

Executive summary

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 experience poorer quality of care when 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 the 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 the tenets of 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 children and young people with developmental disabilities 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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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. 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, children and young people with developmental disabilities are more likely to experience unmet health care needs, poor health and premature mortality, and are deprived of opportunities to thrive.

The aim of this global report is to increase awareness of the significance of investing in intersectoral approaches to promoting health, well-being and participation and access to quality care for persons with developmental disabilities. It 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. It also draws attention to the imperative of strengthening accountability at all levels.

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

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. These include a range of underlying health conditions such as autism, disorders of intellectual development and other conditions listed in the International

Classification of Diseases 11th Revision (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.

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.

With respect to disability, human rights-based approaches include an assurance of the basic rights of all people according to their inherent human worth and the recognition of the inherent right to respect for human dignity and diversity.

WHO’s International Classification of Functioning, Disability and Health (ICF) recognizes that disability results from the interaction of a person’s impairments with various societal, physical or environmental barriers that may prevent their full 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.

Evidence from neuroscience, genetics, developmental psychology and other fields demonstrates that human brain development is most malleable in the earliest periods of life and that in children with developmental disabilities the underlying health conditions are not fixed and finite with unchangeable effects on developmental programming. Building on this concept, an ecological framework situates individual development within concentric circles of influence radiating outwards, including family, community, institutions, policy and the environment. A life-course perspective on developmental disabilities means looking at how all the experiences throughout the life of a person with a developmental disability can affect their health and well-being and also providing support during major life transitions.

A transdiagnostic approach to optimizing health, development, functioning and participation challenges service providers to identify developmental

trajectories and targets for intervention, irrespective of specific diagnosis. Furthermore, the perspective of neurodiversity, grounded on the premise that variation in neurodevelopmental profiles and functioning is inherent to the collective human experience, stimulates researchers, clinicians and policy-makers to use practices that fully embrace strengths-based and participatory approaches, address structures of exclusion and promote equality.

From a public health perspective, the treatment and care gap for children with developmental disabilities demonstrates that universal health coverage is far from being achieved. 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.

Landscape, commitments and context of the report.
The UN Convention on the Rights of Persons with

Disabilities (UNCRPD) and the UN Convention on the Rights of the Child (UNCRC) commit governments to policy changes that contribute to creating the conditions for children and young people with developmental disabilities to enjoy optimal health and inclusion. A number of 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), the WHO Comprehensive Mental Health Action Plan 2013–2030 and the resolutions on disability and rehabilitation (WHA 58.23), on the highest attainable standard of health of persons with disabilities (WHA 74.8) and on epilepsy and other neurological conditions (WHA 73.10).

These commitments are situated in the context of the Sustainable Development Goals (SDGs), in which disability is a cross-cutting issue and early childhood development for inclusive education and mental health are priorities.

Developmental disabilities in focus

Developmental disabilities are common: global estimates based on the 2019 Global Burden of Disease (GBD) study tell us that 316.8 million children and adolescents experience a health condition contributing to developmental disability.

Overall, in the GBD study the prevalence of these conditions ranged from 7.5% among children 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). Based on 2019 GBD data, the five most prevalent conditions contributing to developmental disabilities are hearing loss, idiopathic developmental intellectual disability, ADHD, cerebral palsy and vision loss.

The child functioning module of the multiple indicator cluster surveys (MICS) used by the United Nations Children's Fund (UNICEF) provides complementary data, showing that that one in 10 children has a moderate to severe functional difficulty.

None of the approaches to estimating the prevalence of developmental disabilities in children is perfect. Limitations and complexities that need to be considered when describing the epidemiology of developmental disabilities 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.

The health conditions that contribute to developmental disabilities are heterogeneous. For some, the causal pathway is known, while for others it remains largely unknown. A wide range of genetic and environmental risks and epigenetic mechanisms can impact neurodevelopment.

Extensive evidence shows that children with developmental disabilities are more likely to have poorer health than their peers. People with developmental disabilities are more likely to have obesity, diabetes, heart and respiratory diseases and mental health conditions and have a higher risk of premature death.

