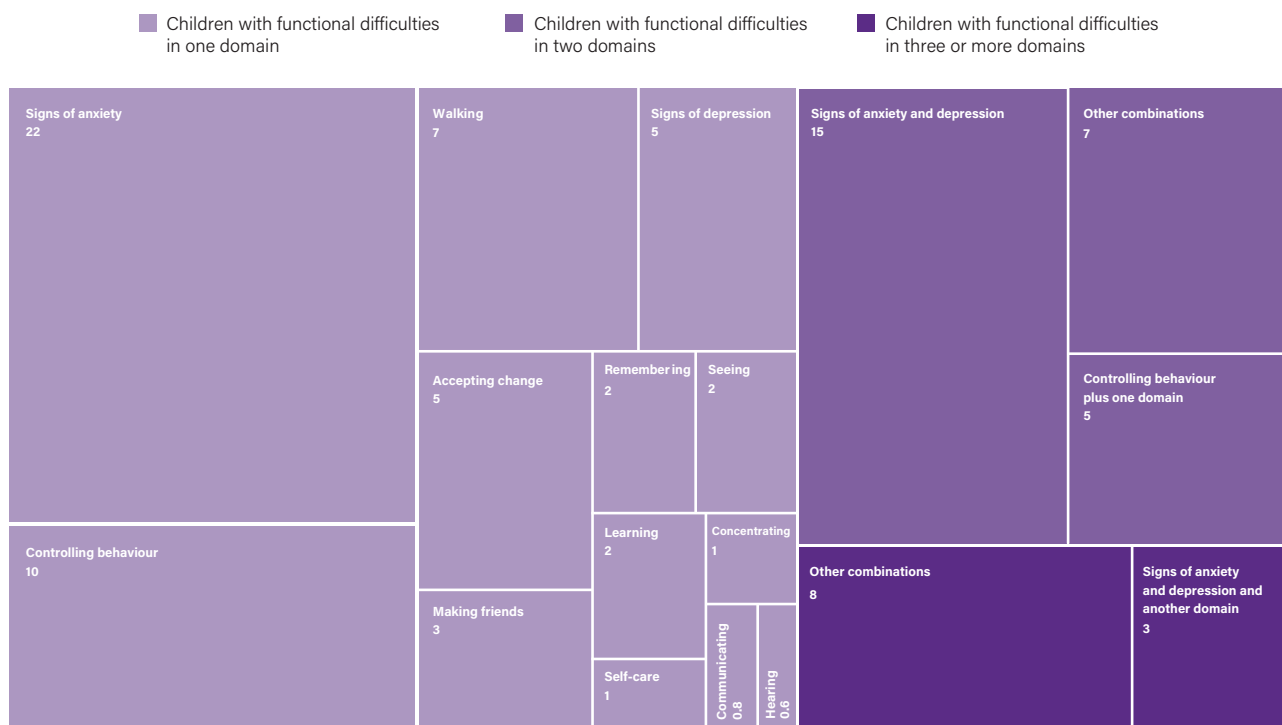
Difficulty in regulating behaviour, learning and communicating are most common for children aged 2–4, and anxiety, depression and difficulty in regulating behaviour predominate among children aged 5–17. A significant proportion of children have functional difficulties in more than one domain, and the proportion increases with age.

Fig. 2.4. Proportions of children aged 2–4 years with functional difficulties



Source: Adapted from *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. New York City (NY): United Nations Children's Fund; 2021.

Fig. 2.5. Proportions of children aged 5–17 years with functional difficulties



Source: Adapted from *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. New York City (NY): United Nations Children's Fund; 2021.

None of the approaches to estimating the prevalence of developmental disabilities in children is perfect. Limitations in methods and concerns about modelling approaches have been described before (59). In addition, none of the methods covers the entire population of children with developmental disabilities: children with milder functional difficulties are being missed in MICS child functioning module surveys, while the GBD study does not provide estimates for some of the health conditions contributing to developmental disabilities.

Different methods provide data that are complementary. The MICS child functioning module data are intended to help understand the prevalence of moderate to severe functional difficulties that, in interaction with various barriers, can place children at increased risk for health inequities. The UNICEF MICS data also provide an opportunity to describe differences in health outcomes and in access to opportunities for children with functional difficulties when compared with other children. However, these estimates are not intended to provide information on the health conditions that contribute to functional difficulties. In contrast, the GBD modelling approach estimates and projects the long-term sequelae associated with diverse but overlapping diagnostic entities. This information can be used to understand health-care needs.

While efforts to continue to improve methods for describing the epidemiology of developmental disabilities are important, the evidence from the available data sources unarguably demonstrates that developmental disabilities are common among children and adolescents, and that public health approaches to equalizing health outcomes in this population should be a priority within the SDG 2030 agenda.

2.2 Risk and protective factors for developmental disabilities

The health conditions that contribute to developmental disabilities are heterogeneous. For some, the causal pathway is known, while for others it remains largely unknown. Genetic and environmental factors can disrupt brain development. Epigenetic mechanisms regulate diverse aspects of neuronal development and can act as an interface between external stimuli and the genome (60).

Many genetic factors have been found to be related to brain structure and to have impacts on the domains of brain functioning. Genetic factors are

also implicated in several congenital syndromes that are frequently associated with cognitive, behavioural or neurological disorders, such as Down syndrome, fragile X syndrome, Rett syndrome and Prader-Willi syndrome, among others. On the other hand, some conditions, such as autism, have a multi-factorial origin, genetic risk playing a role. In these cases, while genetic links have been identified, the disorders are likely caused by interactions between certain genetic profiles and the person's environment leading to epigenetic changes, i.e. changes in gene expression or other forms of effect modification. In this section, only social and environmental risk and protective factors that are potentially amenable to public health interventions are discussed.

Animal, human cell and epidemiological studies suggest that a wide range of environmental risks impact neurodevelopment (61–75).

Risk and protective factors for developmental disabilities have been categorized in a variety of ways: by the timing of exposure (e.g. prenatal, infancy, adolescence), by the nature of exposure (e.g. environmental toxins, nutrition, child poverty) and by the nature or closeness of the link between exposure and adverse health outcomes (e.g. distal or upstream causes vs proximal or downstream causes). For example, exposure to poverty during childhood is widely considered to be an upstream determinant of poorer developmental and brain health (74, 75). The impact of poverty on child development and brain health is, however, largely mediated through a number of downstream pathways, including, for example, less than optimal home environments, poor nutrition and an increased risk of exposure to environmental toxins. While none of these downstream pathways is unique to children living in poverty, they are often associated with poverty.

This section addresses upstream or distal risk factors (sometimes referred to as the “causes of the causes”) and also downstream risk factors, which are important at various stages of the child's development. Protective factors are then described.

Upstream risk factors

All societies have hierarchies of power and prestige. While the specific factors that contribute to hierarchies differ from one country to another, common factors include wealth, birthright, gender, ethnicity, religion, education, disability and migration status. Socioeconomic position is a concept for describing and measuring the extent of hierarchies from indicators

such as income, consumption, wealth, educational attainment and occupational status. A very low socioeconomic position is typically associated with economic and multidimensional poverty. Differences in socioeconomic position shape brain development through differential exposure to a wide range of downstream social and environmental determinants of developmental and brain health. Variations in socioeconomic position are also associated with differential risks of a child for acquiring some of the health conditions (and associated functional impairments) that are included under the umbrella term “developmental disabilities”. Nevertheless, the strength of these associations varies considerably by the health conditions and impairments associated with developmental disabilities.

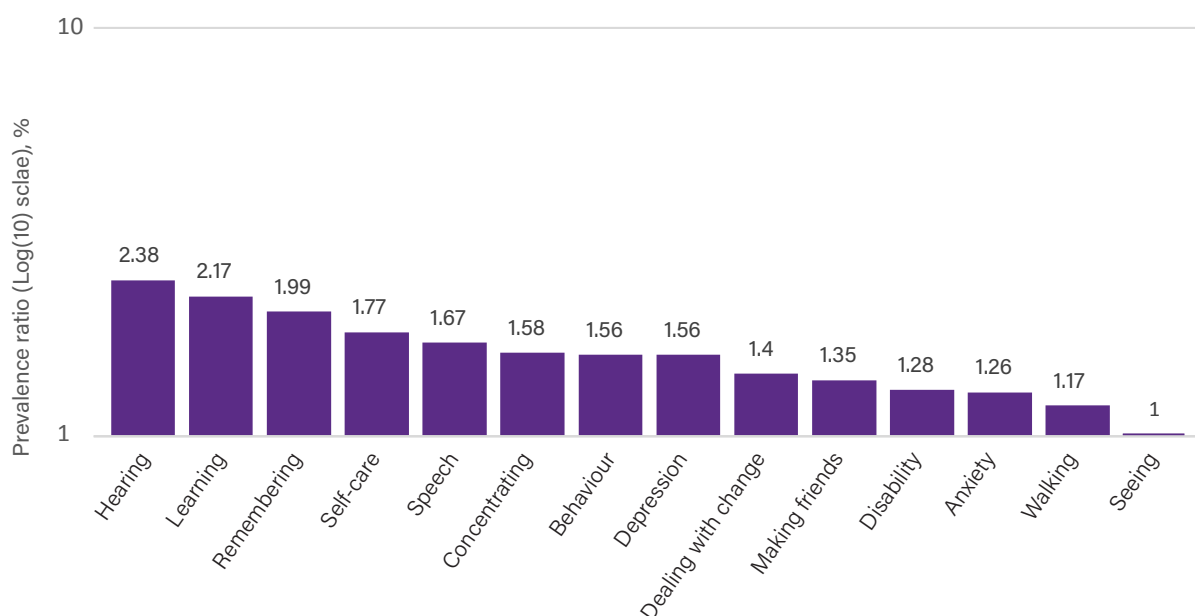
For example, extensive evidence indicates that lower household wealth and low maternal education are strongly associated with the risk of intellectual disability (and functional impairment in learning) among their children. Low maternal education was identified as the second most important factor (after access to improved water and sanitation) in the risk of significant cognitive delay in Bangladesh (76) and among 3–4-year-old children in a study of 51 LMICs (77). In contrast, evidence of an association between

lower household wealth and low maternal education and the risk of ASD has been more mixed (78–81). Fig. 2.6 illustrates the association between within-country variations in household wealth and the risk of functional impairment among 5–17-year-old children in 40 LMICs. The results ranged from no additional risk (adjusted relative risk of 1.0 for vision) to a doubled or greater risk for remembering, learning and hearing (82).

Different aspects of socioeconomic position may be related to different downstream risk factors. Poverty and low parental education have been clearly linked to factors such as poorer nutrition, poorer housing conditions, less optimal parenting practices and health-related behaviours, and poorer access to health and supportive interventions. Minority ethnic status, indigeneity and immigrant status may be particularly closely related to reduced access to health and supportive interventions, including for prenatal and perinatal care. Parental disability related to mental health without essential supports may result in less than optimal parenting.

Opportunities for mitigating risks related to upstream determinants include policy and programming to address the social determinants of health that adversely affect child development, including poverty,

Fig. 2.6. Adjusted relative risk for impairment among 5–17-year-old children living in the 20% poorest households as compared with those living in the 20% richest households in 40 LMICs



Source: Emerson et al & Llewellyn et al, 2022 (82).

gender norms, women's education and employment. The right care for children should start before birth and continue throughout childhood to ensure that the child's brain grows well and reaches its full potential. Policies and health insurance schemes should ensure universal health coverage for all pregnant women, mothers and children. During the preconception period, counselling on maternal and child nutrition, maternal mental health and parenting can contribute to reducing inequalities in exposure to risks and optimize developmental trajectories. The term "nurturing care" is a fundamental principle of what is necessary to achieve optimal child development and brain health. Nurturing care is characterized by a safe and stable environment that promotes healthy, optimal nutrition, protects children from threats and gives them opportunities for early learning through affectionate interactions and relationships (83). Nurturing care includes responsive caregiving, in which parents or other caregivers participate in joint activities with their young children such as smiling, touching, talking, storytelling, listening to music, sharing, reading books and engaging in play (83). These activities help to foster neural connections that strengthen the development of the child's brain. The promotion and protection of maternal and caregivers' mental health is an important component of promoting nurturing care. Nurturing care can help mitigate the impact of socioeconomic determinants and early adversities on children's development trajectories (84). It is important to improve evidence on implementation approaches for promoting nurturing care for children with developmental disabilities (85).

Downstream risk factors

Preconception, prenatal and at birth

Risk factors that occur before birth that are associated with an increased risk of health conditions that affect the developing nervous system and cause impairments in motor, cognitive, language, behaviour and/or sensory functioning include (86–88):

- poor maternal nutrition, including micronutrient deficiencies in iron, folic acid and iodine;
- chronic hypoxia in utero;
- maternal hypotension and thyroid disease;
- infection (e.g. toxoplasmosis; infection with group B streptococcus, rubella, cytomegalovirus, herpes simplex virus or Zika virus; and sexually transmitted infections);
- maternal substance use during pregnancy, including use of alcohol;

- parental consanguinity, which increases the risk of genetic disorders in their offspring, most commonly major congenital conditions and inborn errors of metabolism; and
- parental age.

Some of these factors can lead to fetal or intrauterine growth restriction, preterm delivery and perinatal asphyxia.

Risk factors that occur at or close to birth include:

- pre-term birth, especially extremely premature birth (< 28 weeks);
- low birthweight, especially < 1500 grams; and
- hypoxic ischaemic encephalopathy, which involves a relatively brief loss of oxygen and nutrients at or near the time of birth.

As an example, low birthweight and perinatal hypoxia, respiratory stress and gestational diabetes have been reported to be associated with a diagnosis of ASD, while low birthweight and preterm birth are associated with ADHD, cerebral palsy and seizure disorders (90).

Means to mitigate prenatal and birth-related risks include the provision of counselling on nutrition for caregivers; micronutrient supplementation during preconception and pregnancy (91); access to antenatal and postnatal care and assisted delivery; implementation of evidence-based guidelines for the management of pre- and postnatal conditions such as intrauterine growth restriction and hypoxic ischaemic encephalopathy, infections (including HIV and malaria), maternal vaccination and prevention of substance use during pregnancy. Use of alcohol, illicit drugs and other psychoactive substances predisposes both the developing child and the mother to health and social problems during pregnancy. As substance use affects the developing brain of the child, ensuring the prevention, reduction or ceasing of alcohol or drug use during pregnancy is essential. Access to prevention and treatment services and comprehensive care helps pregnant and breastfeeding women to learn about the effects of substance use (92). Ensuring multiple micronutrient supplementation during pregnancy promotes positive brain health from conception and a positive pregnancy experience (93). General performance in intellectual tests and in aspects of executive and motor function among 7–9-year-old children has been found to be better among those whose mothers had received prenatal iron and folic acid supplementation than in controls (94). In

addition, supplementation with iodine, iron and folic acid reduced the frequency of low birthweight and small-for-gestational-age, which are high-risk factors for developmental disabilities (95–97). Recommended dietary interventions for pregnant women include: (i) daily oral iron and folic acid supplementation with 30 mg to 60 mg of elemental iron and 400 mcg (0.4 mg) of folic acid to prevent maternal anaemia, puerperal sepsis, low birthweight and preterm birth; (ii) for undernourished populations, nutrition education on increasing daily energy and protein intake to reduce the risk of low-birthweight neonates; and (iii) balanced energy and protein supplementation to reduce the risk of stillbirths and small-for-gestational-age neonates (98). Antenatal multiple micronutrient supplements that include iron and folic acid are recommended on the basis of rigorous research (93).

Other public health programmes and policies, such as genetic screening programmes, may be available during pregnancy, during the newborn period or in early adult life before marriage or conception and preconception. Premarital counselling on risks related to age and consanguinity should be available, as should proper education and training of health-care providers in the health and social issues related to consanguinity in highly consanguineous populations.

Childhood

Risk factors occurring in early childhood that are associated with negative effects on development and increased risks of health conditions that affect the developing nervous system and cause impairments in motor, cognitive, language, behaviour and/or sensory functioning include:

- nutrition, including early-life undernutrition and specific deficiencies in iron, iodine, vitamin A and other vitamins;
- little stimulation, at home and in child-care institutions;
- neurotoxic exposures, especially to lead and mercury;
- injuries, including those associated with violence, child abuse, hazardous child labour and road traffic collisions; and
- infections, including bacterial meningitis, severe malarial anaemia, cerebral malaria, congenital rubella and HIV/AIDS.

Means to mitigate risks in early childhood include initiatives to improve gender equity and girls' access to early learning and education, promotion of parenting skills and psychosocial support for

women of reproductive age. Means to mitigate risks related to environmental health include limiting heavy metals such as cadmium, lead and mercury in the environment. Minimizing exposure to lead by, for instance, eliminating old lead paints and inhalation exposure (99) can prevent lead poisoning and neurodevelopmental impairment in children (100).

Means to mitigate risks related to factors in later childhood include initiatives to improve road traffic safety and reduce exposure to violence and infections.

2.3 Health inequities

Extensive evidence from high-income countries shows that children with intellectual disability have a shorter life expectancy (101–105). Children with developmental disabilities are more likely to have poorer health than their peers (106–110). Some differences in health status appear to be associated with the biological basis of the health condition (e.g. congenital cardiac defects and early-onset dementia in people with Down syndrome). Some of the differences are, however, due to the increased risk of exposure of children with developmental disabilities to well-established social determinants of poorer health and well-being, such as poverty, social exclusion, violence and discrimination, including systemic discrimination in educational and health systems (107, 111, 112), and are therefore unjust, unfair and partly avoidable. Children with developmental disabilities often have poorer access to health promotion, health care and education, and higher rates of exposure to stigmatization, than children without developmental disabilities (113–117). Inequality in health and other domains is the result of social, economic, cultural and institutional factors. Moreover, multiple layers of disadvantage can intersect, so that some children with developmental disabilities are worse off than others. These include their country's income, their family's socioeconomic status and their racial and ethnic background, which intersect with their disability to either mitigate or amplify exclusion.

People with developmental disabilities are more likely to have obesity, diabetes, heart and respiratory diseases and mental health conditions (118–121). For example, children with ASD are 1.4 more at risk of developing obesity and adolescents with intellectual disabilities are 1.8 times more at risk of obesity when compared to their peers (119, 120). Children, young people and adults with developmental disabilities have a higher risk of premature death (122, 123). In a cohort of 306 children with epilepsy or cognitive, vision, hearing or motor impairments identified from a

baseline screening of 10 218 children aged 6–9 years in rural Kenya, mortality rates were three to four times higher than controls (124). A longitudinal population-based study in rural eastern Uganda reported an excessively high risk of premature death in children with cerebral palsy, especially in those with severe motor impairments or malnutrition (125). Children with intellectual disabilities have significantly higher rates of avoidable, treatable and preventable mortality when compared with the general population (126–129). The most common underlying, avoidable causes of mortality include epilepsy, choking and respiratory infections (129). Injuries are also associated with increased risk of mortality in persons with autism and in persons with ADHD (121, 128).

The UNICEF report *Seen, counted, included* (130) outlines some of the inequalities experienced by children with disabilities in the domains of health, nurturing family environment, education and learning, exposure to violence and exploitation, environmental cleanliness and safety, poverty, and inequality and discrimination. Compared with children without disabilities, children with developmental disabilities are:

- 34% more likely to be stunted or underweight and 53% more likely to have symptoms of acute respiratory infection;
- 51% more likely to consider themselves unhappy and 41% more likely to feel discriminated against;
- less likely to have had their birth registered, especially for children with disabilities in the poorest households;
- less likely to have received basic vaccinations against vaccine-preventable childhood illnesses when they have multiple functional difficulties;
- more likely to have poorer access to basic drinking water, sanitation and hygiene services;
- 25% less likely to receive early stimulation and responsive care, less likely to receive adequate supervision and less likely to have access to books and toys;
- 25% less likely to access early childhood education and 47% more likely to be out of primary school: children with multiple and severe disabilities are most likely to be out of school, while children of lower-secondary school age who have difficulty in caring for themselves, communicating and concentrating are up to four times more likely to be out of school; and
- 32% more likely to be exposed to violent discipline at home and to participate in child labour.

Overall, children with disabilities experience more types of deprivation and are more likely to experience

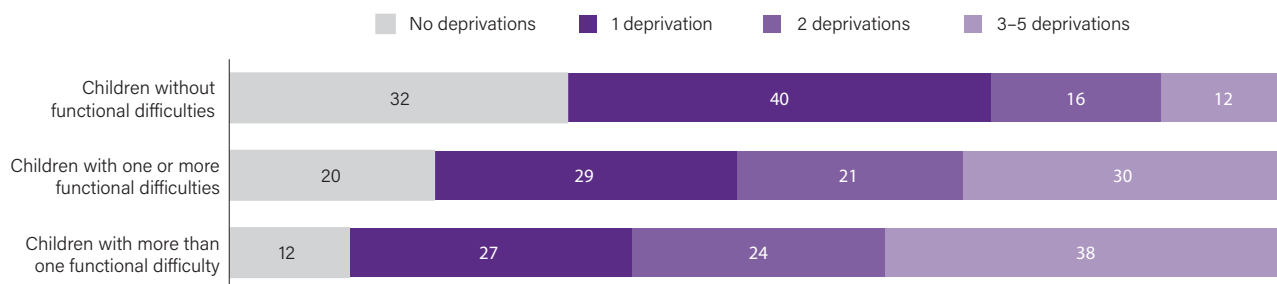
multidimensional poverty than children without disabilities (Figs 2.7–2.9).

The inequalities experienced by children with developmental disabilities outlined by UNICEF (130) have also been reported in research studies across the globe (131). Caregivers of children with developmental disabilities also have greater difficulty in accessing and navigating the health-care system, which leads to more unmet health-care needs for these children (132). The difficulty of caregivers is exacerbated when they are poor and part of minority groups (132). Inequality affects the overall health outcomes of children with developmental disabilities, who are more likely to be exposed to violence, discrimination and child labour than their peers (132–135). Furthermore, the experiences of children with developmental disabilities in LMICs are often accompanied by inequity in access to resources. Belonging to a minority ethnic group increases the divide between developmental disability and equitable access to health care (134, 136).

Globally, individuals with developmental disabilities have unmet health-care needs due to weak, fragmented health-care systems, particularly in LMICs where access to health care is low or non-existent. Different patterns of use of health care by children with developmental disabilities may also reflect disability-related inequality driven by social, economic, physical and stigmatizing barriers. Inequality in health care presents a challenge for individuals with developmental disabilities who have more health-care needs (137).

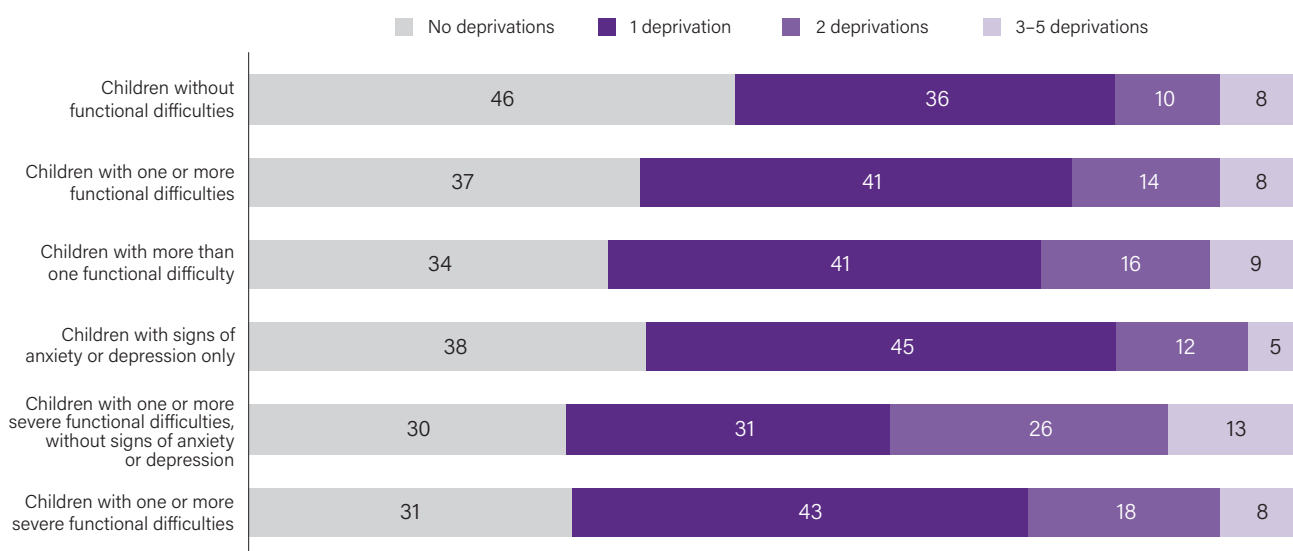
Inequities became more apparent during the COVID-19 pandemic, when persons with developmental disabilities appeared to be more vulnerable to the direct and indirect effects of the pandemic (138–142). People with developmental disabilities had a higher risk for COVID-19 infection, hospitalization, stays in an intensive care unit and death compared with the general population (143–147). Children and adolescents with autism experienced more symptoms of depression and anxiety compared with other children (148). Moreover, parental stress was far greater due to restrictions, changes in routines and worries about their child's health vulnerabilities. This led to caregivers of children with ASD experiencing increased levels of depression and anxiety when compared with other caregivers and with the pre-pandemic context (149). Carers of children with developmental disabilities had significantly greater levels of feelings of defeat/entrapment, anxiety and depression (150). Yet,

Fig. 2.7. Proportions (%) of children aged 2-4 years who live in multidimensional poverty



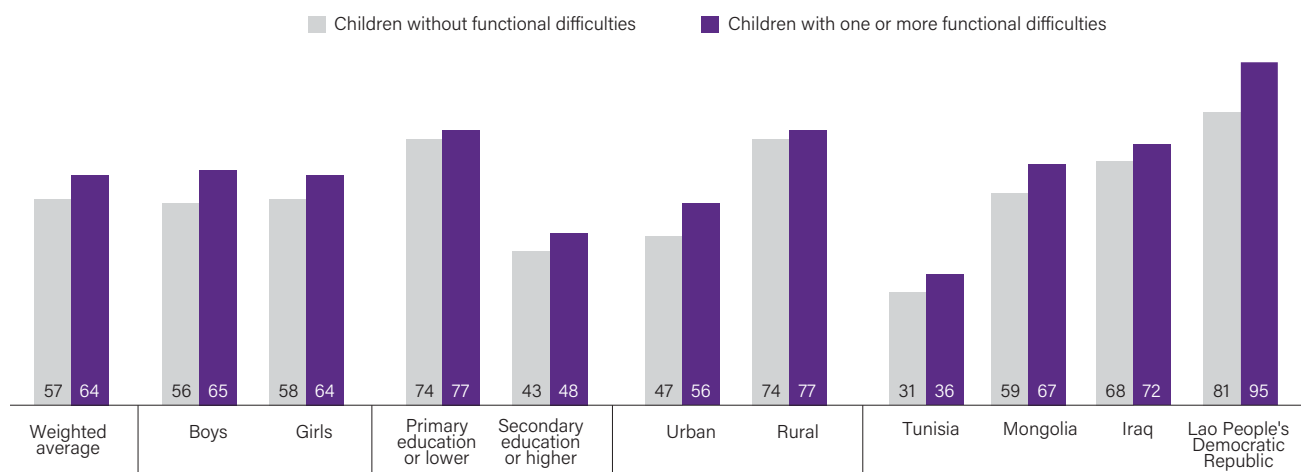
Source: Adapted from *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. New York City (NY): United Nations Children's Fund; 2021.

Fig. 2.8. Proportions (%) of children aged 5-17 years who live in multidimensional poverty



Source: Adapted from *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. New York City (NY): United Nations Children's Fund; 2021.

Fig. 2.9. Proportions (%) of children aged 2-17 years who live in moderate multidimensional poverty



Source: Adapted from *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. New York City (NY): United Nations Children's Fund; 2021.

despite their greater mental health needs, carers of those with developmental disabilities received less social support from a variety of sources than other caregivers (140).

2.4 Implications for action

Developmental disabilities are common: global estimates tell us that 316.8 million children and adolescents experience a health condition contributing to developmental disability, and that one in 10 children has a moderate to severe functional difficulty.

For children and adolescents with developmental disabilities the risk of being exposed early in life to a range of experiences that have negative impacts on health trajectories is significant. These adverse experiences may include poverty, violence, stigma and discrimination, malnutrition and barriers to accessing early learning and health care.

With 7.5% of children under five years estimated to have a developmental disability, there is an opportunity to act early and address barriers that prevent them from accessing opportunities to thrive.

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3. Beyond commitments: implementing legal and policy changes

3.1 Introduction

Optimizing development and health trajectories for children and young people with developmental disabilities requires a societal approach, with the appropriate legal and policy frameworks and financial investments.

The lives of children and young people with developmental disabilities are deeply influenced by their environment. Social determinants and exposure to adversity at home, at school and in their community affect children's development and well-being and the onset of secondary health conditions. Disability results from the interaction between a person with a health condition, such as cerebral palsy, and that person's contextual factors (environmental factors and personal factors) including societal attitudes, access to infrastructure and discriminatory policies (1). Physical, sociocultural and economic barriers influence access to health services, education and support and children's opportunities for participation. Children with disabilities, including those with developmental disabilities, are among the most excluded, discriminated against and unseen members of society, often experiencing violation of their human rights, such as separation from their families, harsh punishment, abuse, harmful treatment and institutionalization.

To ensure the right to health of children with developmental disabilities, attitudinal, environmental and institutional barriers must be addressed. Policies, legislation and government strategies provide the legal commitments and provisions to address and monitor socioeconomic determinants, exposure to adversities and human rights violations and health inequities among young people with developmental disabilities and their families and promote enabling inclusive environments and access to high-quality care and support in line with human rights-based standards. "Policy" outlines what a government ministry intends to achieve and the methods and principles it will use to achieve them. "Legislation" sets out the standards, procedures and principles to be followed to support implementation of policies, including penalties for violations. "Action plans", "frameworks" and "strategies" outline the steps necessary to achieve policy goals and measurable outcomes and timelines.

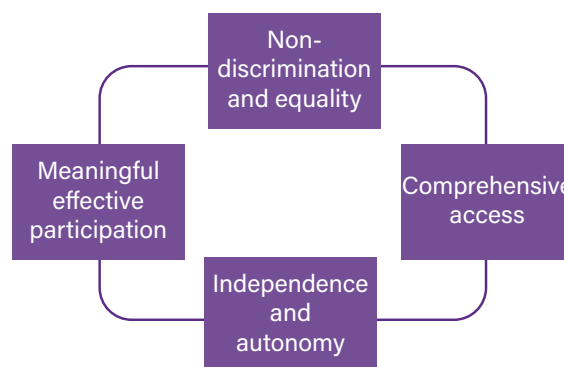
In this chapter, the underlying principles critical to policies, legislation and government strategies are outlined, with examples of policy, legislation and planning to strengthen the inclusion and protection of the rights of children and young people with developmental disabilities (and their families) and to create the conditions for these children to achieve their health and development potential.

3.2 Guiding principles and key areas for policies, legislation and strategies

Governments have the responsibility to respect and fulfil the human rights of all citizens, including children with developmental disabilities. Properly formulated and implemented, national policies, legislation and government strategies can have a significant impact on the health, development and quality of life of these children and young people.

The UNCRC (2) and the UNCRPD (3) are important human rights instruments. These conventions provide governments with a framework for ensuring that children with developmental disabilities enjoy their rights to health, development and participation without discrimination. The key principles of a rights-based approach to inclusion of children with developmental disabilities and promotion of their health, based on those conventions, are outlined in Fig. 3.1 and described below.

Fig 3.1. Key principles of a right-based approach to promotion of health and inclusion for children with developmental disabilities, informed by the UNCRC and UNCRPD



Non-discrimination and equality

Children with disabilities, including those with developmental disabilities, should enjoy all human rights and fundamental freedom on an equal basis with other children (Article 7 of the UNCRPD). This includes equality in opportunities to grow up in nurturing environments and to access early learning and education. Children and young people with developmental disabilities should have access to promotive, preventive, care and rehabilitation interventions on an equal basis with other children and young people, irrespective of and responsive to their gender or gender identity and other intersecting identity factors. Where necessary, “reasonable accommodation”¹ is essential to provide children and young people with developmental disabilities with equal opportunities. Operationalization of this principle requires respect for standards of high-quality care that prevent discriminatory, coercive practices (e.g. forced admission and treatment, institutionalization, seclusion and restraint, inappropriate use of psychotropic drugs).

Comprehensive access

“Universal design” is an approach to ensure that services and products can be used by all people to the greatest extent possible. Enforcing standards of universal design requires attention not only to physical infrastructure but also better access to assistive devices (e.g. noise-cancelling headphones and weighted vests for those with autism). Accessible health information and communications are also essential, as is tackling negative attitudes and perceptions.

Independence and autonomy

Individuals must have the opportunity to make informed choices and to participate actively in decisions about their lives and their health care. Children and young people with developmental disabilities have the right to support (e.g. accessible information in easily read formats) to help them to become autonomous and to give informed consent to interventions, irrespective of the type of disability. The UNCRPD General Comment No. 1 (4) urges States Parties to examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with those of other children.

Meaningful, effective participation

Children and young people with developmental disabilities should have input into health policies and plans to address their rights, as they are the most familiar with the barriers they experience. Their families and caregivers can also provide valuable input, as they constantly witness barriers and are critical advocates for positive change. Organizations of people with disabilities of various types can act as representatives. Article 7 of the UNCRPD states that all actions taken on behalf of a child are in the best interests of the child and should incorporate the views of the child whenever possible.

The UNCRC and the UNCRPD outline the foundational rights of all children, including those with developmental disabilities, to survive; to develop to the fullest; to protection from harmful influences, abuse and exploitation; to grow up in a family environment; and to participate fully in family, cultural and social life, also recognizing the importance of family assistance and support. The SDGs and World Health Assembly resolutions, strategies and action plans on autism, mental health and epilepsy and other neurological conditions reinforce the principles and commitments of the UNCRC and UNCRPD and propose actions with a focus on addressing health determinants, inequities and achieving universal health coverage.

Fig. 3.2 illustrates areas of the human rights framework that are particularly relevant to creating the conditions for optimal development and health of children with developmental disabilities. Key areas for policy are described below.

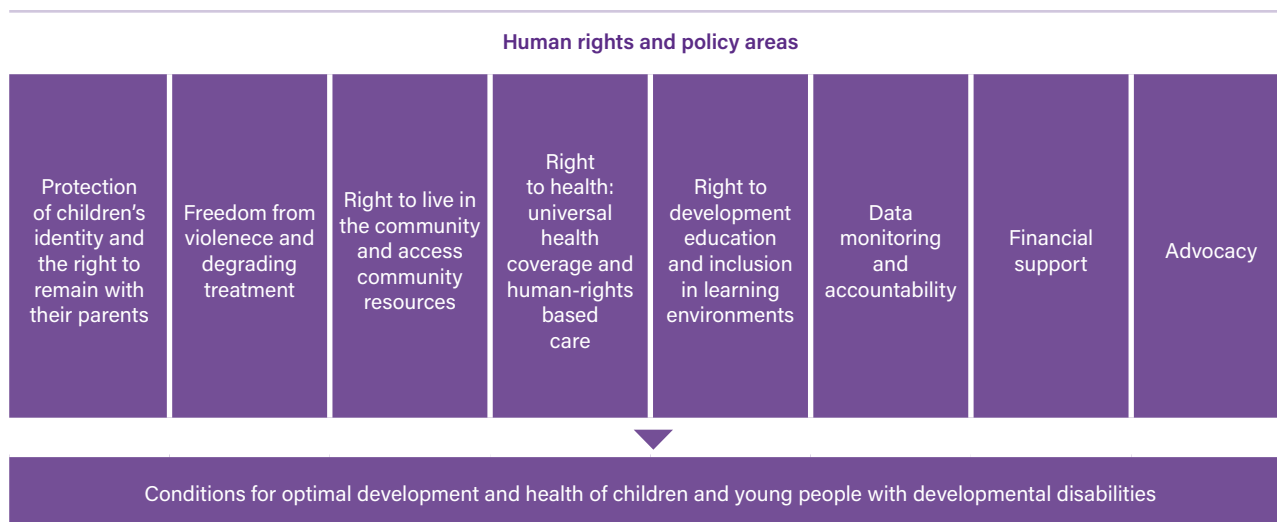
Protection of children's identity and the right to remain with their parents

Children with developmental disabilities should be registered immediately after birth and shall have, as far as possible, the right to know and be cared for by their parents (UNCRPD, Article 18).

Children with disabilities, including those with developmental disabilities, “are best cared for and nurtured within their own family environment”, and they “should never be institutionalized solely on the grounds of disability” (3). Children are not to be separated from their parents unless it is considered that so doing

1 Reasonable accommodation: According to Article 2 of the UNCRPD, “Reasonable accommodation” is attained by necessary, appropriate modification and adjustments that do not impose a disproportionate or undue burden, where necessary in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedom.

Fig. 3.2. Areas of human rights and policy relevant to creating the conditions for optimal development and health of children with developmental disabilities



is in the best interests of the child (Article 9 of the UNCRC, Article 23 of the UNCRPD). “States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care with the wider family, and failing that, within the community in a family setting” (UNCRPD, Article 23). The families of young people with disabilities should be provided with protection and assistance to enable them, when they wish, to live with their families.

Freedom from violence and degrading treatment

Children and young people with developmental disabilities are particularly vulnerable to violence and degrading treatment. The COVID-19 pandemic uncovered widespread institutionalization, demonstrating its harmful impact on the rights and lives of persons with disabilities and the violence, neglect, abuse, ill-treatment and torture, including chemical, mechanical and physical restraints, that they experience in institutions (5).

The UNCRC (Article 37) and the UNCRPD (Article 15) reinforce each other in prohibiting any child and person with disabilities, respectively, from being subjected to “torture or cruel, inhuman or degrading treatment or punishment”. The UN Committee on the Rights of the Child states in its General comment no. 13 that since the extent and intensity of violence exerted on children is alarming, “measures to end violence must be massively strengthened and

expanded in order to effectively put an end to these practices which jeopardize children’s development and societies’ potential non-violent solutions for conflict resolution” (6).

Article 19 of the UNCRC requires States Parties to take all appropriate legislative, administrative, social and educational measures to protect children from “all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse”. States Parties are directed to prevent such occurrences by ensuring “appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers” (UNCRPD, Article 16).

Right to live in the community and access community resources

Governments should legislate to abolish disability-based institutionalization. The UNCRPD stipulates that, for persons with disabilities living in the community, access to both specialized and mainstream services is a fundamental human right. The UNCRC and the UNCRPD require countries to remove barriers such as stigmatization and discrimination that impede the full inclusion of children with disabilities in communities, schools and families and to develop community resources, such as inclusive schools and health and rehabilitation services that are available and accessible to all families, regardless of income.

To avoid institutionalization and ensure that children with developmental disabilities remain in their own communities throughout early childhood and youth, comprehensive, multidisciplinary, responsive services and age-appropriate interventions should be established for children and youth. These should include prevention services; services that provide integrated early childhood development interventions; home care services that provide care from the least to the most intensive; rehabilitation services; educational and vocational services; and parenting and income support for families. These services require a multidisciplinary approach among various sectors and strong links and coordination among actors in the health, education, social and family welfare, employment, justice and other relevant areas. Accessible information should be made available to families and children (5).

In the Joint Statement on the rights of children with disabilities (7), the Committee on the Rights of the Child and the Committee on the Rights of Children with Disabilities recall that, in accordance with both conventions, States Parties have the obligation to adopt targeted strategies for deinstitutionalization, with specific timeframes and adequate budgets and with specific attention to children with intellectual or psychosocial disabilities and children requiring high levels of support, who are often at a higher risk of institutionalization.

Right to health: universal health coverage and human rights-based care

Fragmented, underfunded services in all regions and high- and low- income settings are failing to meet the right to health for children with developmental disabilities. Article 24 of the UNCRC states:

States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health [and] shall strive to ensure that no child is deprived of his or her right of access to such health care services. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

Policies should ensure that children and young people with developmental disabilities are included in interventions intended for all children and can also access targeted interventions for specific impairments. Prevention of placement of children in

institutions must be a priority. The coverage of services, affordability and equitable access are important, with specific provisions for children exposed to adverse conditions of vulnerability and gender-responsive, age-appropriate care. A pragmatic, collaborative approach is necessary to provide needs-based services, with adequate funding for provisions in both government and independent sectors.

Box 3.1. Support framework for people with learning disabilities in United Kingdom

In United Kingdom, the Government and National Health Service (NHS) England have established national plans and programmes to reduce health inequalities and improve care for people with learning disabilities (8). This is one of the priority areas in the NHS Long Term Plan (9), which commits to halving inpatient care for this group by 2023/2024 (compared with 2015 data). As part of the approach, annual primary care health checks for people with learning disabilities were increased in coverage. Introduced in United Kingdom in 2008, annual health checks can strength identification of unmet health needs in persons with learning and intellectual disabilities and facilitate access to preventative care and early interventions (10).

As part of the plan, a new cadre of care workers to support children and young people with learning disabilities was introduced. In 2022, new requirements and commitments were made, with focus on strengthening community care services and reducing inpatient care for people with autism and learning disabilities. These include the Health and Care Act 2022 (11), introducing a new legal requirement for all health and social care service providers registered with the Care Quality Commission to provide employees with training on autism and learning disabilities. The Department for Health and Social Care published an updated Building the Right Support Action Plan for people with a learning disability and autistic people (12) focusing on six areas to develop community services and reduce reliance on inpatient mental health beds.

The progress in reduction of inpatient care and long-term detention for treatment differs according to local areas. In February 2023, there were 2045 people with a learning disability and autistic people receiving inpatient care, of whom over half (56%) had a total stay of two years or longer (13).

The quality of care is an important aspect, which involves building the competence of the workforce to provide individualized, age-adapted, family-centred services and disability- and neurodiversity-inclusive care.

Children with developmental disabilities and their caregivers should be involved in decisions that affect them, through their representative organizations (UNCRPD, Article 12). Children with developmental disabilities have the right to express their views and to be supported in making choices among treatment and service options, in accordance with their age and maturity. Caregivers can support children in making their voices heard. Care coordinators and individualized service plans can support access to community-based service options for children who need extensive care.

Right to development, education and inclusion in learning environments

Early learning opportunities and education are key factors in the promotion of children's development and well-being. Schools and other learning envi-

ronments should provide access to nurturing relationships, opportunities to participate in educational and recreational activities with their peers, access to school health interventions and socio-emotional learning. The UNCRC states that children with disabilities should receive assistance to ensure that they can access and receive education (Article 23) and recognizes the right of children to education "progressively and on the basis of equal opportunity" (Article 28). Article 24 of the UNCRPD further supports the right to education of children with disabilities and commits States Parties to ensure an inclusive educational system at all levels, by not excluding children with disabilities from primary or secondary education and by providing reasonable accommodation and support. The UNCRPD Committee's General Comment 4 (14) provides guidance on teaching strategies aligned with universal design for learning, which consists of a set of principles for creating adaptable learning environments and developing instruction to meet the diverse needs of all learners. The UN Human Rights Council resolution of 22 March 2019 (15) urges States Parties to further this objective by developing and implementing a comprehensive and coordinated

Box 3.2. Instituting a policy of inclusion for learners with disabilities in the Philippines

In 2019, an estimated 60% of Filipino children with disabilities were out of school according to the Department of Social Welfare and Development. Moreover, the inability to access education services and learning resources was one of the major concerns cited in the 2020 survey of the Council for the Welfare of Children Sub-Committee on Children with Disabilities (16).

In 2022, a new law, "Instituting a policy of inclusion and services for learners with disabilities in support of inclusive education" (17) was enacted. The law is foregrounded in a whole-of-community approach for the inclusion of learners with disabilities in the general education system and the community, establishing collaborative and participatory practices, in schools and other community settings, with the engagement of learners with disabilities and their parents and guardians.

The law aims to provide learners with disabilities with free and appropriate public early and basic education and support and related services based on their needs. It also commits to pursue

the objective of ensuring access to the general education system through formal school systems for learners with disabilities, with implementation of alternative delivery modes when required. In support of the inclusion of learners with disabilities in the general education system, the law mandates the Department of Education to establish at least one Inclusive Learning Resource Centre of Learners with Disabilities (ILRC) – a one-stop shop for the delivery of support and related services, featuring multidisciplinary teams of professionals – in all school districts, cities and municipalities.

There is commitment to enhance the capacities of school staff, including teachers and school nurses, and to strengthen early identification of children with disabilities and referral or initiation of interventions in schools. Furthermore, this law institutionalizes the development, implementation and review of individualized education plans and will provide learners with disabilities and their families with additional resources to holistically support their education needs, including accessible materials, consultative mechanisms and family education.

legislative and policy framework that takes into account the rights, requirements and varying needs of children with disabilities at all levels and promotes lifelong opportunities for learning and personal development.

Box 3.2 provides an example of policy addressing education for persons with disabilities in the Philippines. Besides formal education, policy provisions for inclusive approaches to early childhood development programming and in pre-school education are fundamental prerequisites to equalizing access to early learning opportunities. Box 3.3 describes the experience of Peru in operationalizing a strategy for comprehensive early childhood development, with explicit focus on hard-to-reach and at-risk populations.