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 to well-established social determinants of poorer health and well-being, such as poverty, social exclusion, violence and discrimination, and poorer access to health promotion, health care and education. Such differences are therefore unjust, unfair and partly avoidable. Globally, individuals with developmental disabilities have unmet health care needs due to weak, fragmented health-care systems.

Beyond commitments: implementing legal and policy changes

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. Fragmented, underfunded services in all regions and in both high- and low-income settings are failing to meet the right to health for children with developmental disabilities.

Policies, legislation and government strategies provide the legal commitments and provisions to address and monitor socioeconomic determinants, 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.

The UNCRC and the UNCRPD 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 the inclusion of children with developmental disabilities and promotion of their health, based on these conventions, include the following:

- Non-discrimination, respect for physical and mental integrity and equality, including equality to access early learning, education and high-quality care and in opportunities to grow up in nurturing environments.
- Comprehensive access and adoption of “universal design” to ensure that services and products can be used by all people to the greatest extent possible.

- Independence, and autonomy, providing support to children and young people with developmental disabilities to help them to become autonomous, preserve their identities and make informed choices about their lives and their health care.
- Meaningful, effective participation of children and young people, facilitating their active participation in decision-making and in processes to give informed consent to interventions.

While no country has the “perfect” solution to legislation and policy that integrates and promotes a human-right based approach to the health of children with developmental disabilities, good practices and lessons learnt in policy development and implementation emerge. 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 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. 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. The 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.

Key areas for policy relevant to creating the conditions for children and young people to enjoy the highest standard of health and well-being 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 (UNCRPD Article 18). They “are best cared for and nurtured within their own family environment” and they “should never be institutionalized solely on the grounds of disability”. The convention further stipulates that, where the immediate family is unable to care for a child with disabilities, States Parties should undertake every effort to provide

alternative care with the wider family or, failing that, within the community in a family setting (Article 23).

Freedom from violence and degrading treatment

Children and young people with developmental disabilities are particularly vulnerable to violence and degrading treatment. Legislative, administrative, social and educational measures should be taken to protect children and persons with disabilities from all forms of violence, neglect or negligent treatment, degrading treatment or punishment and exploitation.

Right to live in the community and access community resources

Governments should legislate to abolish disability-based institutionalization and have an obligation to adopt targeted strategies for deinstitutionalization, with specific timeframes and adequate budgets, with particular attention to children with intellectual or psychosocial disabilities and children requiring high levels of support. Comprehensive, multi-disciplinary, responsive services and age-appropriate interventions should be established for children and youth in communities.

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

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. The coverage of services, affordability, equitable access and quality of care are all important aspects of this approach. 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

Governments need to ensure an inclusive education system at all levels and the provision of lifelong learning, by developing and implementing a comprehensive and coordinated legislative and policy framework that takes into account the rights, requirements and varying needs of children with disabilities at all levels. The UNCRPD Committee's General Comment No. 4 provides guidance on teaching strategies aligned with universal design for learning.

Data, monitoring and accountability

Governments should collect administrative data and qualitative health data on children with developmental disabilities and use them as a basis for policies and services. Rigorous monitoring, including monitoring of facilities and the placement of children in those facilities, is a pillar for guaranteeing enforcement of rights-based frameworks.

Financial support

Financial support for young persons with developmental disabilities and their families protects them from financial loss and impoverishment and protects their 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, increasing their independence and providing access to health care and other disability-related services.

Advocacy

Governments should create mechanisms to raise awareness about human rights-based approaches to promoting health for children with developmental disabilities and to empower caregivers and young people themselves.

Transforming care systems for children and young people with developmental disabilities

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, interventions to improve functioning and management of co-occurring conditions, have been shown to benefit their health and well-being.

Yet, in all countries, children and young people with developmental disabilities have high levels of undetected and unmanaged health needs. 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 lacking adequate information on services, stigma and low levels of literacy about developmental disabilities. Reliance on specialist models of care means that gaps in access to early interventions persist. Health-care services for children with developmental disabilities are typically fragmented and underfunded. Barriers to access to primary care, including physical and attitudinal barriers and inexperienced or inappropriately trained staff, are thought to contribute to inequitable health outcomes for children with developmental disabilities.