Data, monitoring and accountability

Governments should collect and compile administrative data on children with developmental disabilities and use them as a basis for policies and services. Data should be disaggregated by age, gender, type of impairment, socioeconomic status and, in the case of children in care, include the date of admission and expected date of discharge. Data should be made available in various accessible formats, while ensuring the right to privacy of personal data.

Box 3.3. Peru's *Primero la Infancia* (Supreme Decree N° 010-2016-MIDIS) and *Cuna Mas*

"*Primero la Infancia*" (Supreme Decree N° 010-2016-MIDIS) guides government's approach to early childhood development (ECD) and establishes indicators for the monitoring and evaluation of results. *Cuna Mas* is a large-scale ECD programme that focuses on marginalized urban and underserved rural areas. The programme, established under the Ministry of Development and Social Inclusion, addresses inequity in ECD in vulnerable populations and focuses on prevention of developmental delays. In urban areas, the programme offers day care centres that provide comprehensive care to children aged between six and 36 months. In rural areas, the services are in the form of weekly home visits as well as monthly group sessions. A study that looked at sustainability and the scale-up of the ECD programme with a view to making policy recommendations identified it as one of few ECD-focused home visiting programmes operating at scale in low- and middle-income countries (18).

Rigorous monitoring is a pillar for guaranteeing enforcement of rights-based frameworks. Article 33 of the UNCRPD commits States Parties to designate an independent mechanism to monitor implementation of the UNCRPD, with the involvement and full participation in monitoring of civil society, in particular persons with disabilities and their representative organizations. Monitoring mechanisms should adhere to established principles of accountability and transparency and enable meaningful participation of children with developmental disabilities and their representative organizations.

Article 16, subparagraph 3 of the UNCRPD explicitly states that, to prevent the exploitation, violence and abuse of persons with disabilities, including children with developmental disabilities, States Parties should ensure that all facilities that serve this population are monitored by independent authorities. Article 25 of the UNCRC requires monitoring of facilities and the placement of children in those facilities:

States Parties recognize the right of the child who has been placed by the competent authorities for the purposes of care, protection and treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

Monitoring should be continued during emergencies. When in-person monitoring is not possible, alternative modalities, including digital, should be adopted. Governments should provide accessible, effective pathways to seek redress, reparations and remedies for human rights violations, including institutionalization and harmful treatments.

Financial support

Financial support for young persons with developmental disabilities and their families protects them from financial loss and impoverishment and protects young peoples' rights to a family life, to be cared for in the home and community and to live independently. Individualized funding provides personal budgets for people with disabilities, to increase independence and access to health care and other disability-related costs. The approach has shown positive effects on overall satisfaction, with some evidence also of improvements in quality of life and sense of security.

The criteria for accessing financial benefits depend on the country, some of which involve lengthy administrative procedures. In many cases, access to financial benefits requires registration of a child

Box 3.4. Sustaining commitments to advocate for improved quality of care and social participation for autistic people

In the past 15 years public awareness on autism has improved significantly. Partnerships between advocates, including self-advocates and caregivers' associations, and policy-makers have played major roles in bringing autism and developmental disabilities to the attention of public health leaders.

The experience of the State of Qatar

In December 2007, at the United Nations General Assembly, a resolution supported by Qatar was adopted which designated 2 April as World Autism Awareness Day. Since then, the Government of Qatar has supported high-level dialogues and campaigns at global and national levels to improve understanding and acceptance and increase investments for autism. Following on this movement, and subsequent review of gaps and priorities at national level, a Qatar National Autism Plan (2017–2021) was launched in 2017 (19). The Qatar national plan is based on the research and proposals of six taskforces, technical guidance from the World Health Organization and contributions from family associations.

Under the Qatar National Autism Plan, policy-makers, health care leaders in the public and private sectors and civil society organizations have been working towards reaching 44 goals, with a focus on early diagnosis, quality of care, inclusive health services and continuity of support across the lifespan (19). Central to the approach is awareness raising, promoting cross-ministerial coordination and documentation of good practices to influence social participation for persons with autism.

The South-East Asian regional network

Concerted efforts by influential advocates and governments have led to the formulation and adoption of regional strategic documents on ASD and developmental disabilities in the South-East Asia Region.

Following a high-level meeting hosted by the Government of Bangladesh, the Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities was adopted in 2011. The Declaration called for promoting stronger coordinated action regionally to improve access to quality health-care services for people with autism and other neuro-developmental disabilities. Another outcome of the Conference was the launching of the Southeast Asia Autism Network. In September 2012, the 65th Session of the WHO Regional Committee for South-East Asia adopted the Yogyakarta Resolution on Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders and Developmental Disabilities (SEA/RC65/R8). Adopted unanimously, this resolution led to the first high-level meeting of Ministers for the South Asia Autism Network, in February 2013 in New Delhi, where governments agreed to the Delhi Declaration of the South Asian Autism Network, recommitting to accelerating efforts with a focus on inclusion, participation and community-based care. These high-level dialogues and regional commitment documents sparked increased attention and awareness on autism and developmental disabilities in countries in the region, although the impact for persons with autism is difficult to assess due to the paucity of data.

on a national disability register, whereas, in some countries, registration is a barrier to receiving benefits because of the procedural complexities, delays and reluctance of families to register their child as having a disability or clinical diagnosis.

Advocacy

Governments should create mechanisms to raise awareness about a human rights-based approach to promoting health for children with developmental disabilities. Strategies should be developed to empower young people with disabilities and their

caregivers to lead initiatives and to advocate. Box 3.4 describes efforts to raise awareness and strengthen commitments for improved health for autistic people in Qatar, the South-East Asian region and globally.

3.3 Country experiences in policy development and implementation

National governments are working to comply with the global normative framework for optimizing the health, well-being and participation of children with developmental disabilities through policies,

legislation and strategies. Domestic legislation and policy can catalyse social change and investment into promotion of enabling environments for children and young people with developmental disabilities.

Policy analysis and review of country experiences consistently acknowledge a range of common long-standing barriers preventing governments from achieving policy objectives (20–24). These include: lack of coherence in policy frameworks; waiting lists for accessing services, particularly in the early years; and inadequate support during transitions and for caregivers. Efforts to implement deinstitutionalization are hampered by inadequate investments in development of community-based systems. In some cases, in spite of national care reform policies and initiatives, children continue to experience deprivation of their human rights while being kept for years in safe homes and other forms of residential care that are provided as a transitional measure (25).

No national government has yet fully delivered universal access to health care, support and inclusive environments for children with developmental disabilities. Most countries have a way to go before realizing the highest attainable standard of health for persons with disabilities. Substantive progress has been made for specific policies and legislation for disability rights in some countries (26), but few have cross-cutting, comprehensive approaches that include children and young people with developmental disabilities. Enforcement of existing legislation remains a common challenge, and implementation and monitoring of policies are rarely robust.

While no country has the “perfect” solution to legislation and policy that integrates and promotes a human rights based approach to the health of children with developmental disabilities, good practices and lessons learned in policy development and implementation have emerged.

A supportive policy environment requires conditions such as local governance structures; mechanisms for intersectoral coordination (see Box 3.5); enactment and regular updating of laws and policies to address disability issues and explicit inclusion of provisions for children and young people with developmental

disabilities in all relevant mainstream policies and laws; general and focused awareness-raising; appropriate budgetary allocations; and adequate monitoring and accountability (20, 27, 28).

There is recognition that meeting the health needs of children and young people with developmental disabilities requires targeted provisions for the empowerment, care and support of these children and their families along with provisions for mainstreaming inclusion in services and communities and addressing barriers to accessing health promotion, education and care. This approach is commonly referred to as a twin-track approach (29).

The important influence of broader social and economic determinants of health on the life trajectories of children and young people with developmental disabilities is also established. A health in all policies approach is increasingly being applied in national policy initiatives for children with developmental disabilities. The approach argues for health considerations to be incorporated into decision-making across sectors, such as transport and urban planning, and considers the differential effects that a policy may have on diverse groups (27).

Active involvement of children and young people with developmental disabilities and their families and carers is necessary to ensure that policies reflect real-life concerns.

Box 3.5. Uganda’s national ECD service delivery framework

Uganda’s national ECD service delivery framework (SDF) provides a good example of intersectoral coordination (30). The SDF was developed to guide ECD service providers in all sectors at all levels. It is led by the Ministry of Gender, Labour and Social Development. A functional steering committee called the National Interventions for Disability in Early Childhood Committee exists. A National Integrated ECD Technical Committee was also established as the key national governance mechanism for cross-sectoral coordination.

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4. Transforming care systems for children and young people with developmental disabilities

4.1 The reality for children, families and care systems.

The children and young people referred to in this global report are a heterogeneous group. Some children experience impairments in a particular domain of development, such as motor function or communication; others have impairments across more than one developmental area. Some have received a diagnosis, while others may receive one much later. Some children and young people positively identify as “neurodiverse” or as “neurodivergent”. The severity of impairments and related limitation in activity and functioning vary widely.

Children with neurodevelopmental conditions often have co-occurring health conditions, including physical health problems (e.g. rare and genetic disorders, gastrointestinal conditions, sleep problems) and mental and neurological conditions (e.g. depression, anxiety disorder or epilepsy) (1,2). They are more likely to have co-occurring neurodevelopmental conditions and other noncommunicable conditions (e.g. obesity). Their needs evolve over time, and they often benefit from access to targeted care and support throughout childhood and adolescence.

Developmental disabilities often co-occur with increased individual and familial psychosocial risks. For instance, a child with a developmental disability is much more likely to have a parent with a mental or physical health condition and is more likely to live in a single-parent family and in poverty (3). Children with developmental disabilities are also at increased risk of abuse, neglect and violence and have significantly poorer educational attainment than the general population (4, 5). Parents of children with developmental disabilities have higher levels of stress and depression than other caregivers due to factors that include little support, poor satisfaction with health care, perceived stigmatization and isolation, their children’s extensive needs, financial difficulties, and concern about their child’s future (6). Health-care services play an important role in the lives of children with developmental disabilities and their families and are an important element of a multicomponent societal

approach to improving access to opportunities and resources for better health and well-being.

Different intervention approaches, including psychosocial treatment and interventions to improve functioning, have been shown to benefit the health and well-being of children with developmental disabilities (7, 8). Some are specific to children with particular diagnoses, while others are applicable to more heterogeneous groups of children and their families. The aims of these intervention and support approaches include maximizing young people’s development potential and functioning, promoting well-being, minimizing barriers, promoting enabling environments, and managing co-occurring health conditions. Some children with developmental disabilities may also benefit from medication to control epilepsy and anxiety, reduce aid sleep rhythm, manage muscle stiffness and motor disorders, and help with focus (in children with ADHD) (9). Surgery can be indicated in select cases (e.g. to reduce spasticity) (10).

The heterogeneous clinical features of neurodevelopmental conditions in children and young people have implications for the organization of care. So do the chronic nature of impairments and their intersection with family and socioeconomic factors. The evolving needs of children and young people with developmental disabilities require care at various levels from different professional groups and systems, within the health sector and elsewhere. Care pathways for children with developmental disabilities should therefore be developed and strengthened in the light of all these related factors and systems, and be based on the reality lived by these young persons.

Identification and treatment gaps

Irrespective of their developmental profile or diagnosis, most children with neurodevelopmental conditions encounter barriers in accessing health care. The gaps in treatment vary across countries and from one neurodevelopmental condition to another. In LMICs, the identification and treatment gap for mental and neurodevelopmental disorders is estimated to

be more than 90% (11, 12). The majority of individuals with developmental disabilities and their families struggle to access assessment, as well as diagnostic, interventional, educational and social support.

In all countries, children and young people with developmental disabilities have high levels of undetected and unmanaged health needs (7, 13, 14). There is evidence that children and young adults with intellectual disabilities are more likely than those without an intellectual disability to be hospitalized for conditions that can be managed in primary care settings, such as asthma and diabetes (15). Barriers to primary care access are thought to contribute to these inequitable health outcomes. They include physical and attitudinal barriers, inexperienced or inappropriately trained staff, inadequate health service integration and continuity of care, the associated costs of health care and a perceived lack of time during appointments (16–25).

For autism, despite the evidence of the benefits of early intervention programmes, caregivers of autistic children in countries located in different regions and with different income levels report significant delays in diagnosis and accessing support. For example, a survey conducted between December 2015 and April 2016 with 2520 caregivers of children with ASD from six Latin American and Caribbean countries indicated that, on average, parents were first concerned about their child's development by 22 months of age. However, on average, the diagnosis did not come until the child was around the age of three and a half (26). These data are consistent with research from other countries (27–28). Delay with diagnosis, long waiting lists, ineligibility for care services and high cost are commonly reported factors that delay access to treatment. Other factors include caregivers not having adequate information on services, stigma, and low literacy about developmental disabilities (27, 28). Reliance on specialist models of care sustains gaps in access to early interventions. Health-care services for children with developmental disabilities are typically fragmented and underfunded.

Difficulties in accessing care are compounded by variability in the quality of care. Children with developmental disabilities experience more preventable harms and poorer care quality when compared with their peers. Children with developmental disabilities stay for longer when they are admitted to inpatient care. They are also more susceptible to adverse events and lapses in patient safety during their hospital stay. This is particularly the case for children from socioeconomically disadvantaged and culturally and linguistically diverse backgrounds (29–30).

In most contexts, three things are required to ensure access to mainstream health promotion, prevention and care, and to tailored treatments for children with developmental disabilities. The first is to strengthen multidisciplinary community care, while fully implementing deinstitutionalization. The second is to enhance clinical practices to align with evidence and human-rights based standards. The third is to advance stigma elimination in communities.

This chapter provides guiding principles and good practices for organizing and extending services to meet the needs and aspirations of children with developmental disabilities and their families. These principles and practices are informed by complementary perspectives and frameworks, which are illustrated in Fig. 4.1.

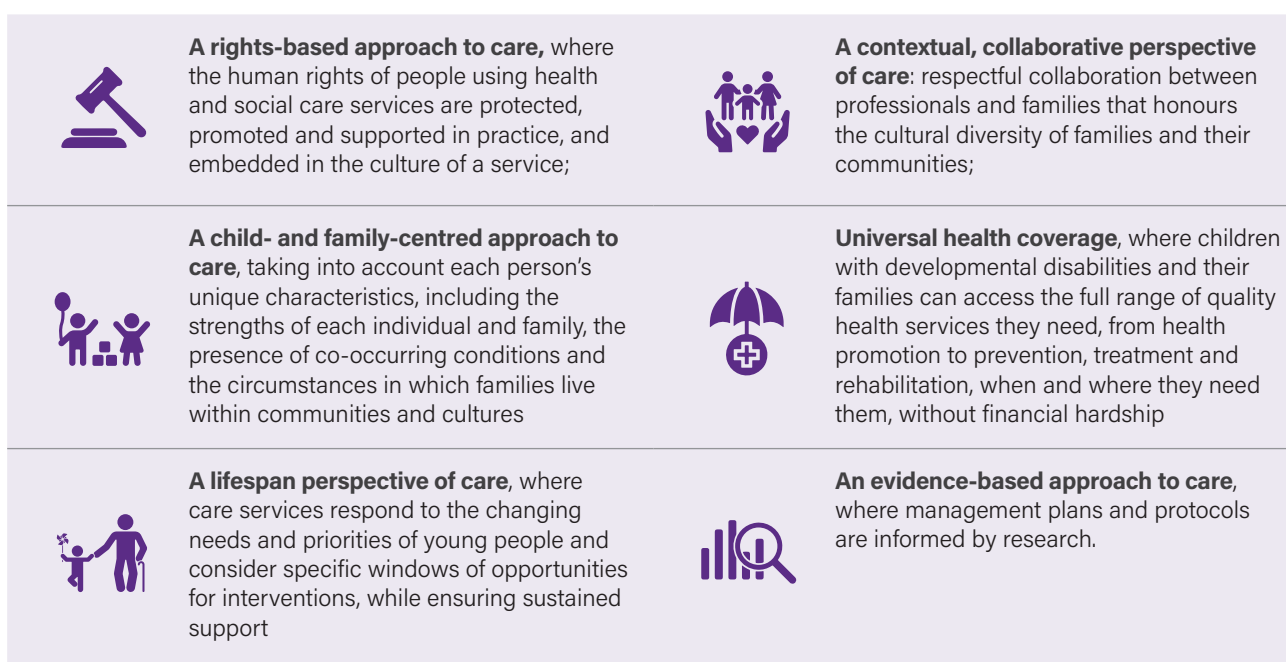
4.2 Designing and strengthening care pathways for children and adolescents with developmental disabilities

There is no “one size fits all” approach to achieving universal health coverage for children and young people with developmental disabilities. This section describes guiding principles and emerging good practices in organizing and delivering care for children and their families, based research on health systems and implementation and reports on users' experiences.

A twin-track approach to care: promoting access to mainstream health promotive and care services while integrating targeted community care and advancing deinstitutionalization

Many barriers must be addressed to create the conditions for equal access to mainstream health-promotive, preventive and care services for children with developmental disabilities. A first step is to make the service physically accessible, by adapting its physical environment (e.g. presence of ramps and lifts; ensuring that the environment is acceptable for children with sensory over-responsiveness) and ensuring that the service is accessible by public transport. An accessible, mainstream child-health service is one that addresses communication barriers (e.g. staff know basic sign language; communication boards are on display; information materials use a variety of easy-read formats, videos with universal design, captions and audio descriptions); and is financially and legally accessible to children with developmental disabilities and their caregivers (31).

Fig. 4.1. Frameworks underpinning the building of care services for children with developmental disabilities and their families



The attitudes of health-care staff are an important aspect of inclusive services, to ensure elimination of any form of discrimination on the basis of disability and to recognize that children with developmental disabilities may require changes in how services are provided, including allowing more time for visits.

There are promising examples of the scale-up of approaches that expand opportunities for persons with developmental disabilities to access health promotion and for the early identification of physical and mental health conditions. These include annual health checks for persons with intellectual disabilities and outreach services for families of children with disabilities (32, 33).

Provision of access to mainstream services for all children and adolescents with developmental disabilities is a necessary step, but alone it is not sufficient. Optimization of the development, health and well-being trajectories of children with developmental disabilities also requires timely access to targeted interventions and support to meet their individual health, educational and social needs, in what is referred to here as a “twin-track” approach (34). Foundational principles for provision of targeted interventions to support children with developmental disabilities are elimination of long-term institutional care and promotion of community care through integrated service networks.

Embed identification and early interventions for children and young people with developmental disabilities into existing care services.

It is important that children and families can access support and treatment as soon as developmental difficulties and co-occurring health problems are recognized. Identification and care for children with developmental disabilities is most likely to be sustainable and scalable when embedded into existing systems of care (35). Countries could integrate targeted interventions for children with developmental disabilities into health, developmental, education and social care services. Table 4.1 lists examples of potential entry points to screening, monitoring, early identification, assessment, intervention and support (36–40).

Collaborative teams of competent care workers deliver tiered systems of needs-based support, treatment, habilitation and rehabilitation

There is increasing recognition of the benefits of using stepped-care approaches in building tiered systems of care for children with developmental disabilities. A stepped-care approach aims to reduce costs to care systems and to families. It involves making available care options of varied levels of intensity, linked through defined care pathways, so that children and

Table 4.1. Examples of opportunities to embed assessment and care for children with developmental disabilities into systems and services of care throughout the lifespan

Developmental phase	Existing service	Example
Antenatal period	Antenatal care visits	<ul style="list-style-type: none"> Provide parenting advice, including on maternal mental health, nutrition, responsive caregiving and the importance of ensuring early learning opportunities. Include information about developmental milestones, early markers of developmental delays and the importance of seeking support.
Neonatal period	Neonatal services	<ul style="list-style-type: none"> Early screening for visual and hearing impairment and for identification of neurodevelopmental conditions, particularly for genetic and metabolic syndromes associated with developmental disabilities. Support for parenting, including on breastfeeding and positioning.
Infancy	Immunization clinics Breastfeeding counselling Early childhood development programmes and integrated early childhood services	<ul style="list-style-type: none"> Developmental monitoring for identification of developmental delays, particularly for motor, language and social-communication delays. Support for parenting.
Preschool years	Well-child and child care visits Early childhood development programmes and integrated early childhood services Preschool programmes	<ul style="list-style-type: none"> Developmental monitoring and identification of neurodevelopmental conditions, including ASD, developmental learning disorders, developmental speech and communication disorders, and disorders of intellectual development. Low-intensity psychosocial interventions focused on social and communication skills training and developmental behavioural approaches. Support for parenting. Provision and training on the use of assistive devices.
School years	Well-child and child care visits	<ul style="list-style-type: none"> Developmental monitoring, identification of neurodevelopmental conditions and other comorbid conditions. Support for parenting.
	School readiness programmes School entry programmes Learning support programmes	<ul style="list-style-type: none"> Developmental monitoring. Individualized beginning reading interventions and other specialized instructional interventions to improve academic performance. Psychosocial interventions focused on social skills, cognitive and organizational skills training.
	Integrated school health programmes	<ul style="list-style-type: none"> Identification of neurodevelopmental conditions (i.e. speech and learning disorders, ADHD) and other comorbid health conditions. Socioemotional learning.
Adolescence	Well-child and child care visits	<ul style="list-style-type: none"> Identification of neurodevelopmental conditions and other comorbid conditions.
	Adolescent health screening and immunization programmes	<ul style="list-style-type: none"> Education, advice and support for self-management of health conditions. Determine the transitional care needs of adolescents with developmental disabilities, and plan a programme for transition to adult life. Training in life skills for independence.
	School leavers' programmes	<ul style="list-style-type: none"> Promotion of mental health and monitoring for emerging mental health conditions, including anxiety disorder and depression, and for ASD not previously identified.
	"One-stop" services Integrated school health programmes	<ul style="list-style-type: none"> Low-intensity psychosocial interventions for the prevention and reduction of behavioural and emotional problems. Personal and social education and relationships and sexuality education.

families can access the less resource intensive – yet effective – treatment first, only “stepping up” to more resource intensive services when needed. The approach is used in the field of mental health, among others (41). In the case of developmental disabilities, the operationalization of stepped-care approaches is influenced by the fact that children with developmental disabilities have widely different, unique needs that may change over time and that may benefit from simultaneous access to a range of services of varied level of intensity (7). For many children and young people, there will be multiple treatment goals. For instance, the care plan for a child with cerebral palsy may involve caregivers’ psychoeducation on feeding practices delivered by a nurse in a community setting, along with pharmacological treatment by a specialist to reduce spasticity.

It is also implicit in this approach that some children and some families with complex health-care needs may be offered treatment of a higher intensity (in terms of either time requirement or involvement of specialized professionals) immediately after assessment. Decisions about the intensity of the intervention, stepping up

or stepping down the intensity of an intervention, or switching to a different approach must be based on assessment of individual and family needs and preferences, data-informed progress monitoring, and the individual’s response (see e.g. 42, 43).

Care pathways are connected between sectors and agencies

An important challenge for services and families is to overcome the “siloes” that exist between sectors in almost all countries. Intersectoral collaboration and coordination must be assured between and within government sectors (e.g. health, social care, education, justice, housing) and other sectors (such as non-profit organizations and the private sector). Intersectoral collaborative care can be strengthened through whole-of-government policies and implementation plans, coalitions and alliances or cooperative initiatives. Individualized service plans can facilitate service coordination, guided by children and families’ needs. Research shows that these plans often exist in high-income countries but are not necessarily used (44).

Box 4.1. Chile Crece Contigo: early identification and intersectoral collaboration for children and their families

In response to social demand to address health and social inequity, a cross-sectoral protection system of integrated services financed by the public sector was launched in 2006 in Chile. Chile Crece Contigo (Chile grows with you) coordinates activities offered across nine ministries, from the prenatal period up to the age of 9 years (45–47). Services are delivered in municipalities and include universal and differentiated benefits, depending on the needs of children and their families. Chile Crece Contigo provides advice on early childhood development online, in social media and in a radio programme for all families and caregivers. It also offers care support services for early life, including antenatal care and education, birth care, newborn care, primary health care, care for children in vulnerable situations, and comprehensive care for hospitalized children. It promotes positive parenting skills, mutual support among participants, prevention of child abuse and maltreatment, and co-responsibility in parenting with hands-on practice. Vulnerable families (e.g. teenage mothers, women with post-partum depression or substance misuse) have access to free care for infants and

preschool children. In addition, low-income families are eligible for financial support.

In 2019, Chile Crece Contigo identified the lack of timely services for eligible children with developmental disabilities and introduced targeted programmes to finance the training of, and services provided by, interdisciplinary teams supporting children with developmental disabilities in 21 communities (comunas) across the country (48). These services, called Inclusive Rooms, involve teams of speech and language pathologists, occupational therapists, and/or physical therapists, who educate the parents and provide direct developmental services for children under four years of age. This pilot programme also coordinates benefits that children with the national disability credential can access, including assistive communication devices, Braille typewriters, as well as other assistive technology. A programme evaluation providing disaggregated data with impacts for children with developmental disabilities is not yet available. Such data is of critical value to inform future efforts in Chile and provide lessons learned for other countries.

An example of successful intersectoral collaboration is the Chile Crece Contigo initiative (see Box 4.1), which now covers the whole country, from universal initiatives, to targeted benefits for children exposed to risks and children with developmental delays (45–48).

Child- and family-centred approaches to decision-making and care, with active engagement of service users

Family-centred services have long been identified as best practice for professionals working with families of children with developmental disabilities (49–51). Such services have several key elements, such as respect for the family as the constant in a child's life, respectful collaboration between professionals and the family, exchange of complete, unbiased information, recognizing and honouring the cultural diversity of families, and recognizing and respecting different means of coping within families (52). In family-centred and partnership approaches, professionals work with families to understand the priorities of parents and caregivers for their child's progress and well-being, and their resources and constraints in bringing up their child. When parents and caregivers are provided with opportunities to strengthen knowledge, understanding, acceptance and skills to engage with and support children, both the caregivers' well-being and their children's development improve (53, 54). The focus also includes the young person's priorities, needs, interests, preferences and choices. Additionally, these approaches are tailored to the child's developmental level and individual strengths. Any new service should be designed with representatives of families and young people, as, too often, services are provided on the basis of professional convenience or convention.

Services, systems and communities integrate “strengths-based” and transdiagnostic approaches to promoting the health, functioning and participation of children with developmental disabilities.

Profiles of strengths and difficulties inform intervention plans for children with developmental disabilities and their families. A medical diagnosis may not be needed for initiating treatment. In fact, a range of interventions focus on supporting skills and developmental competencies for children with delays and difficulties in one or more developmental domains (such as cognitive, reading and writing, communication, social interaction and movement). Approaches to interventions should be mindful of enhancing the child's social participation as well as aiming to improve function. Incremental improvements in engagement in interactions and activities can trigger positive cascade

effects on health, development and quality of life (7), by amplifying opportunities for development and nurturing interactions. Functioning and participation outcomes (such as in sports) is also valued by young people with developmental disabilities themselves. Intervention to improve functioning and participation might include exercise to maintain flexibility and treatment to reduce pain, or it might be obtaining a wheelchair or specialized transport to allow the child to move around the community and join in games. A review of studies published between 2014 and 2019 on interventions for children with cerebral palsy conducted in Africa showed that most interventions addressed impairment rather than functioning, with little attention to the outcomes of participation (55).

Services and systems are accessible, acceptable, culturally appropriate and aligned with standards of care based on human rights.

The most common barriers to access and use of health care for families of children with developmental disabilities in LMIC include financial constraints (such as for transport), geographical inaccessibility of a service, lack of health-care resources, and cultural beliefs (56). Services should preferably be based in communities and tailored to the local care system and cultural context. Contextual factors such as the intervention location, and the education and literacy of young people and caregivers may have a significant impact on intervention uptake and effectiveness. The socioeconomic context of caregivers strongly influences service access and engagement with interventions (57). Example of strategies to address challenges set by the socioeconomic context may include collaboration with poverty eradication and women's empowerment initiatives, and instituting financial benefit schemes for families of children with disabilities.

Children with developmental disabilities are more likely to be the victims of harmful care practices, in violation of human right conventions (see Box 4.2).

Services and systems ensure continuous surveillance, early identification of developmental disabilities and support for children, adolescents and their caregivers at specific stages of development.

Identification and monitoring

Perinatal period

Some groups of mothers benefit from careful monitoring during their pregnancy (58). They include those who are HIV positive, have a mental health

Box 4.2. Harmful practices in interventions and diagnosis

Persons with developmental disabilities, and particularly persons with intellectual disabilities, are more exposed to involuntary care and restraint measures, including physical and chemical restraint (59, 60). Various studies have identified some common elements of good practices in efforts to limit restrictive practices, including strong leadership in care facilities based on national policy, strict monitoring systems, staff trained on management of difficult behaviours and other aspects of care, and changes in attitudes on the use of restraints, with restraints being identified as treatment failure (61).

False claims of effective treatment may contribute to delaying access to evidence-based care and, in some cases, expose children to harm. A specific example is “facilitated communication” or the “rapid prompting method”, used for cases of autism, supposedly to enable non-speaking individuals to communicate, despite strong evidence of a false claim. The direct harm includes denial of a voice to people with disabilities, and examples in which carers were falsely accused of abuse (62–64). Perhaps the most common harmful intervention everywhere is inappropriate prescribing (too much or too little) of medications for children with developmental disabilities. Medical practitioners far too often use atypical antipsychotic medications, antidepressants, anti-epilepsy medications and other “licensed” medications to

treat behavioural difficulties such as aggression, temper tantrums or self-injury (65). Clinical guidelines often emphasize the importance of a thorough examination of the child’s health and behaviour and the child’s environment (i.e. the meaning or function of a particular behaviour) before initiation of treatment with psychotropic medications (36, 66). Clinical practice documents often point to the need for careful clinical monitoring for side effects, clinical response, adherence, treatment acceptability and dose adjustment, and warn against the use of psychotropic drugs as a substitute for unavailable psychosocial interventions (36, 66).

Harmful practices in diagnosis are also common. For example, the rapid increase in diagnosis of autism across the world has in part been driven by better understanding and awareness, training and diagnostic tools, which had led to diagnostic substitution (e.g. recognition of someone with autism rather than intellectual disability). There are, however, reports of diagnostic inaccuracy and overdiagnosis. In an extreme example, one study in India suggested that only 20% of children under eight years who had been diagnosed at some time with autism met the criteria for the diagnosis (67). Similar concern has been raised about ADHD. Diagnosis is more accurate for conditions such as cerebral palsy, but differential diagnosis may be difficult at an early age.

condition, and/or have a history of substance or alcohol misuse, and those who have had obstetric complications. Some groups of infants are more likely to experience developmental delays and disabilities, such as those born prematurely and those with genetic syndromes (some of which may be identified perinatally) such as Down syndrome, tuberous sclerosis complex, fragile X syndrome and phenylketonuria. For high-risk mothers and caregivers of at-risk infants, monitoring is an opportunity to access early identification of developmental delays, developmental disabilities and other co-occurring medical conditions, as well as appropriate advice and psychoeducation (58, 68, 69, 70). Neonatal care services can include: 1) a series of evaluations and timely diagnosis, encouraging attendance at follow-up programmes for at-risk neonates; 2) assessment of family’s psychosocial needs (by a psychologist and

social worker); and 3) workshops and educational material on bringing up children, encouraging development, preventing neurosensory complications (early screening) and preventing acute respiratory infections (e.g. not smoking, keeping vaccinations up to date) (68).

Early childhood and preschool

Many developmental disabilities become evident gradually. For example, unusual motor patterns in the first year of life may resolve, but may also be early signs of cerebral palsy leading to a diagnosis of cerebral palsy that can typically be made around 12 months of age. Characteristics of autism often become evident in the second year of life, when parents may become concerned by the absence of spoken language and symbolic play. Thus,

parental concern is often the first indication of a developmental disability (71). Children with potential developmental disabilities may also be identified by community informants or door-to-door screening. The Integrated Child Development Services programmes in India (72) and Chile Crece Contigo (see Box 4.1) are two examples.

Tools for early identification and monitoring of developmental delays must be validated in the country and language(s) in which they are used; they should also be open-access and available with training in how to use them. Some tools to identify impairments have been developed specifically in LMIC, such as the Rapid neurological assessment tool in Bangladesh for children aged 0–24 months and 2–5, 5–9 and 10–16 years (73). The assessment is conducted by a child health professional, who presents tasks to the child and interviews carers. Professionals in several LMIC have been trained in use of the instrument, and video training has been evaluated (74). Other tools for monitoring universal early child development have been validated in LMIC. In a review of such screening tools (75) for children aged 0–3 years, that which was rated highest was the Guide for Monitoring Child Development (76, 77), which has been validated in four countries and is used in various LMIC. It involves interviewing caregivers to assess whether the child can attain 85 “milestones” in seven domains; it also contains guidance on supporting early child development.

For some conditions, specific early behavioural markers (“red flags”) indicate that further assessment is necessary. In the case of autism, they include limited use of gestures to communicate, delayed speech or lack of social babbling, no warm or joyful expressions, not responding when someone calls their name and rituals in play, such as lining things up. Parents may seek information for themselves, for example, by watching online videotapes, with typical development comparisons of children aged 18–24 months. Such videos have been used in training professionals in South Africa (78).

School years and adolescence

Not all neurodevelopmental conditions are evident in the early years. In particular, ADHD, ASD and developmental learning disabilities may begin to be suspected in early or middle childhood, when the child should be able to cope with the expectations of the community or teachers for social behaviour, concentration and learning. Parental concern changes over time, particularly when children reach adolescence. Associated conditions such as pain

(related to spasticity), epilepsy and emotional or sleep problems may also emerge later. Hence, the identification of process cannot be a “one-off” exercise. Care systems across sectors, including schools, can provide for surveillance, supporting family well-being and monitoring of children’s strengths and difficulties over time, with the possibility of referral for assessment and treatment.

Assessment and diagnosis

Many high-income countries ‘HICs’ have developed guidelines on assessment and diagnosis for children with developmental disabilities (see for example: 66, 79, 80). These guidelines emphasise that caregiver or other concern should lead to multi-disciplinary assessment where team members observe and interact with the child in more than one setting, and jointly reach agreement on diagnosis and formulation of needs and intervention goals.

Multidisciplinary assessment does not necessarily imply a large team, given resource limitations. One example is the innovation in Bangladesh of “developmental therapists” who have trained in interdisciplinary skills (including physiotherapy, occupational therapy, speech and language therapy) to work alongside paediatricians and psychologists/counsellors (81). Assessment is not only directed at obtaining a picture of the child’s functional strengths and difficulties; it is also the first step in helping parents to understand their child, and in building a potential relationship. Parents’ primary concerns are enquired about and listened to early on in the assessment process and they obtain some preliminary advice on handling their child’s difficulties.

Most tools for assessing communication skills, cognitive skills, motor skills and other attributes were developed and validated in high-income countries; however, many are costly, professionals must be trained in their use, they may not be available in the local language, and may not have been validated in different settings. Health and education staff who carry out such assessments should consider whether the tasks are appropriate in order to avoid underestimating a child’s skills. For example, an unfamiliar task such as completing a board puzzle might measure the ability of a child to adapt to a new situation rather than their cognitive ability (82).

Adaptive behaviour scales and criterion-referenced assessment tools for measuring everyday skills, arranged by the ages at which the majority of typically developing children will have attained them, may be

more useful in certain clinical settings, as they lead naturally to the choice of appropriate goals of therapy. One example is the Pediatric Evaluation of Disability Inventory, which has been adapted, translated and validated in various countries, including Uganda (83). A computerized version allows only relevant questions to be asked (i.e. neither too difficult nor too easy) (84). This version has been translated into several languages, and was validated in Brazil. A version with additional items for children with ASD has also been developed (85). Such tools make it possible to check children's progress over time as they acquire new skills. The Gross Motor Function Measure for children with cerebral palsy is criterion-referenced but can also be related to reference curves for comparison between children (86). Such measures then allow checking of progress over time as children acquire new skills.

WHO's *Package of interventions for rehabilitation* outlines the essential elements of assessment approaches to inform rehabilitation plans for neurodevelopmental disorders (87).

4.3 Selected approaches to care and support

Early identification of difficulties should ensure appropriate early intervention, to make best use of the plasticity of brain development in infancy and early childhood (88). Even for children whose difficulties may not be identified in the first years of life, there is a clear rationale and increasing evidence of effectiveness of early intervention (89–91).

Adolescence and the transition to adulthood are also key points where support and intervention may be particularly important for two different, but related reasons. Firstly, adolescence is a period of rapid development during which individuals experience profound physical, social and psychological changes, and during which the maturing brain is highly susceptible to environmental influences (92). As such, adolescence offers great potential for health promotion and preventive interventions to influence health and developmental outcomes (93–95). Secondly, adolescence and the transition to adulthood are also associated with reduction in formal and informal support systems for young people, and with increased expectations to become independent.

There are a wide range of interventions that can influence the development and health trajectories of children and young people with developmental disabilities. Some of the interventions focus on the

health capital, functioning and skills of children and young people. These interventions may include, for example, psychological therapies to improve social skills in autistic children, and vocational training for adolescents with intellectual disabilities. Prevention and management of co-occurring conditions, including mental health problems and non-communicable conditions, is another important target of intervention, relevant to enhancing children's health capital. Other interventions focus on barriers and resources in the environment, with the aim of enhancing opportunities and supports for health, learning and participation for children with developmental disabilities. Such interventions include family-based and classroom-based approaches to improve participation, early stimulation and learning at home and in schools. Care approaches often integrate individual skills building and environmental interventions.

The mainstay of support for children and young people with developmental disabilities is evidence-based psychosocial and other non-pharmacological interventions, including assistive technology, and care in communities. For children and younger adolescents, care usually involves the parents or caregivers (33, 34). This can be direct service provision of parenting programmes and/or support for parental mental health needs. For adolescents, care should reflect emerging agency and autonomy and should be developmentally appropriate. Psychotropic medications (e.g. to control epilepsy and anxiety, aid sleep rhythms or help in focusing attention in young people with ADHD) and surgery (e.g. to reduce spasticity) can also play a role and complement psychosocial interventions and interventions for rehabilitation when indicated for reduction of symptoms.

In some cases, treatments for children with developmental disabilities may be indicated for children with a specific diagnosis. As an example, the initiation of treatment with methylphenidate in adolescents with ADHD requires a diagnostic assessment (36). In other cases, treatment approaches can benefit children who present delays or impairments in specific developmental domains, irrespective of diagnosis. It is important that children, adolescents and their caregivers are given access to a range of treatment and rehabilitation (87) options and are empowered to make informed choices.

The remaining part of this section provides examples of treatments, rehabilitation interventions and support that can benefit children of different ages with different developmental disabilities and their families.

Support for parents and caregivers

At diagnosis, regardless of the age of the child, all families should be offered parent education and training that includes information about the child's condition(s), how to explain it to other family members, managing parent and caregiver stress, and basic strategies to help their child progress (96). Parents and caregivers value receiving up-to-date information about support services, funding for any home adaptations or equipment, and help in finding appropriate school placements and educational support (97).

Helping parents to cope with their child's disability is vital for the well-being of the child and other family members. A parent who is struggling to make ends meet, to balance the needs of all the family, and to cope with stigmatizing attitudes will find it difficult to take on new learning and activities and to be a patient, attentive parent. Children with poor understanding of language tend to have more emotional symptoms, which are associated with greater psychological distress in parents and caregivers (98). Education and training of parents and carers can provide both support for their emotional well-being, and specific information and skills to support their children's development, such as improving language and communication in children with intellectual disability or autism.

Examples of psychosocial interventions across childhood and adolescence

Infancy

Young children who have been assessed as having neurodevelopmental conditions can benefit from indicated and specialist interventions. For example, infants and young children identified as being severely hearing impaired should be considered for cochlear implants or training in signing. Visual acuity in infants with severe visual impairment can be improved with early intervention (99, 100). In infants considered to be at risk of developmental disabilities, early targeted interventions can improve caregivers' competences and child development outcomes. For example, the "Partners for learning" approach for children who experienced birth asphyxia has been evaluated in India, Pakistan and Zambia (101).

Preschool

High-quality evidence on preschool-age children with ASD indicates the efficacy of social-communication interventions (102). Some of these have been adapted

for use in LMICs, such as in South Africa (103) and in India and Pakistan (104). In the latter example, the Parent-mediated intervention for ASD in South Asia has been further developed to assist parents and carers in managing their children's behaviour (105).

WHO has made available an intervention package for parents and families of children with delay or impairment in social communication domains with a focus on "caregiver skills training" (CST), even in the absence of a formal diagnosis of a developmental disorder or disability (106). Parents and children attend nine group sessions and receive three home visits. The curriculum covers communication, daily living skills, managing behaviour, and coping by caregivers. The approach is family-centred and accessible to families with low-literacy levels, and involves task-sharing (training of local group facilitators by specialists). An eLearning version is also available (107).

Similar to CST, the caregiver group interventions developed under the "Ubuntu" umbrella (108) by the London School of Hygiene and Tropical Medicine (UK) are offered through a local support group format. The interventions consist of 10 sessions providing information about essential care practices, such as feeding, positioning, communication and play. The suite of interventions provides resources, skills building and support for families of infants with developmental disabilities, children with cerebral palsy, and children with congenital Zika syndrome. Other training programmes developed specifically for parents of preschool children with ADHD have been shown to reduce symptoms, problem behaviour and negative parenting practices (109).

In children with developmental speech disorders, early communication interventions involving direct instruction approaches can improve expressive phonological skills and reduce stuttering (110, 111).

School-age children

During school years, problems with attention, hyperactivity and learning academic skills can become apparent. Children with developmental disabilities may experience symptoms of emotional distress. For example, a review of peer-reviewed literature has suggested that about one third of children and adolescents with cerebral palsy have mental health problems, with children who also have an intellectual disability possibly having higher rates (112). The rates are even higher in children and adolescents with ADHD and/or ASD (113, 114).

As children become more oriented towards their peers and social norms become more complex, they may experience confusion, exclusion and bullying, resulting in anxiety, low self-esteem and loneliness. For example, it has been shown that autistic children in high-income countries are bullied three to four times more often than those without a disability (115).

Schools are important sites for providing early interventions for developmental disabilities and preventing, and addressing mental health problems in children. For example, the Latin American Network of Health Promoting Schools and a similar Caribbean network use schools to identify mental health problems and to promote healthy lifestyles, involving families and the community (116). It is unclear to what extent children with developmental disabilities have been included, although use of child-to-child (or youth-to-youth) strategies suggests that individual adaptations could be made. In some high-resource settings, beginning-to-read interventions are provided in school settings by specialists (special education teachers) and non-specialists (teacher assistants) to improve communication and academic performance in children with intellectual disabilities (117). Specialized instructional techniques can improve academic performance, including writing skills, reading comprehension and maths in children and adolescents with developmental learning disorders (118), while task-oriented instruction can improve motor skills and task performance in children with developmental coordination disorders (119, 120). Psychosocial interventions focused on social skills, cognitive and organizational skills training can also be delivered in school settings to improve development and functioning in children with ADHD (121–123).

Adolescence

In adolescence, personal and social education is an important aspect to be addressed. For example, sex education is often ignored for children and adolescents with developmental disabilities. Lack of accurate sexual knowledge and, for some (e.g. those with ASD or intellectual disability), additional difficulty in understanding social nuances places them at increased risk of sexual victimization (124). It is important to enhance competences of health care providers, teachers and parents on approaches to sex education and adaptations of learning strategies for adolescents with developmental disabilities (125). As an example, Supporting Teens with Autism on Relationships has been adapted to the style of learning of autistic young people (e.g. requiring concrete examples) and successfully used by parents (126).

In adolescence, plans are made for the transition to adult life. Young people with developmental disabilities have such plans and dreams, and they and their families should be supported in finding resources and organizations to fulfil them. For example, many studies have indicated that the outcomes of young people with ADHD in adulthood are poorer, with more educational impairment, a lower likelihood of finishing school, lower occupational attainment, less job stability, lower income and increased risk of homelessness when compared with peers (127). Schools can arrange training in work and life skills for independence. A manual for transition of young people with ASD has been developed and tested in the USA, but it is not yet evaluated in other settings (128, 129).

4.4 Use of digital and other technologies for identification, intervention, training and co-design

The past few decades have generated much excitement about the potential use of digital technologies to support people with developmental disabilities (see for example: 130). Examples include robotics (e.g. robots to help children learn to communicate), joint activity surfaces (e.g. to help a group of people interact through play), wearable technologies (e.g. to measure activity or arousal level to predict seizures or aggressive outbursts), and many Internet tools that can be used on desktop computers, laptops, tablets and smartphones (e.g. games to build specific skills or apps for screening autism). The COVID-19 pandemic accelerated the shift towards digital technology for information, communication, remote education and virtual health-care services (131).

WHO has created a classification of digital health interventions as a shared language to describe the uses of digital technologies (131). Four main groups of primary users were proposed: clients (members of the general public), health-care providers, health system or resource managers, and data services. Table 4.2 shows these groups, with some of the purposes for which digital technology could be used in the context of developmental disabilities.

Not all technologies are likely to be implementable globally, and Internet tools, and tablet and smartphone technologies appear to be more feasible in economically, culturally and linguistically diverse settings (130).