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 than their peers. They stay for longer when they are admitted to inpatient care, and they are also more susceptible to adverse events and lapses in patient safety during their hospital stay.

The heterogeneous clinical features of neuro-developmental conditions, the chronic nature of impairments and their intersection with family and socioeconomic factors have implications for the organization of care. The evolving needs of children and young people with developmental disabilities mean that they 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 should be based on the reality lived by these young persons.

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.

An important principle in the provision of care for children with developmental disabilities is the twin-track approach to care. This involves supporting access to mainstream health promotive and care services by addressing attitudinal, physical and communication barriers while offering targeted community care to meet each child's individual health, educational and social needs. There are promising examples where approaches have been scaled up to 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.

It is important to embed identification and early interventions for children and young people with developmental disabilities into existing care services to enable timely recognition of support needs and opportunities. Countries could integrate targeted interventions into health, developmental, education and social care services, such as neonatal and immunization services, breastfeeding counselling, early childhood development programmes, well child and child care visits, preschool programmes, school health services, adolescent health screening, school leavers' programmes and one-stop services.

There is increasing recognition of the benefits of using stepped care approaches in building tiered systems of care for children with developmental disabilities. The approach involves making available care options of varying levels of intensity, linked through defined care

pathways, so that children and families can access less resource-intensive (yet effective) treatments first, only “stepping up” to more resource-intensive services when needed. 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 requirements 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 the assessment of individual and family needs and preferences, data-informed progress monitoring and the individual’s response.

A common challenge for services and families is to overcome the “siloes” that exist between sectors in almost all countries. An important principle for organizing care is the development of care pathways that are connected between sectors and agencies. Individualized service plans can facilitate service coordination, guided by the needs of children and families.

Child- and family-centred services have long been identified as best practice for professionals working with children with developmental disabilities. The focus is on establishing partnership and respectful collaboration between professionals, the family and the young person in order to understand priorities, needs, resources, interests, preferences and choices.

Profiles of strengths and difficulties inform intervention plans for children with developmental disabilities and their families. Approaches to interventions should be mindful of enhancing the child’s functioning and social participation and should consider transdiagnostic strategies and approaches that can be provided in the absence of a clinical diagnosis, whenever applicable.

Contextual factors such as the location of the intervention, cultural beliefs and stigma towards disability and the education and literacy of young people and caregivers may have a significant impact on intervention uptake and effectiveness. Services and systems need to be tailored to fit local care systems and the cultural context. Most importantly, they should be aligned with human-rights based standards of care.

Some common elements of good practice in efforts to eliminate harmful practices and limit restraint measures have emerged. These include strong leadership in care facilities based on national policy, strict monitoring systems, staff training on management of difficult behaviours and other aspects of care, and changes in attitudes to the use of restraints, with restraints being identified as treatment failure. Another important aspect of improving human rights-based care is monitoring the prescribing of medication, as inappropriate prescribing for the management of behavioural difficulties is common.

Promoting participation

Fundamentally, participation means the involvement of people in activities and decisions that affect their lives. Active participation by young people with developmental disabilities empowers them to play a vital role in their own development and in the development of their communities. 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 and connectedness. Participation is a fundamental right. However, from early in life, children with developmental disabilities often have fewer opportunities for learning, participation in sports and activities and social interaction, and experience stigma and exclusion. 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.

Various legal and policy provisions and interventions 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. They focus on addressing barriers and developing opportunities for participation in different contexts. Chapter 5 provides some examples of actions to promote participation for children and young people with developmental disabilities.

Stigma and exclusion are common experiences for children with developmental disabilities. Awareness-raising and education are essential to help communities overcome prejudices. This should be informed by an understanding of local contexts and with the engagement of young people and families. Use of social and behaviour change communication to improve awareness of disability rights and facilitate interpersonal dialogue can change attitudes.

In the context of health care, actions to promote the participation of children and young people with developmental disabilities include 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.

Children with sensory, physical or intellectual disabilities are 2.5 times more likely than their peers to have never attended school. Important aspects of inclusive education include an accessible physical environment, individualized support and assistive devices for specific impairments, family-school partnerships and the implementation of teaching strategies, curricula and assessments in ways that promote adaptable learning environments that meet the diverse needs of all children, in line with universal design for learning.