Digital devices have been progressively introduced in rehabilitation programmes for children with developmental disabilities. In children and adolescents with

Table 4.2. Technology for developmental disabilities

User group	Purpose	Example
General public: children and adolescents Parents and caregivers	Augmenting or providing alternative means to communicate	Various augmentative and alternative communication devices
	Skill-building activities	Games and web-accessible educational activities, virtual coaching, mental health interventions by virtual reality
	Communicating with peers	Internet, smartphone, tablets (e.g. for hearing-impaired children)
	Keeping electronic records of information and reports	Emails from professionals, questionnaires on progress
	Communicating with other families	Internet groups
	Accessing information about developmental disabilities and e-learning courses	Internet searches, e-learning platforms
	Seeking advice from professionals	Email communication, apps with feedback, sharing videos of child behaviour
Service providers	Maintaining medical records	Electronic medical records
	Advising families	Telemedicine facilities
	Peer support, training and continuous professional development	Webinars, web-based resources
	Electronic aids to intervention	Smartphone apps to support interventions
	Educational activities	Various electronic tools for teaching
Health systems and resource managers	Human resource management	Identifying and supporting appropriate development of health systems according to health system challenges and needs
	Financial management	Monitoring costs and activities associated with developmental disabilities
	"Signposting"	Providing up-to-date information about the available services
Data services, including "big data"	Identification of subgroups of developmental disabilities	"Digital phenotyping", including voice-processing, eye-tracking and other sensing technologies
	Identification of early markers of risk for developmental disabilities to be used in screening	Remote analysis of behavioural videos
	Economic modelling	Generation of economic models to determine the costs and cost-benefit ratios of specific care pathways and interventions
	Identification of appropriate markers of intervention outcomes	Questionnaires, behaviour counts, outcome measures rated by parents and carers

intellectual disabilities, digital interventions can be effective in improving working memory and academic skills, and can positively affect social and behavioural skills (133). These interventions use games or videos on computers or handheld devices to enhance skills on tasks (e.g. mazes, puzzles, matching, discrimination, and sequences) (134). Some studies on the effectiveness of therapy for children with cerebral palsy delivered over the Internet have had

encouraging results (e.g. physiotherapy (135) and articulation therapy (136)). A review of attempts in high-income countries to make training in interventions for autism available on the Internet concluded that some appear to be as efficacious as face-to-face training (136, 137); however, accessibility, acceptability and longer-term outcomes should be evaluated carefully. There are promising experiences with the use of tablet-based training programmes

to teach and guide caregivers, community-based workers and teachers in the delivery of parenting and brief psychological interventions in remote rural communities (138).

Despite the potential of these technological advances, several important risks and limitations should be considered. The same high standard for the evidence bases for medications, psychological interventions and medical devices should be maintained for digital health tools. Yet, there is limited evidence for the efficacy of many of the apps, games, activities and technological interventions proposed (e.g. robotics and virtual reality). Researchers in different countries developed tools for evaluation (139). There is a risk that the digital divide between rich and poor will widen rather than shrink unless concerted action is taken by governments, in partnership with industry and other stakeholders (140). A number of other risks should be monitored in using digital technologies for children with developmental disabilities, including risks to privacy and confidentiality of information, exposure of children to cyber-bullying and access to unreliable sources of information on the Internet.

4.5 Competences, human resources and services

A competent workforce is the backbone of an inclusive health system. Care providers at different levels of care need to achieve and maintain skills for the inclusion of children with developmental disabilities in routine health promotion and care, and for the provision of individualized treatment and support according to their needs. In a tiered system of care, diverse providers adopt different but complementary roles. Care providers will also have to learn skills to coordinate and collaborate with other members of the care team within and across services, in the health systems and with services in other sectors. Table 4.3 provides examples of competencies for care providers working at different levels of the health system.

Primary care services play an important role in early identification of developmental disabilities and coordination of care, but in many countries doctors and nurses receive little training in neurology, mental health and disability inclusion. General practitioners and nurses in outpatient care facilities

Table 4.3. Competences for staff at different levels of the care system

Provider	Examples of competences
Community providers For example, early childhood development providers, lay counsellors, community workers, social workers, teachers	<ul style="list-style-type: none"> > Can perform developmental monitoring and surveillance > Can provide psychoeducation, counselling and low-intensity psychosocial interventions > Can facilitate access to financial and psychological support > Can facilitate dialogue to support development of individualized comprehensive support plans > Can work in interdisciplinary and collaborative teams > Can implement outreach activities
General health care providers For example, general practitioners, nurses, case managers	<ul style="list-style-type: none"> > Can perform developmental monitoring and identify children with developmental disabilities > Can support youth and families with treatment goal setting > Can facilitate development of individualized comprehensive support plans > Can promote shared decision-making with the child and/or family > Can facilitate coordination of care, liaison with other sectors and referrals to specialists > Can identify and manage health risks and comorbid conditions > Can monitor intervention outcomes and treatment side-effects
Specialists For example, speech therapists, psychologists, psychiatrists, paediatricians, occupational therapists, specialized teachers, school mental health nurse	<ul style="list-style-type: none"> > Can perform diagnostic and functional assessments > Can develop individualized care and rehabilitation plans > Can manage complex cases and provide treatment and rehabilitation interventions based on specialized training > Can work in collaborative care teams > Can supervise, train and support non-specialists

will often see, but not always recognize, children with developmental delays and behavioural problems. Competencies and attitudes among primary care and general health care staff are consistently reported to be among the important factors that influence experiences of health care for children and young people with developmental disabilities and their families (17). WHO's Mental Health Gap Action Programme (mhGAP) Intervention Guide and related implementation tools have been used to facilitate identification of developmental disabilities and to build competences for provision of psychoeducation, initiation of care management plans and coordination of care in a range of LMICs (8). Under the mhGAP approach, some of the counselling and clinical care tasks are delivered by trained non-specialist providers with the support of specialists. Structural aspects of health-care systems – including workloads, workforce motivational factors, as well as protocols for delivery of psychological intervention – appear to play a fundamental role in facilitating or hindering the achievement of mhGAP goals (141–144).

Building competencies for delivery of care for children with developmental disabilities in communities requires the integration of different cadres of specialists into primary health care and community-based services. Co-location models involve locating mental health specialists, such as counsellors or psychologists, in primary care facilities. Consultation models have specialists “on call” to advise primary health providers. Collaborative care models are the most tightly integrated approaches. In collaborative care, the team comprises a care manager and general medical provider based in a primary health care facility, together with an external care specialist based at a secondary or tertiary care facility. A large body of evidence – including in LMICs – supports the use of collaborative care to improve experiences with navigating different services (7).

Collaborative care models can also create efficiencies in establishing tasks and roles of specialist care providers. This is particularly relevant given the fact that specialists with competencies in assessment, care and rehabilitation for developmental disabilities are largely insufficient. The mental health workforce for children and adolescents across different cadres in LMICs, as reported in WHO's Mental Health Atlas 2020, is scarce or non-existent for some categories such as speech therapists and occupational therapists. For children and adolescents there is a global median of just three mental health workers of any kind per 100 000; the equivalent in low-income countries is 0.1 (145).

Efforts to expand the specialist workforce are growing. As an example, the Centre for Child and Adolescent Mental Health at the University of Ibadan, Nigeria was established to build capacity in child mental health in west Africa and other lower-resource settings. It has trained 157 professionals from 14 countries in sub-Saharan Africa since 2013. Alumni have pioneered child and adolescent care services, such as the Centre for Early Development and Learning and Care in Ibadan, a multidisciplinary facility providing holistic care for children with neurodevelopmental conditions and a multidisciplinary clinic at the Komfo Anokye Teaching Hospital in Kumasi, Ghana (146).

4.6 Continuous collection of data for monitoring, evaluation and improvement of care

Children with developmental disabilities experience inequitable quality and safety outcomes in hospital and other health-care settings (29, 147–149). For example, persons with intellectual disabilities can experience delay or discrimination in diagnostic procedures or treatments, delays in treatment of pain, and inappropriate communication strategies resulting in lack of information, inadequate engagement in treatment choices and communication related errors (150). Governments and intersectoral alliances for children with developmental disabilities have the mandate to set standards for care quality and for guidelines and targets for best practices. Responsible bodies should commit themselves to continuous monitoring and evaluation of quality of care for children with developmental disabilities, and have mechanisms for data-informed strengthening of services.

An important condition for systems to monitor and address inequities in quality of care is the accurate recognition and recording of developmental disabilities when children and young people access health-care services. The available data points to the fact that, in the majority of cases, developmental disabilities are not recorded in health registers (145, 149). When electronic health data systems identify children with developmental disabilities, standard care quality metrics can distinguish problematic areas for further exploration and improvement.

Frameworks for monitoring quality of care for persons with developmental disabilities frequently involve the collection of data on care system performance (e.g. service coordination, workforce, access, costs, alignment with human-rights and evidence-based

practices), health outcomes and family experiences (e.g. satisfaction, quality of life, community participation, choice and decision making) (151).

There is growing recognition of the importance of service users' perspectives and engagement in strategies to assess and improve quality of care for persons with developmental disabilities (152). As a consequence, surveys based on participant reports are increasingly being used to appraise service quality and system performance. Engaging children and families in clinical incident reporting may enhance understanding of safety risks for children with intellectual disabilities in hospital (147). It is important to develop or adapt patient experience measures of care quality to enable children with developmental disabilities to voice their preferences of health care, and actively participate in the care improvement process.

4.7 Special considerations in humanitarian settings

All the complexities outlined in choosing and implementing models of service and interventions for children with developmental disabilities and their families are compounded in settings affected by armed conflict, oppression and/or natural disasters. For example, in Turkana, Kenya, where the population lives in poverty and is often affected by drought, children with disabilities were twice as likely to be malnourished than neighbouring children, and were unable to access feeding programmes as these were provided at school, which many disabled children did not attend (153).

The United Nations High Commissioner for Refugees has estimated that there are 108.4 million forcibly displaced people worldwide, 41 per cent of whom are under the age of 18 (154). Children with and without disabilities experience threats and repeated loss (of

family members, friends, routine and comforts). The consequences, for both parents and children, are often overwhelming anxiety and sadness, which, for some, lead to depressive disorder and post-traumatic stress (155, 156). The greater vulnerability of some disabled children to abuse and trafficking should be an additional consideration in application of child protection procedures.

Promoting health in refugee children with disabilities involves setting up psychosocial referral systems for children and their families, ensuring that child-friendly spaces and early learning and education programmes include children with developmental disabilities, and training emergency-response and care staff in disability inclusion (157). An example of a programme for refugee children with developmental disabilities is a "trauma-informed" parent-teacher cooperative training programme for Syrian refugee autistic children in Türkiye (158), which recommended flexible methods of delivering training, including online, due to distance, political unrest or lack of safety.

The COVID-19 pandemic has magnified weaknesses in global health, education, social and economic systems, resulting in major humanitarian concerns. For children with developmental disabilities and their families, COVID-19 has caused significant distress, in part attributable to the virus, but also due to the socioeconomic and emotional burden caused by lockdowns (159, 160). Nevertheless, many health and education services have innovated strategies, such as adding sign-language interpretation to lessons delivered on television, creating educational mini-videos for the parents of children with developmental disabilities, and providing training to teachers to support learning by children at home (161). Such strategies will have wide applicability in the future.

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5. Promoting participation

Fundamentally, participation is the involvement of people in activities and decisions that affect their lives. Participation is both an input and an outcome of interventions for children with developmental disabilities (1). Active participation of young people with developmental disabilities empowers them to play a vital role in their own development and in the development of their communities (2). Participation is a direct challenge to the stigmatization and discrimination experienced by children with developmental disabilities and their families.

Related to participation is the concept of inclusion. Inclusion means promoting the full participation of individuals and groups in all aspects of community life. Whether at school or work, in clubs or playgrounds, at the health centre or the supermarket, the right to inclusion requires the removal of barriers and social structures which impede participation.

5.1 Normative framework

Participation is a fundamental right; it is a guiding principle of the Universal Declaration of Human Rights and numerous other Conventions and Declarations. The UNCRC (3) promotes the right of children with disabilities to have their views considered in actions that affect them, in line with their developing capacity for self-determination. Building on this, the Preamble of the UNCRPD states that participation is critical to achieving the fulfilment of human rights for people with disabilities, arguing that it “will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty” (4). Accordingly, Article 4 of the CRPD introduces a requirement on governments to consult with organizations that represent children with disabilities on laws and policies that affect them.

Participation is also central to achievement of the SDGs, which include a commitment to leaving no one behind in addressing poverty and human development. In the case of children with developmental disabilities, this implies removing barriers to participation that they and their families might encounter, thereby promoting their potential to thrive and transforming health and human potential in healthy communities.

5.2 The importance of participation for child outcomes

All children have the same basic needs for love and acceptance through the presence of and participation in a family and a community (5). Participation in various meaningful activities in different environments (including home, school and community) is critical for all children, including those with developmental disabilities, for developing skills, expressing creativity, experiencing enjoyment and developing a sense of identity and self-esteem (1, 4, 6).

From early in life, infants and children with developmental disabilities have fewer opportunities for early stimulation and early learning, as their impairments in motor, communication and social skills can reduce caregiver responsiveness and interfere with establishing and sustaining caregiver-child interactions, which are foundational elements for the promotion of child development (7). From as early as 5 years, children with developmental disabilities participate less frequently in communities than their peers (7, 8). They can flourish only in a context conducive to their participation. Children with developmental disabilities must be engaged in health, development, education, learning and recreational programmes to ensure their well-being and social inclusion.

5.3 Restrictions to participation

Participation restrictions are defined in the context of the ICF as “problems an individual may experience in [their] involvement in life situations”, while disability is defined as: “... an interaction between features of the person and features of the overall context in which the person lives” (9). The ICF considers functioning at the levels of impairments, limitations on activity and restrictions to participation, focusing on the way in which health conditions interact with personal and external factors. The ICF definition therefore captures the extent to which a child’s environment supports participation in daily activities. Participation can be made easier or more difficult by environmental factors, such as assistive technology, digital technology, support and relationships, services, policies and the beliefs of others (10).

5.4 Measuring participation

Participation can be defined objectively (e.g. number of situations, frequency, location), subjectively (e.g. enjoyment, satisfaction, importance) or by context and time (6). Participation is complex to measure because of the interrelated pathways among individuals and interpersonal, familial, social and cultural exposures and values. Participation is therefore not measured routinely in public monitoring. When it is measured, it is often operationalized in limited terms, such as access to and involvement in recreational activities. There is nevertheless consensus that participation should be measured in relation to children and adolescents

Box 5.1. Measuring participation among children and young people in Uganda

In rural eastern Uganda, participation was examined in a population-based, cross-sectional study among children and young people with and without cerebral palsy. The population in the region was largely comprised of rural subsistence farmers, with more than 60% living below the poverty line (11). Traditionally in the region, having a child with a disability was deemed a punishment due to witchcraft or wrongdoing (12). These views of disability coupled with poor living conditions and limited access to health, education and social services (12, 13) often hinder participation. In this context, children and young people with disabilities experience diminished participation in social activities due to the lack of knowledge and cultural norms that perpetuate discrimination and stigmatization.

Participation, defined as attendance and involvement in activities of daily living, was examined among 82 children and young people with cerebral palsy and 81 peers without cerebral palsy. It was found that children with cerebral palsy participated less in activities of daily living than those without cerebral palsy (14). Furthermore, a greater difference in participation was seen in community-based activities compared with home-based activities (14). Children with less severe impairments engaged in participation more frequently than those with severe impairments. The limited access to health and rehabilitation services for children in Uganda could also have informed the lower scores related to functional skills and the slower rates of improvement in gross motor function and mobility, when compared with children in higher-income settings (15, 16).

with developmental disabilities. An example of the measurement of participation among Ugandan children and young people is described in Box 5.1. Tracking progress in international frameworks and achieving national goals depends on accurate, reliable figures on their participation (see also chapter 6).

5.5 Strengthening participation

Promotion of the participation of children with developmental disabilities should be framed in an ecosystemic perspective – addressing policy, environmental, community, family and individual factors – and focus on addressing barriers and developing opportunities for participation in enabling environments. For example, the Disabled Children’s Action Group in South Africa introduced an initiative to address the gaps and challenges in child justice systems for children with developmental disabilities. The intervention strengthened the provision of support services for social participation of children with developmental disabilities, including a care dependency grant, rehabilitation services, early childhood development services, assistive devices, inclusive education and access to health facilities (17). The aim of the intervention was to remove the barriers that hinder children and adolescents with developmental disabilities from exercising their right to participate in society.

Various legal and policy provisions and planning are necessary to support children and adolescents with developmental disabilities to participate optimally, be included meaningfully, access the services they want and ultimately reach their full potential. Some of the areas critical to participation are discussed below.

Eliminating stigmatization and segregation

Stigmatization occurs when a community endorses prejudiced ideas, which typically manifest as negative emotional responses and devaluation (18–20). Children and adolescents with developmental disabilities are commonly considered to be “damaged”, “dependent” and “incapable of participation”. Material exclusion and stigmatization reinforce one another, and both can have harmful psychological effects on children and adolescents with developmental disabilities and their families (21). When negative ideas are internalized, the exclusion is more difficult to overcome. Parents of children and adolescents with developmental disabilities experience anxiety about their child being rejected, teased or otherwise

emotionally or physically hurt by their peers and other community members (22–24). Stigmatization can affect the life chances of children and young persons with developmental disabilities, including learning opportunities, social interactions, earning capacity, risk of criminality and health status (18). Stigmatization can also isolate both children and adolescents with developmental disabilities from their families, limiting support and belonging (24), with possible negative effects on family cohesion.

Children with ADHD, for example, experience stigmatizing responses from their peers, such as the perception that they are dangerous and/or that they are personally responsible for symptoms; these responses can manifest in anger, fear and social distancing (25). Parents and teachers may also make negative assumptions about the academic ability of children and adolescents with developmental disabilities (25). Children and adolescents with developmental disabilities are also more likely to experience bullying and violence (26). A national prevalence study on bully victimization among students with disabilities in the United States of America (USA) found that elementary and middle school students with ASD were at the greatest risk of experiencing repeated victimization (27). Children with cerebral palsy have often been labelled with derogatory names by their peers and persons in their community, leading to isolation and social distancing (28). Caregivers of children with developmental disabilities also experience stress, stigmatization and discrimination, particularly in some cultural contexts (29, 30).

Awareness-raising and education are essential to help communities overcome prejudices (31). Use of social and behaviour change communication to improve awareness of disability rights and facilitate interpersonal dialogue can change attitudes. Thus, non-participation of children and adolescents with developmental disabilities is not inevitable, as it often results from attitudinal barriers, not functional limitations. Situating disability beside race and gender as another axis of diversity and discrimination can help build understanding. However, it is important to recognize that most children and adolescents with developmental disabilities, unlike women and members of oppressed racial groups, grow up as the only “different” person in their family, so that they lack the protection from internalizing stigmatization that stems from shared experience (32). The neurodiversity movement has contributed significantly to advancing a strengths-based narrative that values the potential of and the diversity in neurocognitive profiles.

Not all children and adolescents with developmental disabilities experience the same negative attitudes. Attitudinal barriers can be compounded by other factors, such as gender, ethnicity, type of impairment or income status. As a result, children and young people with developmental disabilities cannot be considered a single, homogeneous group for social and behaviour change communication. Awareness-raising programmes should take into consideration the intersections among different characteristics.

Furthermore, because of the influential position of professionals involved in key services (including teachers and health professionals) in the lives of children and adolescents with developmental disabilities, they should receive tuition in disability, diversity and inclusion during vocational training. The emergence of groups of adults with disabilities who have achieved success in education and employment is essential for addressing stigmatization, as they function as role models for children and adolescents with developmental disabilities (33). Clear career pathways for children and adolescents with developmental disabilities also help to reduce stigmatization; this requires the involvement of employers and business owners (in various industries) in awareness programmes and partnerships with universities and institutions for vocational studies.

Institutional care and segregated social services for persons with developmental disabilities threaten their dignity and independence and contribute to disadvantages in education, employment and community participation. Young people with developmental disabilities and their caregivers should be included in deinstitutionalization and supported in transitions of care and in making decisions about care and living arrangements (34, 35). The provision of care in the family and community, rehabilitation and habilitation approaches and schools that include children with developmental disabilities should be priorities to ensure participation and that children remain living with families and in communities.

Promoting participation in health care

Children and adolescents with developmental disabilities often experience barriers to health care, including stigmatization (see above), poorly trained health professionals, physical inaccessibility of buildings (including clinics and hospitals) and inaccessible information (36, 37). Barriers to promotive and preventive services for children and adolescents with developmental disabilities may result in them having poorer health and shorter life expectancy than

their peers (38). Promotive and preventive services appear to be changing, however, with increasing priority for health promotion for children and adolescents with developmental disabilities. Partnerships between health service providers and parents increasingly form the basis for prevention of secondary conditions and promotion of healthy lifestyles.

Action to promote the participation of children and young people with developmental disabilities in health care includes training care providers to remove attitudinal and communication barriers; strengthening care providers' competence to promote shared, informed decision-making with young people and their caregivers, as appropriate, on the targets and modalities of interventions and care pathways; and promoting meaningful engagement of young people with developmental disabilities and caregivers in designing, delivering and monitoring health-care services.

The training provided to health professionals should include instruction by people with disabilities, such as helping them to engage directly with children and adolescents with developmental disabilities in making decisions about their health care (37). Shared decision-making as a means of participation in health care includes bidirectional sharing of information about treatment options (including planning, delivery and co-design of care) and preferences, according to individual views, family goals and cultural and societal values (39). Health professionals also require skills in engaging with caregivers of children and adolescents with developmental delays and disabilities to find strategies for increasing the independence of children and adolescents with developmental disabilities, while maintaining the necessary parental involvement and support.

Children and adolescents with developmental disabilities should be involved in designing interventions about what works for them. One study showed that young people's views must be elicited in developing self-management practices for adolescents with ADHD and their families, as what is acceptable to adults may be resisted by adolescents (40). Meaningful participation of children and their caregivers in health care has been found to increase quality of life (41).

Promoting participation in education

Children and adolescents with disabilities are more likely to be excluded from education than those without (42). Children with sensory, physical or intellectual disabilities are 2.5 times more likely than children without disabilities to have never attended school (43). Teachers are not taught about diversity

and inclusive education, and in some countries they have little understanding of teaching strategies specific for children with impairments (44, 45). Even where inclusion is commonplace, equal participation of children and adolescents with developmental disabilities is not guaranteed in all aspects of the curriculum. One study in the USA, for example, found that 50–60% of children with intellectual disabilities participated in classes and 69% in field trips, but only 33% in playground games (46). Young adolescents with intellectual disabilities in South Africa also engaged less than their peers in activities related to personal care and development (47).

A persistent barrier to education experienced by children and adolescents with developmental disabilities is low expectations; prejudice and negative attitudes about the ability of these children and adolescents to learn in general educational settings with other children are common among parents (44) and teachers (48). Such beliefs are contrary to the UNCRPD, which calls for the inclusion of children and adolescents with developmental disabilities not only in promoting their own participation but so that all children and adolescents benefit from their interaction with a diverse student population (44, 49).

The UNCRPD Committee's General Comment 4 (50) describes what inclusive education entails:

- Universal design for learning promotes the preparation of environments to meet the widest diversity of learners and can contribute to a school environment that is more accessible and welcoming for all. General Comment 4 provides guidance on teaching strategies, curricula and assessments aligned with universal design for learning, "which consists of a set of principles providing teachers and other staff with a structure for creating adaptable learning environments and developing instruction to meet the diverse needs of all learners."
- The physical environment may exclude children with physical disabilities from access at the outset. Universal design principles and national accessibility standards also help to ensure that school infrastructure is accessible to children and adolescents with developmental disabilities. New schools should be built and existing schools adapted to meet these standards. See Box 5.2 for an example of the use of universal design.
- Individualized support for specific impairments must be provided (43, 50). For example, children with cerebral palsy might require assistive devices for mobility and communication in order to benefit from an inclusive classroom.

- Family-school partnerships are a cornerstone of effective educational inclusion of children and adolescents with developmental disabilities (51). Building connections between families and school staff requires recognition of cultural beliefs about disability and the purpose of education, while also promoting participation (52, 53). The participation of families should therefore be actively sought and encouraged. Teachers should develop skills in facilitating such partnerships (49). A collaborative model, in which teachers work with specialists in the classroom, enhances inclusion by avoiding “pulling out” children and adolescents with developmental disabilities from the class for individual support sessions (54).
- Teacher education is essential to achieving inclusive education, requiring knowledge about specific disabilities, awareness of disability rights and insight into ableist practices that discriminate against children and adolescents with developmental delays and disabilities

Box 5.2. Good practice: universal design in Norway

Norway is pioneering universal design in striving for a fully universally designed country by 2025. The Government’s Action plan for universal design, led by the Ministry of Children and Equality, operationalizes policy for equality and sustainability by building better, more equal surroundings for people with disabilities (55).

Before the plan, several Acts and Regulations were amended to ensure that there were policy or legal provisions for universal design and that accessibility was mandated in all sectors. The action plan covers four main areas: building and construction; planning and outdoor areas; transport; and information and communication technology. The plan includes a number of goals and priorities related to young people, including addressing inequalities in education, transport and leisure-time activities, and a focus on urban infrastructure and making information and communication technology accessible to young people with disabilities.

Norway’s universal design action plan is an example of how a sector-wide, multi-sectoral, integrated plan can facilitate cooperation among national and subnational parties to achieve the goals of the UNCRPD.

(44, 48). Teacher education should include techniques and materials to support children and adolescents with developmental delays and disabilities, strategies for individualized instruction that responds to different learning styles and abilities, and tuition in developing individual education programmes (50). At times, it is appropriate for children and adolescents with developmental delays and disabilities to work towards their own goals rather than being subject to standardized assessments that may disadvantage them (56).

While identification of developmental disabilities at school can be beneficial, this should be done with care, as misconceptions and stigmatization can negatively affect children and their families (55).

Improving participation of families

Both the ICF (6) and the Nurturing Care Framework (57) position the family as the central environmental force in the lives of children and adolescents. Families play a pivotal role in nurturing relationships and the early environment of children and adolescents with developmental disabilities (58). Families must therefore have the skills and support necessary to promote health, development and participation.

Service provision for children and adolescents with developmental disabilities should be aligned with the principles of family-centred services in domains such as health, education and social protection. A basic principle of family-centred services is sustained partnerships between parents and professionals, such as teachers, health practitioners and community development workers, with the involvement of parents and caregivers in every aspect of service provision (59). Approaches that are family-centred result in more positive outcomes in children and also increase parents’ satisfaction with services and reduce their stress (60). Parents of children and adolescents with developmental disabilities often describe continual struggles with many service providers, which drain their physical and emotional resources. Coordination of health and other services is an important means of reducing parent stress (61). Instruments such as the Family Needs Assessment Tool are useful for collecting details of the support required by families of children and adolescents with developmental disabilities, to inform programme planning (62). CASE-C is an instrument with which parents and practitioners can identify environmental barriers to participation and collaborate in planning strategies to overcome

them (63). Similarly, methods such as “occupational performance coaching” provide a framework in which practitioners partner with parents to enable participation of children and adolescents with developmental delays and disabilities at home and in the community (64).

Understanding the strategies developed by families to promote their child’s participation helps practitioners to provide more useful support (65). Further, families trained in psychosocial interventions and strategies for inclusion can support the participation and thriving of children and adolescents with developmental delays and disabilities (66). The parents of children with physical disabilities can create environments that support participation at home and in the community (67). Parents can also encourage and support their child’s participation, as they understand which activities their child will find meaningful and enjoyable. The actions of parents must, however, be complemented by barrier-free environments, supportive professionals and other facilitative aspects, including skilled professional staff and adequate information (68).

Parental and self-advocacy

Children with developmental disabilities often have few expectations of participating and must therefore be empowered and supported to advocate for their needs. Awareness campaigns and advocacy by people with developmental disabilities and/or coordinated by organizations of persons with disabilities remain critical. Furthermore, as countries establish opportunities for youth leadership, efforts should be made to promote the participation of young people with developmental disabilities in planning and coordinating youth-related programmes.

Parents and caregivers also well understand the barriers experienced by children and adolescents with developmental disabilities; therefore, enabling them to raise awareness of and address those barriers is critical. Studies show how parents and caregivers can change and use the environment to support and develop the capabilities of their children (60). Such strategies include establishing a network of contacts with people in similar circumstances, who are often other families of children and adolescents with developmental disabilities; informing and instructing others on how best to support the participation of their child, such as explaining to their teacher how teaching materials may be made more accessible; and advocating and creating opportunities for their child (69).

Supporting parents’ mental health

Because of the complex emotional and economic demands of caring for children and adolescents with developmental disabilities, difficulty in accessing services and prejudiced attitudes, parents often experience symptoms of emotional distress, which may manifest as anxiety or depression. Experience indicates a relation between the severity of impairment, the availability of essential services and resources and the emotional well-being of parents (68). The mental health of parents of children and adolescents with developmental disabilities requires attention, for their own health and for the benefit of their children. Ensuring that caregivers have access to high-quality mental health services is essential to safeguarding and optimizing their children’s opportunities to participate (67). Caregiver-mediated interventions for families of children with developmental disabilities therefore often include sessions on caregivers’ mental health and well-being, and evidence suggests that they can improve the mental health and resilience of parents of children with developmental disabilities and reduce their emotional distress (71, 72). In poor communities, self-help groups for caregiver empowerment improve parents’ perceptions of the availability of social support, reduce perceptions of the severity of their child’s disability and create a perceived reduction in extrinsic factors that affect the caregiver’s role (72).

Improving participation in communities

Compared with their peers, children with developmental disabilities often face limited choices and opportunities to engage in recreational activities, sports, social events and spiritual and personal development activities (73, 74). Individual factors (health, function, age, past experiences), family factors (good health, family expectations and support), community attitudes, presence or not of supportive networks, accessibility of spaces, requirements for adaptive equipment and costs shape their participation in recreational activities and their social roles (75, 76). Strengthening participation in recreational, sport and other community activities throughout childhood and adolescence can build a sense of belonging and connectedness, as well as opportunities for independent living and employment in adulthood, all of which impact well-being trajectories and quality of life (77).

Community-based inclusive development (CBID), which was originally known as community-based rehabilitation, is a community development strategy

that aims to maximize opportunities for health, education, livelihoods, social life and community participation for people with disabilities and their families (78). CBID is founded on self-empowerment and the participation of persons with disabilities in their communities as the basis of collective action to build equitable and inclusive communities. The implementation approach involves participatory community mapping to understand resources and barriers to inclusion, followed by capacity-building, awareness-raising and community-led monitoring.

Programme strategies are tailored to local contexts. In the CBID project supported by CBM in the Indonesian province of Aceh, self-help groups had a central role in advocating at local levels on issues relating to poverty and people with disabilities (79). In Lao People's Democratic Republic, a CBID demonstration programme is supported by the United States Agency for International Development and implemented by the nongovernmental organization World Education Inc., in close collaboration with Humanity and Inclusion and with government and non-government partners. In this context, the approach encompasses individual case management and community mobilization to remove barriers to participation by utilizing innovative interventions that directly address the health, livelihoods and social needs of people with disabilities (80). CBID teams of lay social workers directly support people with disabilities to identify their needs, and work with families, communities, local authorities and relevant service providers to meet their support requirements.

Participation and employment

Youth with developmental disabilities struggle with finding opportunities in the labour market, and in the transition between education and the workplace. Across 32 countries that are members of the Organization for Economic Cooperation and Development, about 30% of youth with disabilities and nearly 70% of those with high support requirements were not in employment, education or training (NEET) in 2019, compared with only one in eight youth without a disability (81).

Encouraging businesses to adopt inclusive recruitment and employment policies and practices is important and requires employers to facilitate working conditions and support that are tailored to an individual's needs and preferences. The skills divide contributes to the large disability employment gap. Mainstream programmes to help NEETs and to facilitate their transition to the labour market

must have a stronger focus on building skills and addressing barriers for youth with disabilities, while providing them with adequate social protection (81). Vocational and continuous learning programmes that are integrated into workplaces have emerged as promising practices (82). Supported employment programmes offer opportunities for people with disabilities to learn the job skills they need in their workplace and build the capacity of employers to match job opportunities and create conditions for inclusion. Examples of workplace accommodations for autistic people include: modification of work schedules; physical changes to the workspace; equipment and devices; job restructuring; adjustment of supervisory methods; and job coaching.

Other intersectoral interventions to improve access to employment for young people with developmental disabilities include establishing social enterprises and livelihood programmes.

Improving participation in the digital space

The digital environment is a fundamental part of children's daily lives and interactions in a number of contexts. It can have a role in formal and informal education, health services, recreation, maintaining links to culture, socializing, expressing identity and creativity through the creation of digital content and engagement with activism and citizenship initiatives and groups, and as a space for consumption.

Digital participation means that people are able to participate in the use and design of the Internet, digital media and modern technologies (83). There are three main aspects of digital participation (84): a) participation in digital technologies, meaning access to and competent usage of digital devices; b) participation through digital technologies, meaning participation through alternative access options; and c) participation within the digital world, meaning active participation in social networks, digital services and media.

A child's experience of the digital world is mediated by their unique characteristics. This is particularly true of children with disabilities. For them, the digital world presents both huge opportunities and challenges. Digital technologies can empower children with developmental disabilities in ways that help them expand opportunities for social participation and improve functioning (85–88). For children who require mobility support, for example, digital location imaging can help them to understand if an area is wheelchair accessible.

In other ways, the digital environment can expose children to dangers and increase inequalities in participation. In fact, children with disabilities are more vulnerable to risks, including conduct (e.g. bullying, misinformation), privacy (e.g. hacking) and commercial (e.g. economic exploitation) risks. Persons with developmental disabilities are one of many groups in our society who are often affected by digital divides (89).

There is some evidence showing that people with disabilities use the Internet and Internet-enabled devices and services less often than people without disabilities (90, 91). However, access to and usage of digital media depend on age, living situation and the type of impairment (90, 92). One study found that, among people with disabilities, people with intellectual disabilities were those with the lowest smartphone utilization rates (93).

The two main reasons for the lower use of digital services by persons with disabilities are lack of accessibility and lack of digital skills (also called digital literacy).

There have been important developments in digital accessibility, with technical aids and smartphone applications becoming increasingly available for people with hearing or visual impairments. Features of digital design, such as voice, chat and video functions can offer alternatives to children with communication impairments. Some countries have policy obligations and guidelines to consider reasonable adjustments for people with disabilities in the design and development of public sector digital services, including mobile apps.

Digital literacy is the ability to understand and to use information from a variety of digital sources and comprises competencies such as Internet searching, hypertext navigation, knowledge assembly and content evaluation (94, 95). Inadequate knowledge or training as well as insufficient support to develop digital skills are common barriers for persons with intellectual disabilities (96–99).

Policies and research can play important roles in providing the parameters for children with developmental disabilities to be protected and enabled to realize the benefits of the digital environment.

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6. Public health monitoring of children with developmental disabilities

The SDG mandate to promote health, well-being, children's development and universal health coverage, "leaving no-one behind", has provided momentum for the development of policies and services to include and protect the health and well-being of all children. As discussed in chapters 1 and 3, other guiding documents have operationalized this mandate into frameworks and plans (1–3). Yet to make progress in achieving the ambitious targets of the SDGs and to understand the impacts of these targets for children with developmental disabilities, better data must be collected to monitor and evaluate progress for this population at community, subnational, national and global levels. The aim is to track actions to improve health outcomes for children with developmental disabilities, at all levels of society and with the involvement of relevant sectors and civil society organizations.

There is currently no adequate framework or overall guidance for monitoring progress in ensuring access and quality of care and enabling environments for the promotion of the development, health, well-being and participation of children and young people with developmental disabilities. There are examples of national surveillance programmes to monitor the prevalence of developmental disabilities, and in some countries the national health information system includes data on service use, diagnosis and risk factors (4, 5). However, efforts to document health inequities in countries are insufficient. In most countries data on service access and health outcomes for children with developmental disabilities are scant (6, 7). There are, however, several global incentives for the measurement of outputs and outcomes relevant for all children and for persons with disabilities, which include many of the indicators required for monitoring health outcomes and health inequities of children with developmental disabilities.

6.1 International frameworks and global accountability

A number of global incentives and mechanisms for monitoring national plans, actions and outcomes provide potential means for strengthening public health monitoring for children and young people with

developmental disabilities. Some are tied to specific consensus documents and legal treaties (like the SDGs, the UNCRPD or the UNCRC), while others reflect high-level attempts to find a global monitoring mechanism for child and adolescent health. Although the indicators used in some of these initiatives provide relevant information about the progress of children and young people with developmental disabilities, most would have to be disaggregated by health condition, disability or functioning status to inform tailored efforts. Furthermore, new indicators should be developed that are relevant to the lives, health, well-being and participation of children and young people with developmental disabilities.

The Global Strategy for Women's, Children's and Adolescents' Health (1) and Countdown 2030 (8) each provide a framework and a dashboard for tracking indicators of women and children's health, including demographics, coverage, policy, systems, financing, service delivery, nutritional status and equity.

Three other initiatives to harmonize and standardize monitoring of progress for children and young people are:

- the Child Health Accountability Tracking Technical Advisory Group (9), a group that reports on the harmonization and standardization of child health and well-being indicators to WHO and UNICEF;
- the Global Action for the Measurement of Adolescent Health (10), which provides technical guidance on defining a set of indicators of adolescent health; and
- the UNICEF, WHO and CAP Child Health and Well-Being Dashboard (11), which facilitates monitoring and comparison of a selection of indicators by region, country, age group, domain and income.

Each has a database of indicators of health and well-being outcomes in a variety of domains, including education, nutrition, mental health, violence, environment, injuries and communicable and noncommunicable diseases. Additional frameworks and initiatives also include indicators that are relevant to children and young people with developmental

disabilities, such as the WHO Comprehensive Mental Health Action Plan 2013–2030 (2), the WHO Global Disability Action Plan 2014–2021 (12), WHO's *Global report on health equity for persons with disabilities* (13), the Nurturing Care Framework Early Childhood Development: A framework for helping children survive and thrive to transform health and human potential (14) and the Intersectoral Global Action Plan on epilepsy and other neurological disorders 2022–2031 (15).

While disaggregation of existing indicators by disability and age group would improve public health monitoring in this population, each of the monitoring initiatives mentioned above could be further adapted to provide a more complete picture of progress for optimizing outcomes for children and young people with developmental disabilities. An appropriate process must be used to ensure that data are collected at various levels in the complex ecosystem of children with developmental disabilities and their families, including on government policies, services and the children and their families. Areas that are priorities for monitoring are described below, organized as inputs, outputs and outcomes. Fig. 6.1 provides priority areas for monitoring and example indicators.

6.2 Inputs

In the context of monitoring, inputs are the conditions that must be created for the achievement of outcomes. In the context of the global landscape of children and young people with developmental disabilities, the inputs include the leadership, governance, legal and policy frameworks that guide action; creating favourable conditions for inclusion and participation; investing in and financing health care, education and socioeconomic inclusion; workforce development and transformation of care systems; and development of robust monitoring and information systems to track progress.

Leadership, governance, laws and policies

The voices of children and young people with developmental disabilities and their families are often not heard, and their rights and needs are often not protected in legal and policy frameworks. The ratification of the UNCRC and UNCRPD by individual countries is important. Although legal and policy inputs vary, and some are difficult to measure, the following should be monitored: mechanisms to coordinate intersectoral actions to improve the health of children with developmental disabilities; policies and laws that guarantee equitable access of children and young

people with developmental disabilities to health-care services according to need without incurring financial hardship; and policies and standards to ensure high-quality, inclusive, human rights-based health services for children with developmental disabilities.

Examples of indicators:

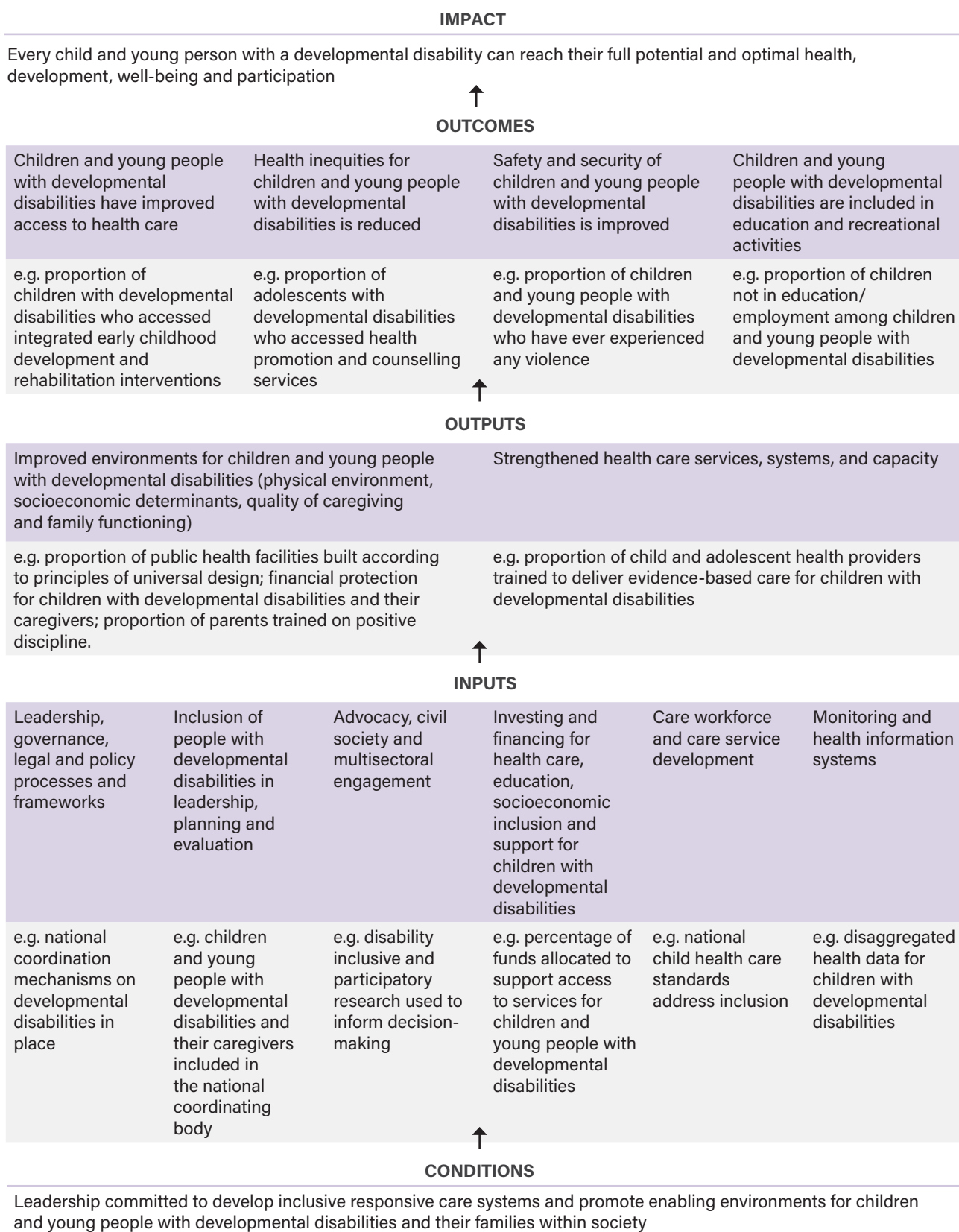
- mechanisms for national coordination on developmental disabilities in place, with the involvement of relevant sectors;
- legal and policy provisions that guarantee equitable access of children and young people with developmental disabilities to health-care services, according to needs and without incurring financial hardship;
- a national law that guarantees universal access to primary health care, including provisions for inclusive health care;
- laws for exemption of children and young people with developmental disabilities from user fees for assessment, psychosocial treatment and rehabilitation;
- standards on quality of care that include early childhood development, health care and rehabilitation services for children and young people with developmental disabilities;
- a legal age for married adolescents with developmental disabilities to provide consent for rehabilitation and mental health-care services without spousal consent, and without the consent of their parents or a legal guardian;
- a national law and/or policy that ensures the right of children and young people with developmental disabilities to access assistive devices from the WHO list of priority assistive products; and
- social protection and labour laws that ensure full enjoyment of human rights and fundamental freedoms on an equal basis with other children and within which the best interests of the child are a primary consideration.

Creating favourable conditions for inclusion and participation

Inclusion of persons with developmental disabilities in leadership, planning and evaluation

Governments should ensure responsive, inclusive, participatory and representative decision-making at all levels, as stated by SDG target 16.7. Policy-makers with lived experience of developmental disabilities can champion disability inclusion and take active roles in educating the public and in addressing stigmatization

Figure 6.1. Priority areas for monitoring and example indicators, defined as inputs, outputs and outcomes



of people with developmental disabilities. Knowledge of inclusive approaches and attitudes should also be monitored and enhanced at the highest levels of public offices, district administrations and national services.

Examples of indicators:

- the views of children and young people with developmental disabilities are included in relevant national coordinating bodies; and
- proportions of positions in public institutions, legislatures, public service and judiciary filled by people with developmental disabilities.

Advocacy, civil society and multisectoral engagement

Governance to improve the health of children with developmental disabilities involves actions at multiple ecological levels, as well as multistakeholder and multisectoral partnerships. Investment in – and meaningful engagement of – civil society organizations, including carers and advocacy groups, are core requirements.

Examples of indicators:

- mechanism for multistakeholder coordination and/or consultation established;
- policy information and communication is accessible to caregivers and self-advocates; and
- disability-inclusive research used to inform decision-making.