Teacher education is essential to achieving inclusive education, and this requires knowledge about specific disabilities, awareness of disability rights, strategies for individualized instruction that responds to different learning styles and abilities, and tuition in developing individual education programmes.

Families can play a pivotal role in promoting opportunities for participation by children and adolescents. Interventions can strengthen the skills and support necessary for caregivers of children with developmental disabilities to promote their child's participation at home, at school and in other community spaces. Training for caregivers can include strategies to enhance engagement in play and home routines, approaches to build and sustain partnerships with health and education professionals and advocacy skills.

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.

As an example, community-based inclusive development (CBID), formerly 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. 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, with programme strategies tailored to local contexts.

Youth with developmental disabilities struggle with finding opportunities in the labour market and in the transition between education and the workplace. Across 32 member countries of the Organisation 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.¹ 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, for instance, include modification of work schedules, physical changes to the workspace and equipment and devices, job restructuring, adjustment of supervisory methods and job coaching.

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

1 Disability, work and inclusion: mainstreaming in all policies and practices. Paris: OECD Publishing; 2022 (<https://doi.org/10.1787/1eaa5e9c-en>).

Public health monitoring for children with developmental disabilities

The SDG mandate to promote health, well-being, children's development, school readiness and universal health coverage, "leaving no-one behind", has provided momentum to the development of policies and services to include and protect the health and well-being of all children.

There are several global incentives for the measurement of outputs and outcomes relevant for all children and for persons with disabilities, tied to specific consensus documents and legal treaties (such as the SDGs, the UNCRPD or the UNCRC) or global monitoring mechanisms for child and adolescent health and disability. However, 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 development, health, well-being and participation 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 children and their families themselves. Areas that are priorities for monitoring can be organized as inputs, outputs and outcomes, as shown in Fig. 1.

The development of monitoring and evaluation (M&E) 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.

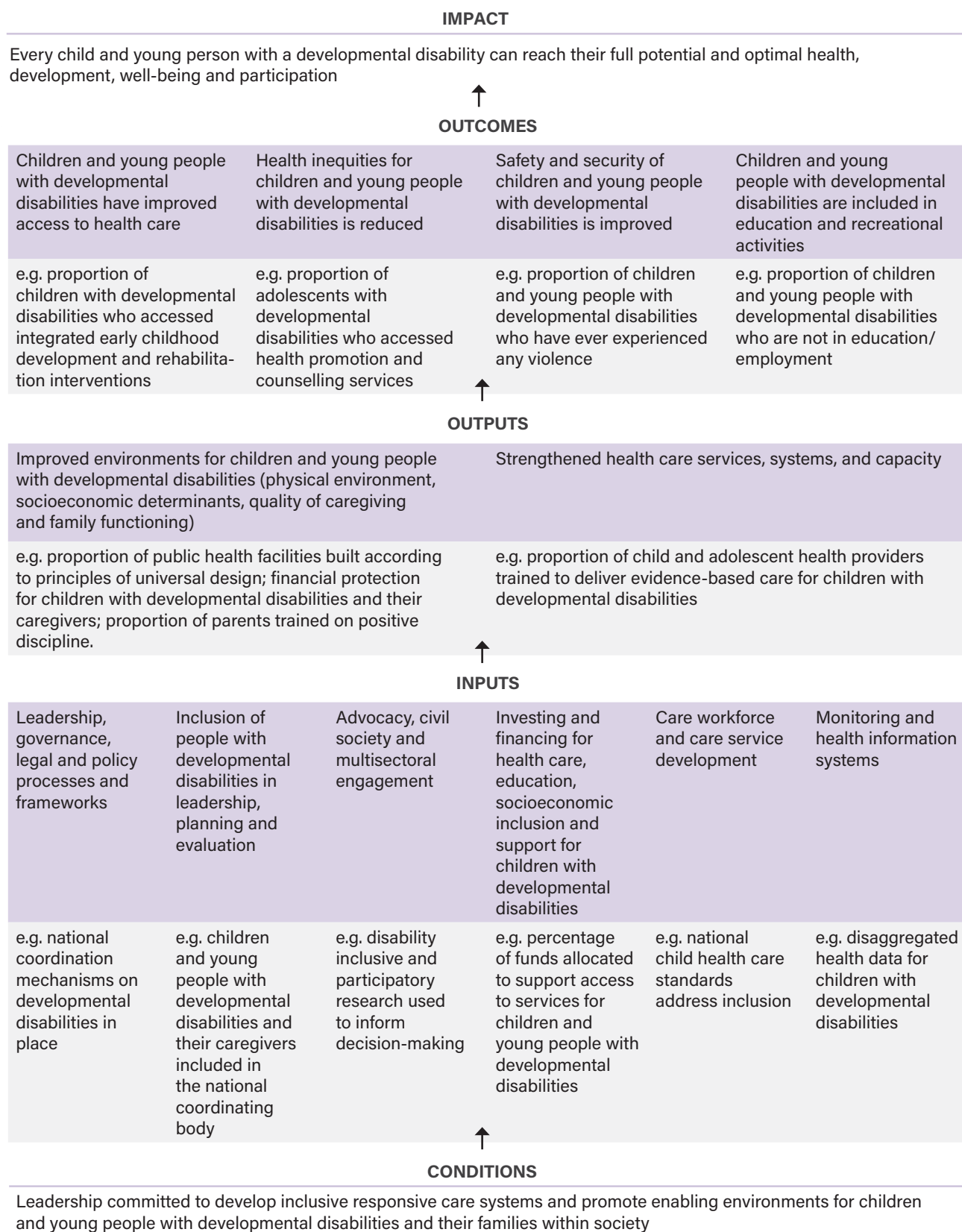
At the level of the child's environment, an M&E framework should consider measures related to the physical environment, socioeconomic determinants, quality of caregiving and family functioning.