Investment and financing for health care, education, socioeconomic inclusion and support

Financing for health care, inclusive education and social protection should be monitored and analysed to understand the funding flows for developmental disabilities and the positive outcomes of this funding.

The best way to determine financing for health care, education and socioeconomic inclusion for children with developmental disabilities is not evident. Analysis of return on investment is a convenient means for comparing the efficiency of different methods, expressed in terms of the expected flow of positive outcomes. It differs from a cost-effectiveness analysis, which measures only health-related benefits. For example, the economic and social benefits of better well-being for children with developmental disabilities include both its intrinsic value (improved well-being) and its instrumental value (ability to form and maintain relationships, to study, to work

or to pursue leisure interests). WHO's OneHealth Tool (16) provides a fully integrated framework for planning health systems resources. A relevant initiative in Europe is "childonomics" (17), which combines economic discipline with child rights within a conceptual framework and provides a method for measuring the long-term social and economic returns on investing in children and families.

Examples of indicators:

- proportion of funds allocated for constructing inclusive structural amenities (public transport, disability-friendly services, buildings, environments, roads);
- proportion of funds allocated to ensure access of children and young people with developmental disabilities to health-care services;
- proportion of funds allocated for promotion, care and rehabilitation services and equipment for children and young people with developmental disabilities;
- proportion of households with children and young people with developmental disabilities that incur catastrophic out-of-pocket expenditure on health services;
- expenditure per student with a developmental disability on health and education according to level of education and source of funding;
- proportion of funds allocated to ensure access for children and young people with developmental disabilities to social protection; and
- proportion of funds allocated for collection of disaggregated data on children and young people with developmental disabilities.

Care workforce and care service development

A competent health-care workforce and inclusive and accessible health-care services are core pillars of responsive health systems.

National standards for the organization of care; quality improvement and monitoring strategies; guidelines for clinical assessment, screening, management and rehabilitation; and human resource development plans and curricula are among the most important requirements for provision of timely and age-appropriate access to support and care for children and young people with developmental disabilities.

Examples of indicators:

- physically accessible health facilities;
- standards on collaborative care for child health primary health-care services;

- standards for inclusive child and adolescent health services;
- competence in assessment and management of developmental disabilities included in national competency standards for child and adolescent health-care providers; and
- availability of continuous professional training in developmental disabilities for primary health-care clinicians and nurses.

Monitoring and health information systems

SDG 3 targets 3.2.2, 3.3.1 and 3.3.2 commit countries to collect data on the causes and prevalence of mortality among newborns and children under 5 years and on morbidity, including nutritional status. Many countries have data systems for tracking child health and education. Collection of data on children and young people with developmental disabilities is not specified. Information on child health and nutritional status disaggregated by disability would be informative for monitoring equity in health outcomes.

Improvement in care system quality and identification of groups exposed to risk and experiencing unmet needs is possible if a national information system is created for every diagnostic category of developmental disability. The related data must be collected completely and in a timely manner, integrating information across care systems.

Some initiatives have been made to create systems for data collection and monitoring in real time, for instance the RapidPro UNICEF digital monitoring system (18), cerebral palsy registers in Bangladesh and Sweden (19, 20) and the use of real-time monitoring systems in child protection (21).

Examples of indicators:

- existence of a framework for monitoring the effectiveness of multistakeholder achievement of the SDGs, for inclusion of children and young people with developmental disabilities;
- existence of age- and sex-disaggregated data on the health of children and young people with developmental disabilities in the national health information system; and
- routine collection of core indicators of the health outcomes of children and young people with developmental disabilities reported every two years to national health and social information systems.

6.3 Outputs

The development of monitoring and evaluation frameworks to track efforts to improve health outcomes in children with developmental disabilities need to consider outputs (i.e. products, services) at the level of the young person's environment and at the level of care systems.

Improved environments for children and young people with developmental disabilities (physical environment, socioeconomic determinants, quality of caregiving and family functioning)

A monitoring and evaluation framework must include measures to monitor exposures that influence health and well-being for children with developmental disabilities. It is important to consider the physical environment, socioeconomic determinants and cultural context, including stigma, poverty and violence. Nurturing home environments and social connectedness in schools have major influences on well-being and development; hence, efforts should be made to collect data on proxy indicators such as caregivers' mental health, proportion of caregivers trained on parenting and proportion of schools implementing policies that value diversity and inclusion.

Outputs to address stigmatization in community, health and education systems may include training, awareness-raising activities and media sensitization and engagement to challenge attitudinal barriers among lay people and care providers.

A high-quality natural environment, including access to green spaces, is vital for everyone and is monitored through SDG indicator 11.7.1, which addresses the average proportion of the built-up area of cities that is open space for public use for all, by sex, age and persons with disabilities. This indicator promotes open spaces for safe, inclusive, resilient navigation through cities, their quality and their accessibility for populations with disabilities. The data can be disaggregated by type of disability, including developmental disabilities. UN-HABITAT (22) uses satellite imagery, government land documents and community maps to estimate the proportion of the population of the city or urban areas with access to open public spaces within 400 m walking distance, with disaggregation by sex, age and persons with disabilities.

Examples of indicators:

- proportion of health-care, education and social care workers who receive training in inclusion

approaches for children with developmental disabilities;

- proportion of public health facilities built according to principles of universal design;
- financial protection for children with developmental disabilities and their caregivers;
- proportion of caregivers of children and adolescents with developmental disabilities who are trained on parenting and positive discipline;
- proportion of schools implementing policies that value diversities and inclusion;
- proportion of children and young people with developmental disabilities who have access to a local self-advocacy group;
- proportion of children and young people with developmental disabilities who have access to green spaces near to where they live;
- proportion of population of children and young people with developmental disabilities with access to open public space within 400 m;
- proportion of public health, education and social welfare facilities that are built according to the principles of universal design; and
- proportion of children with developmental disabilities who can access all the spaces they require (within the community, health structures and school).

Strengthened services, systems and capacity

Indicators of the availability of services, systems and capacity should include: availability of inclusive health care; availability of competent workforce, trained to deliver human rights-based and evidence-based care for children with developmental disabilities; accessible and affordable health-care services for assessment and management of developmental conditions; provision of diagnostics, medicines, psychological treatment and rehabilitation; assistive devices and technology; inclusive education (including early learning); and inclusive, disability-responsive social services and protection.

Examples of indicators:

- proportion of child and adolescent health-care providers who receive training in assessment and management of developmental disabilities;
- proportion of teachers and school administrators who receive training in inclusive education;
- availability of psychological therapy, health care and diagnostics, treatments and rehabilitation;
- adequacy of coverage with assistive devices of children and young people with developmental

disabilities by age and type of impairment;

- availability of early learning for children with disabilities; and
- proportion of schools in an area that have access to specialists in inclusive education.

6.4 Outcomes

Outcomes are the penultimate or ultimate results of inputs and outputs. The desired impact is a society where every child and young person with a developmental condition can reach their full potential and optimal standard of health, development, well-being and participation. When intersectoral actions produce improved environments and services for children with developmental disabilities, the consequent benefits can be defined as follows: children and young people with developmental disabilities have improved access to health care; reduced health inequities; improved safety and security; and improved inclusion in educational and recreational activities.

Example of indicators:

- proportion of children with developmental disabilities who access integrated early childhood-development and rehabilitation intervention;
- proportion of adolescents with developmental disabilities who access health promotion, rehabilitation and counselling services;
- proportion of children and young people with developmental disabilities who access assistive devices and technology;
- vaccination coverage among children with developmental disabilities;
- mortality rate among children and young people with developmental disabilities;
- proportion of children and young people with developmental disabilities who experience preventable co-occurring mental health and other health conditions;
- rates of school completion among children and young people with developmental disabilities;
- rates of stigmatization and discrimination against children and young people with developmental disabilities in health care, education and the community;
- proportion of children with developmental disabilities in institutions;
- rate of child labour among children and young people with developmental disabilities;
- proportion of children and young people with developmental disabilities who have experienced sexual or any other violence;

- proportion of children and young people with disabilities in a population covered by social protection systems;
- proportion of children with developmental disabilities who have access to early learning; and
- proportion of children and young people with developmental disabilities not in education/employment.

Initiatives and tools to monitor outcomes

Several countries have surveillance systems to monitor the number and characteristics of children and young people with specific conditions and/or exposed to risks and vulnerabilities. These include preterm birth follow-up and cerebral palsy registers, data from hearing and vision screening and, in some settings, networks for monitoring ASD, ADHD, ID and other specific neurodevelopmental disorders (23, 24). These national registers and the databases can be used in monitoring, evaluation and learning by providing linked data on large numbers of children registered in national management information systems.

Other initiatives focus on population-based measurement of functioning and disability (25, 26). The Washington Group Questions is a short six-item tool designed to identify people with limitations in functioning (267). The questions can be included in existing data collection activity within a programme-level monitoring and evaluation framework or can be incorporated into smaller-scale surveys. This tool is used widely within the MICS8 programme developed by UNICEF to provide internationally comparable, statistically rigorous data on the situation of children and women (27).

The Washington Group/UNICEF Module on Child Functioning covers children aged 2–17 years, and assesses functioning difficulties in different

domains including hearing, vision, communication/comprehension, learning, mobility and emotions. It is intended for use in national household surveys and censuses and can be useful for understanding inequities in health, nutrition and education. Limitations of the tool are that it provides data only for children > 2 years and may misrepresent the number of children with milder difficulties (28). Furthermore, it does not provide specific information on children's medical condition or level of functioning or on the child's present participation in activities and interventions provided within health, education and social care. The WHO Global Scales for Early Development (GSED) (25) provides a standardized method for measuring the development of children up to 36 months of age across diverse cultures and contexts. It has been created to serve as a population-level assessment of early childhood development and uses an innovative metric, the Developmental score (D-score) – a scale with interval properties – to measure children's development.

What is success?

Success in public-health monitoring for children with developmental disabilities is a situation where data collection systems and efforts, by the health and other relevant sectors, include and disaggregate information for children and young people with developmental disabilities. This would enable the tracking of health, development, well-being and participation determinants and outcomes; related unmet health needs; and health inequities or human rights violations. Success would also be where data are used to inform policies, services and advocacy, with the engagement of youth.

Monitoring and evaluation procedures will depend on geopolitical location because of inherent differences in resources, structures, services and legal instruments.

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7. The way forward

More than 7% of the world’s children under 5 and 14% of adolescents have a developmental disability, based on an analysis of data from the Global Burden of Disease Study 2019, as described in chapter 2. These young people are 51% more likely to consider themselves unhappy and 41% more likely to feel discriminated against (1). Limited opportunities to participate and interact with peers and to access learning and health care are a reality for many. Children, young people and adults with developmental disabilities also have increased risks for chronic health conditions and premature death (2,3).

Collective and sustained efforts and greater investment in changing social and care systems are needed to ensure that the rights of children and young people with developmental disabilities to enjoy the highest standards of health, well-being and

participation are realized. Midway to the deadline set out in the 2030 Agenda for Sustainable Development, the global community needs to turn words into action and accelerate implementation of policy and service changes to build back fairer for persons with developmental disabilities, anchoring investments in universal health coverage, disability inclusion and school readiness efforts.

The final chapter of this global report outlines a framework for action to optimize the health, well-being and participation of children and young people with developmental disabilities, in the context of whole-of-society collaborative work and investments (see Fig. 71). Each area for action will require adaptation to the cultural context to address the specific needs and priorities of children with developmental disabilities and their families in different parts of the world.

Fig. 7.1. Key action areas to accelerate changes in policies and care systems for better health, development and participation for children and young people with developmental disabilities



Action Area 1. Strengthen coordination and accountability mechanisms to improve outcomes for children and young people with developmental disabilities and their families

Establishment of multisectoral programmes to ensure that services are coordinated among sectors must be a priority, to ensure that the needs of children and young people with developmental disabilities and their families are met holistically. Coordination should include consideration for developmental disabilities within age-specific programmes, alongside coordinated approaches targeting subgroups of children with different diagnoses or exposed to specific adversities, and targeting different sectors. Impact in this area requires strengthened interagency cooperation, leadership and governance, with the allocation of budget resources across all relevant sectors and commensurate with identified needs and targets.

Increased accountability requires better definition and implementation of intersectoral strategies to monitor resources, inputs, the performance of care systems and the health, well-being, development and participation of children and young people with developmental disabilities. This will require the adoption of a set of indicators linked to national action plans and to global commitments, including SDG 3.4 and SDG 4.2.

Action Area 2. Deepen commitment at all levels

Growth in global activism and the COVID-19 pandemic have increased political attention to the imperative of equitable opportunities for health, development, well-being and participation for children and young people with developmental disabilities. However, the commitment expressed by policy-makers can only translate into meaningful changes if accompanied by a substantial increase in institutional commitment – policies and plans – and budgetary commitment. Financial investments need to be oriented – or reoriented – towards enhancing services and systems, with particular focus on education and community-based health care and improving supports and opportunities at family and community level. It is important to establish mechanisms for reviewing national expenditures and global health financing in ways that allow monitoring of opportunities for children with developmental disabilities to reach their optimal health and development potential and school readiness, in alignment with SDG commitments.

Action Area 3. Create opportunities for young people with developmental disabilities and their families to participate in advocacy, leadership, policy, programming and monitoring

Advocacy is the first step in raising awareness to ensure better public understanding of developmental disabilities, helping to address stigmatization and discrimination and preventing violation of human rights.

Effective advocacy increases awareness of the social determinants of developmental disabilities and of the barriers to inclusion and to access to health, education and social care services that children and families face, and how together these have impacts on the well-being and health outcomes of individuals and their families. Advocacy disseminates good practices in the delivery of interventions and organization of services; promotion of optimal health (including brain health, mental health and well-being, and improved health-seeking behaviour); access to care and early learning opportunities; and participation in society.

As experts with lived experience, adults, children and young people with developmental disabilities and their caregivers must be included in developing policy and programming relevant to their lives, and in implementation and evaluation. Their participation is essential to ensure a rights-based approach, and is also important for enhancing the relevance, feasibility, effectiveness and sustainability of overall programmes and policies. Adults, children and young people with developmental disabilities and their caregivers should be included intentionally, especially when they represent populations that have been underrepresented in such discussions, such as individuals who are more severely affected, communicate differently or cannot advocate for themselves.

Effective advocacy reflects each country's culture and systems. Effective advocacy can influence political will and mobilize resources for prioritization of policies on developmental disabilities, including in broader international commitments such as those enshrined in the SDGs and the UNCRPD.

Action Area 4. Address the social determinants of health, well-being and participation of children with developmental disabilities in policies, programmes and financing

Policy provisions and legal frameworks are necessary to protect children with developmental disabilities from risks and adversities including exposure to violence and abuse, to guarantee provision of and

access to social services and education and to safeguard the human rights and social protection of children and young people with developmental disabilities and their caregivers.

An important step is the removal of barriers to financing and affordability to ensure that children with developmental disabilities and their caregivers can afford and access assistive technology and the health care they need without extreme out-of-pocket or catastrophic expenditure.

Action Area 5. Strengthen multisectoral policy-making to address inequities in health care and optimize development and health trajectories

Policy provisions should guarantee equitable, appropriate access to health promotion, prevention and care. This must include access to indicated care and support, including timely identification, psychological interventions and habilitation and rehabilitation services for all children with developmental disabilities, according to their evolving needs. Policy and legal frameworks relevant to children with developmental disabilities should be reflected in mainstream policies and plans for child and adolescent health, disability, social protection and education. They may also be addressed in independent plans in order to cover the full spectrum of relevant provisions for children with developmental disabilities when necessary.

Policies, laws and health financing mechanisms need to be designed, or reformed or updated, to integrate a rights-based approach and to ensure universal health coverage of children, adolescents and young people with developmental disabilities. Meaningful implementation requires effective health system governance and service arrangements, such as revenue raising (e.g. from government budgets, compulsory or voluntary prepaid insurance schemes), pooling funds and purchasing services (such as allocation of resources to health service providers) to ensure access to timely, affordable, high-quality services and support.

Policy development must be accompanied by communication strategies to ensure the participation and use of policies by people with developmental disabilities and their families.

Action Area 6. Strengthen services throughout the life-course in line with a twin-track approach to inclusive and people-centred evidence-based care

Mainstream services for health promotion, prevention and care in all sectors should be made inclusive and

accessible to children with developmental disabilities and their families, as part of work towards universal health coverage. At the same time, systems must be strengthened in all sectors to provide specialized services for the specific, evolving needs of children with developmental disabilities and their families along the continuum of care, into primary (including community), secondary and tertiary levels of the health-care system. Establishing and sustaining competence-based workforce development strategies and quality assurance mechanisms is important for the success of both mainstream and specialized services.

Particular attention should be paid to strengthening early identification and access to care for the development, well-being and functioning of children and young people with developmental conditions; to managing co-occurring problems and diseases; to improving support during transitions, such as from preschool to school and from school to independent living; and to promotion of health beyond childhood and adolescence and throughout the life-course.

All services, mainstream and specialized, should be child- and family-centred, adapted to the needs of the child and their family, and delivered in an accessible, acceptable, culturally appropriate way, close to where children live. They should be developed with the engagement of adults, children and young people with developmental disabilities and their families, as experts with lived experience.

Action Area 7. Ensure that caregivers and children with developmental disabilities have access to information and support

Service users, including children and young people with developmental disabilities, have the right to accurate information and to be empowered and supported in decision-making, according to their evolving capacity. Inadequate information is commonly reported as one of the factors that contribute to delays in seeking care and to experiencing poorer satisfaction with care. Tailored policy provisions and strategies can help ensure that children with developmental disabilities and their caregivers access information on treatment options, receive support with navigating care and access to psychoeducation, psychosocial support, parenting and caregiving interventions, and financial and social assistance, according to their needs.

Action Area 8. Remove barriers to participation in society, address stigmatization and discrimination, and foster environments that enable meaningful inclusion of children with developmental disabilities and their families in all spheres of life

Actions must be coordinated among sectors to create societies that facilitate inclusion and functioning, and in which the barriers that make impairments in children with developmental conditions disabling are minimized or removed. Barriers to service delivery (including to physical access, information, communication and coordination) must be removed in all health care programmes. This will include maximizing participation by adjusting the built environment in all services and sectors and in the community, and by promoting nurturing interactions in families, schools and neighbourhoods. Such adjustments should consider:

- promoting a culture in which diversity, inclusion and respect are valued, social connectedness is promoted and hostile and/or discriminatory behaviour is not accepted;
- adopting and supporting communication strategies to promote the expression and comprehension of children with various speech, language and communication abilities and preferences;
- monitoring and managing the physical and sensory environment to facilitate participation;
- promoting access to health information in formats that are accessible to children and young people with developmental delays and disabilities, and to caregivers with various levels of literacy;
- promoting access to education and opportunities for learning across the life-course, with allocation of adequate financial and human resources;
- promoting access to a range of assistance, assistive devices and support services for children and caregivers, and supporting transitions to independent living for young people with developmental disabilities; and
- enhancing or redesigning the development of human resource capacity to ensure competent care and positive attitudes in health-care workers and other professionals.

Action Area 9. Strengthen health information systems, monitoring of programmes and services, and research for data-driven decisions and accountability

An appropriate process and plan must be established to ensure that data are collected at various levels in the ecosystem of children with developmental disabilities

and their families, including on government policies, services and the children and their families. This will include:

- strengthening the coverage and detail of data collected routinely on the outcomes of children with developmental disabilities and their families;
- improving routine monitoring and evaluation of policies and programmes for children with developmental disabilities, and ensuring that the data are disaggregated by age, gender and geographical setting;
- promoting the generation, evaluation and documentation of innovative local solutions to optimize the health, development and well-being of children and young people with developmental disabilities;
- monitoring inequalities in health and education outcomes and exposures to risks, disparities in access to opportunities and services, harmful practices and human rights violations in all sectors to ensure compliance with human rights frameworks and nationally and internationally recognized guidance (such as stated in the UNCRPD); and
- monitoring the quality of health care and alignment with evidence-based practices, human rights-based care and personalized child- and family-centred care, with tools that are sensitive to cultural and contextual considerations and with the engagement of service users.

While there is substantive evidence to inform actions, there are still gaps in information that should be filled to optimize policy, programming and monitoring. There is consensus that the priorities for future research on developmental disabilities should be those areas that make a difference to the daily lives of children and their families (4, 5) and that experts with lived experience, including children and young people with developmental disabilities and their caregivers, should be involved to a greater extent in knowledge generation. Box 7.1 discusses priorities for research. It is important that findings from research and periodic assessments of the performance of health systems and other relevant services are disseminated to the general public, donors and other stakeholders.

Action Area 10. Develop inclusive plans and protocols for health emergency preparedness and response

Children with developmental disabilities require specific attention and tailored strategies in emergency preparedness and response frameworks to avoid unnecessary distress, delays in access to information and support, and discrimination.

Box 7.1. Priorities for knowledge generation and opportunities for research

Experts' ratings of priorities and inputs from researchers, young people with developmental disabilities, self-advocates and caregivers indicate several areas in which research should receive more attention (3–14).

There is a need for greater recognition of **health disparities**. In particular, research is needed to improve understanding of the **core social determinants of health inequalities** among people with developmental disabilities in different contexts and how these can be addressed.

We need to learn more about **approaches to improve attitudes towards disability**, including among health professionals, educational professionals and policy-makers, and how to monitor changes towards inclusive health care, inclusive education and inclusive communities. It is particularly important to give attention to implementation for, and the impacts on, children with more severe limitations in functioning.

Research should be conducted on strategies for **early identification and early interventions**, on transition services to optimize outcomes, and on addressing **barriers to accessing life-long services** for health promotion. More investment is needed on research to **test interventions that can optimize development, functioning, participation, health and well-being** during childhood and during transitions, and can be delivered through different delivery platforms. Clinical trials on early childhood development programmes for all caregivers often exclude children with developmental disabilities. A review of 100 titles of registered clinical trials evaluating early childhood development interventions indicated that at least 50% of the trials excluded children with disabilities (14). Studies that identify how to maximize the reach and effectiveness of such interventions for children with developmental disabilities are warranted.

Given the high prevalence of mental health conditions in young people and their higher occurrence

in young people with developmental disabilities, it is important that **interventions for preventing mental health conditions and provision of mental health care** are tested in this population. This is singularly lacking at present.

Scoping reviews mapping research on developmental disabilities against the ICF domains point to the fact that research focuses on interventions to reduce impairments, whereas activities, **participation and environmental factors** are minimally addressed. There is very limited investment on research exploring outcomes after young adulthood.

Collating **best practices** for increasing the skills of care professionals in all sectors and for how health information systems could better **monitor the performance of systems** for the health and well-being of children and young people with developmental disabilities is also a priority for research.

The **benefits of individualized approaches to care** are recognized by children and their caregivers. Research can help establish which component of an intervention or strategy, and its frequency, intensity and timing, benefits which group of children and caregivers and how to set individualized goals for care plans. Research on models for scaling up services to meet human rights objectives and standards of high-quality care is hugely inadequate, particularly in LMICs. The implementation of family-centred care requires good understanding of strategies to catalyse organizational changes and competency-building for health-care professionals.

Another priority is improving evidence on the role of **technology** in increasing access to interventions for assessment and promotion of functioning. To ensure relevance, research must **involve people with lived experience** of developmental disabilities (patients, parents, siblings) when conceiving studies, collecting results and analysing findings.

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Examples of health conditions in children and young people with developmental disabilities

In this global report, the term “children and young people with developmental disabilities” is used to refer to children and young people with health conditions that affect the developing nervous system and cause impairments in motor, cognitive, language, behaviour and/or sensory functioning. In interaction with various barriers and contextual factors, these impairments may hinder children’s full and effective participation in society on an equal basis with others.

The underlying health conditions of children and young people with developmental disabilities are heterogeneous in terms of aetiology and clinical presentation. They include autism, disorders of intellectual development and other conditions listed in ICD-11 under neurodevelopmental disorders, and also a much broader group of congenital conditions (such as Down syndrome) or conditions acquired at birth (such as cerebral palsy) or during childhood. Table A1.1 provides examples of these underlying health conditions, their ICD-11 codes and examples of potentially associated limitations in functioning and participation.

Table A1.1. Main categories of developmental disabilities, with examples of underlying health conditions and potentially associated functioning and participation limitations

Category	Example(s) of health conditions (ICD-11 codes)	Examples of potential limitations in functioning and participation (ICF codes)
Cognitive and learning	Disorders of intellectual development (6A00) Mild (6A00.0) Moderate (6A00.1) Severe (6A00.2) Profound ID (6A00.3)	Learning to read (d140) Acquiring complex skills (d1551) Learning and applying knowledge (d100) Memory functions (b144) Thinking (d163) Preschool education (d815) School education (d820) Higher education (d830) Remunerative employment (d850) Recreation and leisure (d920) Play (d9200) Sports (d9201) Arts and culture (d9202) Community life (d910) Ceremonies (d9102)
	Developmental learning disorder (6A03) With impairment in reading (dyslexia) (6A03.0) With impairment in written expression (6A03.1) With impairment in mathematics (dyscalculia) (6A03.2) With other specified impairment of learning (6A03.3)	Learning to read (d140) Learning and applying knowledge (d100) School education (d820) Higher education (d830) Remunerative employment (d850) Arts and culture (d9202) Community life (d910)
Behaviour	ASD (6A02)	Social cues and relationships (d7104) Speaking (d330) Socializing (d9205) Forming relationships (d7200)
	ADHD (6A05)	Sustaining attention (b1400) School education (d820)
Motor	Developmental motor coordination disorder (6A04) Cerebral palsy (8D20, 8D21, 8D22, 8D2Y, 8D2Z) Post-polio progressive muscular atrophy (8B62) Muscular dystrophies (8C70) Spina bifida (LA02) Spinal muscular atrophies (8B61) Spastic cerebral palsy (8D20)	Voice and speech functions (b399) Expression of spoken language (b16710) Walking (d450) Eating (d550) Toileting (d530) Transferring oneself while sitting (d4200) Sports (d9201)
Speech and language	Developmental speech or language disorder (6A01)	Expression of language (b1671) Reception of language (b1670) Speaking (d330) Producing messages in sign language (d340)

Category	Example(s) of health conditions (ICD-11 codes)	Examples of potential limitations in functioning and participation (ICF codes)
Vision	Vision impairment including blindness (9D90) Vitamin A deficiency with night blindness (5B55.0)	Seeing functions (b210) Reading (d166) Community life (d910)
Hearing	Congenital hearing impairment (AB50, AB50.0, AB50.1, AB50.2) Acquired hearing impairment (AB51, AB51.0, AB51.1, AB51.2) Deafness not otherwise specified (AB52)	Hearing functions (b230) Listening (d115) Communicating – receiving spoken messages (d310) Arts and culture (d9202)
Seizure disorders	Epilepsy due to prenatal/perinatal brain insult (8A60.0Y) Epilepsy due to injuries to the head (8A60.5) Epilepsy or seizures unspecified (8A6Z)	Preschool education (d815) School education (d820) Higher education (d830) Remunerative employment (d850) Recreation and leisure (d920) Play (d9200) Sports (d9201)

Methods for systematic review of studies providing prevalence estimates for developmental disabilities in children and adolescents

An online search of the English-language medical literature was conducted using PubMed to identify studies on the frequency of developmental disabilities. Search terms included developmental disability and prevalence. Additional selection criteria for studies to review included childhood onset of the disorder (birth to age 18 years) and publication between January 2000 and March 2021.

After reviewing the titles and abstracts of the 458 publications identified through this electronic search, 376 studies were excluded because they lacked data on the prevalence of developmental disabilities in defined populations. The full texts of the remaining 82 publications were reviewed and 37 studies met inclusion criteria. No sample size restrictions were imposed. Six additional studies were identified through reference tracking. The results from 43 publications were included, providing information on sample size, on data sources and analytic methods and on the frequency of developmental disabilities (broadly defined and not limited to a single disorder or type of disability) in populations.

Two of the publications reported the results of surveys on the prevalence of developmental delay and risk for disability from multiple countries, including 18 countries that incorporated the Ten Questions child disability module in their UNICEF Multi-Indicator Cluster Surveys (MICS) conducted in 2005–2006 (see reference 42 in Table A2.1), and 63 countries that incorporated a 10-item Early Child Development Index into their MICS or Demographic and Health Surveys (DHS) in 2010–2016 (see reference 43 in Table A2.1).

The results reported in the 43 publications are summarized in Table A2.1. Among the articles selected for inclusion, 21 were based on parental reports or survey data on disabilities or delays with no clinical confirmation, six were based on parent reports of the number of children diagnosed with disabilities, nine were epidemiological studies on the frequency of disabilities in the population based on developmental screening and/or clinical confirmation of case status, six were based on administrative data, and two were systematic reviews. The studies reviewed included data collected in 37 countries located in five continents.

Table A2.1. Summary of studies reporting the prevalence of developmental disabilities in children and identified through review of peer-reviewed literature (between January 2000 and March 2021)

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
Studies identified through search of peer-reviewed literature							
1	2003–2017	Developmental disorders (intellectual disability, ASD, sensory disorders, learning disorder, cerebral palsy, ADHD, language disorders, developmental delay)	0–6 years	Administrative prevalence, National Health Insurance Service data	754 972 cases	Republic of Korea (entire country)	2003–2007: 8.0 (7.8, 8.2) 2008–2012: 14.0 (13.8, 14.2) 2013–2017: 23.0 (22.8, 23.2)
2	2008–2009	Developmental disabilities (speech and language delay/disorder, motor delay/ cerebral palsy, ADHD, ASD, global developmental delay, intellectual disability, emotional/ behavioural, chromosomal anomaly, hearing impairment, vision impairment)	4 months–6 years	Two-phase prevalence study (screening followed by diagnostic assessments)	3214 (children seen in primary health care)	China	113.6 (103.1, 125.0)
3	2017	Developmental delay (communication, gross motor, fine motor, problem-solving, personal-social)	2 months–6 years	Cross-sectional, probability sample of households for MICS, Ages and Stages Questionnaire, V3	3566 (3200 households)	Ceara, Brazil	92.0 (81.0, 105.0) or 92.0 (82.9, 101.9)
4	2009–2017	Developmental disability (≥ 1 of 10 disabilities: ADHD, ASD, blindness, cerebral palsy, moderate to profound hearing loss, learning disability, ID, seizures in the past 12 months, stuttering or stammering in the past 12 months, or any other developmental delay)	3–17	US National Health Interview Survey (NHIS), parent report	88 530 (unweighted)	United States of America (USA), probability samples	169.3 ^a

a No CI provided, weighted prevalence.

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
5	2014	Developmental disabilities, including attention deficit disorder (ADD) and ADHD, ASD, blindness, cerebral palsy, deaf/a lot of trouble hearing, learning disability, mental retardation, seizures, stuttering and other developmental delays	3–17	US National Health Interview Survey (NHIS), parent report	1133 (un-weighted)	USA (Hawaii), probability sample	112.0
6	1980–2010	Intellectual disability, ASD, cerebral palsy	0–6 years	Birth cohort prevalence, administrative data	660 924 live births	Australia	15.8 (15.5, 16.1)
7	2003–2015	Developmental disability defined as impairment or restriction lasting at least six months (sensory, speech, ID, physical restriction, psychological, brain damage, other)	0–14 years	National Survey of Disability, Aging and Carers; parental responses to screening questions	16 704 (unweighted)	Australia, national probability samples	82.5 (in 2003) 69.5 (in 2008) 69.1 (in 2012) 74.2 (in 2015)
8	2008–2010	Developmental disability, including gross motor, fine motor, hearing, vision, speech and cognitive disability	4–6 years	Two-phase survey, screening with the Ten Questions followed by medical assessment of all children	1330	KwaZulu-Natal, South Africa	215.8 (194.5, 238.7)
9	2017	Special Health Care Needs, including sensory, cognitive and mobility impairments, epilepsy, behavioural and psychiatric problems, Down syndrome, autism, dysarthria, impaired physical development, and asthma	6–14 years	Community survey, parental report, Children with Special Healthcare Needs (CSHCN) screener questionnaire	501 children, 405 households/families	Alexandria, Egypt, multi-stage cluster probability sample	121.8 (96.0, 153.4)
10	2016	ASD, intellectual disability, and other developmental delays	3–17 years	National Health Interview Survey, parent reports of diagnoses of developmental disability	Not provided	USA, national probability sample	69.9 (62.8, 77.6)

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
11	2013	Suspected developmental delay, including communication, gross motor, fine motor, problem solving, personal-social and overall developmental delay	0–3 years (0–35 months)	Telephone survey using the Ages and Stages Questionnaire, parent reports of developmental delays, UNICEF MICS5	2120 children, cluster sample of 83 villages, 68.9% of all children in the villages were included	China, six counties in two provinces (Shanxi and Guizhou), high-poverty areas	373.1 (352.8, 393.9)
12	2017	Developmental delay, overall and in communication and gross motor skills	1–3 years (8–39 months)	Household survey in 15 communities, using Ages and Stages Q-3 (ASQ-3)	593 children	Peru, Amazon Region	268.1 (234.0, 305.2)
13	2011–2013	Parental moderate to high level of concern about child's development	1.5 years	Parents' Evaluation of Developmental Status (PEDS) questionnaire	565 (27.9% of cohort of 2025 enrolled at birth)	Australia, South-western Sydney, socioeconomically deprived area	325.7 (288.3, 365.4)
14	Not provided	Screening positive for neurodevelopmental delay (diagnosed conditions among those screening positive: cerebral palsy, seizures, ASD, developmental delay, nutritional deficiency)	0–3 years	Parental survey during immunization visits. Screening for disability based on parental reports using Infant Development Inventory, Child Development Review, CDC Milestone Moments	3011	Lagos State, Nigeria	9.0 (5.2, 13.1)
15	2011–2012	Developmental delay (including communication, gross motor, fine motor, problem-solving, personal-social)	1 year (12 months)	Parent survey at well child visits, birth cohort of 1555; Ages and Stages Questionnaire with Norwegian cut-offs	832 (sub-sample with follow-up at age 12 months)	Norway, five municipalities	61.3 (46.9, 79.7)
16	2013–2014	Developmental delay (scores below cut-off levels in two or more of six developmental areas)	0–5 years (3–60 months)	Cross-sectional survey in primary health-care centres, parent face-to-face interviews, Ages and Stages Questionnaire	1514	Izmir city, Türkiye	64.7 (53.4, 78.20)
17	Not provided (published in 2014)	Developmental disability, as indicated by TQ+ (delayed milestones, vision, hearing, communication, movement, seizure, learning, speech and/or intellectual impairment)	6–9 years	Cross-sectional survey, face-to-face parent interviews, Ten Questions, random sample of children enrolled in public elementary schools	905	Brazil, municipalities in four regions (North, Northeast, Center-West, Southeast)	384.5 (353.4, 416.6)

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
18	Not provided, (published in 2013)	Neurological disorders (hearing, vision, motor, epilepsy, development)	0.5–2 years)	Two-phase prevalence survey, parent screening questionnaire followed by diagnostic assessments of screened positives and sample of negatives	4801 infants screened (diagnostic assessments of 459), weighted analysis	India, Lucknow district, rural and urban areas selected using cluster sampling	27.9 (12.2, 43.6)
19	2009	“Childhood disabling conditions” (developmental delays, mental and physical disabilities, cerebral palsy, ASD, speech, ADHD, resulting in significant difficulties with expected impacts on daily living)	0–18 years	Administrative prevalence, based on analysis of general practice records	10 756	Bristol, United Kingdom	49.3 (45.4, 53.6)
20	2000	Developmental delays identified on Australian Developmental Screening Test	2 years	Birth cohort from 2000 screened at age 2 years using Australian Developmental Screening Test	1018 children screened at age 2 years	Auckland, New Zealand	351.7 (323.0, 381.5)
21	2004	Developmental disabilities and delays	0–2 years	Follow-up of birth cohort (born 1999–2001) to age 2 years, outcome = referral to early intervention programme for children with developmental disabilities and delays	342 643	New York City, USA	138.8 (137.6, 140.0)
22	1997–2008	Developmental disability	3–17 years	National Health Interview Survey (NHIS)	119 367 (unweighted)	USA, probability samples	3–10 years: 117.8 11–17 years: 128.4
23	2008	Intellectual and developmental disability indicated by special education needs, including intellectual disability, ASD and learning disability	7–15 years	Administrative prevalence, analysis of England school and census data	5 180 550	England, United Kingdom (all school children, ages 7–15)	48.0 (47.8, 48.2)
24	2004–2005	Children with disabilities (mobility, fine motor, daily living, communication, learning)	0–18 years	Family Resources Survey of British households, weighted analysis	16 012, unweighted sample	United Kingdom, national probability sample	73.0 (69.0, 77.0)

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
25	Not provided (published in 2010)	Children with disabilities and functional difficulties, including developmental delay, vision impairment, hearing impairment, ASD, cerebral palsy, ADHD, speech and language difficulties	1–6 years	Survey of all preschools in two counties, response rate 50.1%, key informant reports from the schools	9098	Sweden, two counties (not named)	173.0 ^{b c}
26	Not provided (published in 2009)	Developmental delay, deformity or disability	0–5 years	Household survey	12 520	India, rural Kerala, Alappuzha district	24.8 (22.2, 27.7)
27	2004–2005	Developmental delay (personal-social, fine motor adaptive, gross motor, language)	1 year (12 months)	Follow-up of all births traceable at 12 months, Denver II Screening Test	3907	Brazil, southern city of Pelotas	214.0 (201.4, 227.1)
28	2003–2004	Developmental delay (physical, mental)	2 years (24 months)	Birth cohort, Early Childhood Longitudinal Study, Bayley Scales of Infant Development, abbreviated version, weighted analysis	8950 (un-weighted number assessed at 24 months, from 10 200 that were assessed at age 9 months)	USA, national probability sample of births, followed to kindergarten	138.0 (136.6, 139.4)
29	2004–2005	Developmental delay, neurodevelopmental disability (gross motor, personal-social, auditory language delay, overall delay)	0–5 years (< 60 months)	Cross-sectional survey, screening in several areas of the city via parent and teacher interviews; those screening positive were evaluated with an EAD-1 scale	2043 children screened, 288 suspected cases were evaluated with the EAD-1, 67 children found to have abnormalities on EAD-1	Colombia, Bogota	32.8 (25.9, 41.4)

b CI not provided; need to account for cluster sample of preschools.

c Schools reporting no children with disabilities or functional difficulties were excluded.

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
30	Not provided; sampling frame from 1998	Developmental delay (personal-social, fine motor adaptive skills, language skills, gross motor skills), Child Behavior Checklist, limitations in adaptive behaviour, physical development, cognitive development, communication	3 years	Two-phase household prevalence survey, screening using the Denver Developmental Screening Test, followed by developmental assessments of those screening positive and a sample (~35) screening negative. No false negatives found. Weighted analysis	Unweighted sample size of 694 children screened, 90 evaluated by a pediatrician in phase 2	United Arab Emirates, probability sample of three emirates (Dubai, Al Ain in Abu Dhabi, and Ras Khaimah)	Screening positive for delay: 84.0 (64.0, 107.0) Disability prevalence estimate from developmental assessments: 24.4 (12.8, 35.6)
31	2001–2002	Developmental delay (screened positive) and moderate to severe developmental disability on developmental assessment (epilepsy, intellectual disability, hearing, motor, language or vision disability)	6–9 years	Household survey, two-phase prevalence survey, Ten Questions screen followed by developmental assessments of all screening positive and sample of those screening negative	10 218 screened, 1576 assessed in phase 2	Kenya, rural district	61.0 (48.0, 74.0)
32	2000	Four developmental disabilities (intellectual disability, cerebral palsy, vision, hearing)	8 years	Administrative prevalence, multiple source public health surveillance (MADDSP)	43 133	USA, Metropolitan Atlanta	15.0 (13.9, 16.2) of one or more of the four disabilities
33	1994–1995	Functional limitations (disability), including mobility, communication, self-care, learning	5–17 years	National Health Interview Survey (NHIS), telephone survey, parental report	41 300 (unweighted sample)	USA, national probability sample (NHIS)	120.0 ^d
34	1994–1995	Functional delays (based on parent responses to items indicating children's functioning in attention, interaction, communication, mobility) and general delays (parent reports that they think the child has developmental delays)	4–59 months, < 5 years	National Health Interview Survey (NHIS), Telephone survey, parental report	15 291 (unweighted sample)	USA, national probability sample (NHIS)	Functional delay: 33.0 (30.1, 35.9) General delay: 34.0 (30.7, 37.3)

d CI not reported for all disabilities combined.

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
35	Not provided (published in 2002)	Childhood disabilities (perceptual, learning, cerebral palsy, hearing loss, motor, seizure disorders)	0–9 years	Two-phase prevalence survey, screening (Ten Questions screen, adapted to include children < 2 years), developmental assessments of those screening positive (unclear whether any screening negative were evaluated)	2036 children screened, 168 screened positive	South Africa, rural KwaZulu-Natal	60.0 (50.0, 71.0)
36	1994–1995	Any intellectual or developmental disability	0–17 years	National Health Interview Survey (NHIS) Disability Supplements	70 349 128	USA, probability sample	0–5 years: 38.4 (38.3, 38.5) 6–17 years: 31.7 (31.6, 31.8)
Additional studies, identified from reviews and other sources							
37	2015	Children with special health-care needs are defined in the literature as “those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”	0–18 years	Survey of Children with Special Healthcare Needs, parental responses to screening questions	10 122 (un-weighted sample size)	USA, State of Ohio, probability sample	250.0
38	2009–2016	Cerebral palsy, intellectual disability, hearing loss, blindness	3–17 years	National Health Interview Survey (NHIS)	81 088 (un-weighted)	USA, national probability sample	19.6 (18.4, 21.0)
39	Not provided (published in 2018)	Neurodevelopmental disorders (vision impairment, epilepsy, cerebral palsy and other motor impairments, hearing impairment, speech and language impairments, ASD and intellectual disability, and ADHD) in 6–9-year-old children	2–9 years	Household survey, screening with a 39-item Neurodevelopmental Screening Test (NDST) followed by comprehensive clinical assessments of all children enrolled	3964	India, five regions, probability sample	Ages 2–5 years: 92.0 (75.0, 112.0) Ages 6–9 years: 136.0 (113.0, 162.0)

Reference	Data year(s)	Disability	Age range	Study design, data source	Sample size (denominator)	Geographic area	Prevalence per 1,000 (CI)
Summary or ranges of prevalence estimates provided by reviews, data syntheses or multi-site summaries							
40	2010–2017	Developmental disabilities	0–18 years (and sub-groups within this range)	Systematic review of USA developmental disability prevalence studies published since 2000, but for children focused on 2010–2017	Systematic review. 11 studies identified for children	USA	Range = 45.8–69.9 ^e
41	2016	Developmental disabilities, including vision loss, hearing loss, intellectual disability, ASD, epilepsy, ADHD	0–5 years	GBD prevalence estimates, data synthesis and modelling	Based on data synthesis and modelling, assumed denominator is all children < 5 years globally	Global	84.0 (77.0, 91.0)
42	2005–2006	Developmental delay, high risk for developmental disability	2–9 years	Household Survey, Ten Question Screen, caregiver report, UNICEF MICS3 surveys	191 199 (unweighted pooled sample size)	18 LMICs	Median = 230 Range = 30–480
43	2010–2016	Developmental delays in one or more of four domains: physical, social-emotional, learning and literacy-numeracy	3–4.9 years (36–59 months)	Early Child Development Index (10 items), maternal report, UNICEF MICS and Demographic and Health Surveys	330 613	63 LMICs	Median = 265 Range = 32–673

e This refers to studies published in 2010 and later.

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Annex 3.

Prevalence of selected conditions that contribute to developmental disability based on GBD 2019 data

Fig. 2.3 in chapter 2 shows the GBD 2019 prevalence estimates for the five most prevalent conditions among those that contribute to developmental disabilities. These conditions are: hearing loss,

idiopathic developmental intellectual disability, ADHD, cerebral palsy and vision loss. The data used to compile Fig. 2.3 and disaggregated for males and females are provided in Table A3.1.

Table A3.1. Prevalence of selected conditions that contribute to developmental disability, by male and female, based on 2019 GBD data

Conditions	Age (years)			
	Under 5	5–9	10–14	15–19
Female				
ADHD	0.1%	1.1%	1.5%	1.2%
Cerebral palsy	1.6%	1.2%	1.2%	1.2%
Hearing loss	0.7%	3.8%	4.1%	4.9%
Idiopathic developmental intellectual disability	1.7%	2.0%	2.0%	1.9%
Vision loss	0.6%	1.4%	1.5%	1.5%
Male				
ADHD	0.3%	3.1%	4.1%	3.2%
Cerebral palsy	1.7%	1.3%	1.2%	1.2%
Hearing loss	0.8%	4.5%	4.7%	5.6%
Idiopathic developmental intellectual disability	1.7%	2.1%	2.0%	1.9%
Vision loss	0.5%	1.3%	1.3%	1.4%
Both (males and females)				
ADHD	0.2%	2.1%	2.9%	2.3%
Cerebral palsy	1.6%	1.2%	1.2%	1.2%
Hearing loss	0.7%	4.2%	4.4%	5.3%
Idiopathic developmental intellectual disability	1.7%	2.0%	2.0%	1.9%
Vision loss	0.5%	1.3%	1.4%	1.4%

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