Indicators of the availability of services, systems and capacity should include: availability of inclusive health care; availability of a 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.

When intersectoral actions produce improved environments and services for children and young people with developmental disabilities, the consequent benefits for them are improved access to health care, reduced health inequities, improved safety and security and improved inclusion in educational and recreational activities.

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 right violations. Success would also be where data are used to inform policies, services and advocacy, with the engagement of youth.

Fig. 1. Priority areas for monitoring and example indicators



The way forward

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 efforts towards universal health coverage, disability inclusion and school readiness for all.

The final section of this 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. 2). 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.

Ten key action areas are proposed to accelerate changes in policies and care systems for better health, well-being 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.

The establishment of multisectoral programmes must be a priority, to ensure that the needs and preferences of children and young people with developmental disabilities and their families are met holistically. This requires strengthened interagency cooperation and 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.

Commitments made by policy-makers can only translate into meaningful change if they are accompanied by a substantial increase in institutional and budgetary commitments. Financial investments need to be oriented towards enhancing services and systems, with particular focus on education and community-based health care and improving supports and opportunities at family and community levels. It is important to establish mechanisms for reviewing national expenditures and global health financing in ways that allow the monitoring of opportunities for children with developmental disabilities to reach their optimal health and development potential and school readiness, in alignment with the 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.

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. Effective advocacy should reflect each country's particular culture and systems.

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, 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 families 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.

Policies, laws and health financing mechanisms need to be designed or updated to integrate a rights-based approach and to ensure UHC for children, adolescents and young people with developmental disabilities. Policy provisions should guarantee equitable access to health promotion, prevention and care for all children and young people with developmental disabilities, according to their evolving needs, and 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 on timely identification and care.

Policy development must be accompanied by communication strategies to ensure the participation of 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 inclusive and accessible to children with developmental disabilities and their families. 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

Fig. 2. 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



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. Services 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.

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 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 between 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. Efforts should consider approaches to adjust the built environment in all services and sectors and in the community, to promote a culture in which diversity, inclusion

and respect are valued and to ensure access to education and opportunities for learning across the life-course. Barriers to service delivery (including to physical access, information, communication and coordination) must be removed in all health-care programmes.

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 should include monitoring of 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.

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 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. 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; currently, research into models for scaling up services to meet human rights objectives and standards of high-quality care is hugely inadequate. Another priority is improving evidence on strategies to address barriers to accessing life-long services for health promotion.

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.

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