

PRACTICE
GUIDE

**INCLUSION OF CHILDREN
AND YOUNG PEOPLE WITH
DISABILITIES IN ROUTINE
GENERAL HEALTH CARE**

Acknowledgements

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Introduction

1



Introduction

Nearly 240 million children have disabilities – 1 in 10 of all children worldwide.¹ Children and young people with disabilities remain among the most excluded, discriminated-against and invisible members of society. It is because of this that UNICEF's Strategic Plan 2022–2025 and UNICEF's Disability Inclusion Policy and Strategy 2022–2030 commit to advancing disability rights across all of UNICEF's work, including through support to the families, parents and caregivers of children and young people with disabilities. The United Nations (UN) Disability Inclusion Strategy marks a broader UN-wide commitment to strengthen disability inclusion and advance disability rights across development and humanitarian sectors, including in health.

A key component of UNICEF's broader commitment to disability rights is the intention to address inequities in health outcomes that negatively affect children and young people with disabilities. Additionally, UNICEF strives to strengthen inclusion in health systems, including in emergency preparedness, response and resilience. Health systems frequently fail to respond adequately to both the general and specific health needs of children and young people with disabilities and their right to health is consistently violated. These children and young people have unequal access to quality healthcare services and greater unmet health needs that likely contribute to higher mortality, delayed development and life-long poorer-than-average health.

Health services need to be more inclusive of children and young people with disabilities (and their families, parents and/or caregivers) and more responsive to their general and specific health needs. This Practice Guide has been developed to support a greater focus on disability inclusion across UNICEF-supported health programmes to help drive improvements that are affordable to children and young people with disabilities in accessibility, acceptability, quality and inclusiveness.



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¹ United Nations Children's Fund, 'Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities', UNICEF, New York, 2021.

1.1 What is disability?

Disability is a complex and evolving concept. As stated in the Convention on the Rights of Persons with Disabilities, people with disabilities include:

“...those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others”

(Article 1, UN Convention on the Rights of Persons with Disabilities).

Impairments (e.g., physical, cognitive or sensory) become disabling when they interact with prevailing attitudes, behaviours and policies or physical spaces to effectively prevent the individual(s) from participating fully in society. For example, inaccessible signage or footpaths denies access to hospitals for individuals with visual, physical or intellectual impairments.

The framework of the International Classification of Functioning, Disability and Health (ICF) relies on a three-level model to describe the concept of disability. According to the ICF, disability can occur as:

- An impairment in body function or structure (for example, a cataract or opacity of the natural lens of the eye, which prevents the passage of rays of light and impairs or destroys sight);
- A limitation in activity (for example, low vision or inability to see, read or engage in other activities);
- A restriction in participation (for example, exclusion from school or participation in other social, recreational or other events or roles).



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People with disabilities (including children and young people) are not a homogenous group. Impairments can combine with other key factors and characteristics (including differences based on age, gender, sexual orientation, ethnicity, family support, socio-economic circumstances, rural versus urban locations and other issues) to compound the level of marginalization. There are differences based on whether impairments are obvious to and noticed by third parties (e.g., severe mobility impairments) or not (e.g., less severe cognitive impairments). There are also differences based on the existence and interaction of co-morbidities.

This understanding of disability acknowledges the important role that social context has in defining disability as not merely a medical condition or diagnosis (as per the medical model) but rather, as a failure of policy, cultural and physical environments to accommodate differences in function.

Introduction

1.2 What is 'disability inclusive' health?

Health and quality healthcare are critical concerns for children and young people with disabilities. While these children and young people may require specialized care directly related to specific impairments and underlying health conditions, they also require the same routine general healthcare services as the wider population.

Disability inclusion in health ensures that children and young people with disabilities can take full and equal advantage of the same health services and information as those without disabilities. They therefore benefit from the same health promotion, prevention, treatment and emergency services (e.g., immunizations, management of injuries, family planning and nutrition services) and rehabilitation services. Including children and young people with disabilities in healthcare services requires a 'twin-track approach' that adapts existing services and/or products to remove potential barriers to their participation (e.g., providing accessible communications, infrastructural upgrades and staff training) and delivers services targeted only at children and young people with disabilities (e.g., to bolster treatment or rehabilitation).

1.2.1 Importance of multisectoral support

High quality healthcare relies upon health systems that include all people with disabilities (including children and young people), but also hinges upon other key rights such as access to birth registration, education and social protection. Birth registration has a profound impact on a child's subsequent health and well-being throughout their life-course. A lack of access to education or social protection affects an individual's ability to access appropriate healthcare. This interconnection flows in the opposite direction too; for example, poor health can negatively affect an individual's ability to attend school. The interdependence between health and other key sectors underscores the importance of not focusing solely on the health sector to improve the health of children and young people with disabilities, but to adopt a holistic multi-sectoral approach. That said, this Practice Guide focuses on health systems and healthcare.

1.3 Overarching normative framework

The right to health is a well-established human right that is included in the International Covenant on Economic, Social and Cultural Rights (Article 12) and the Convention on the Rights of the Child (Article 24). The Convention on the Rights of the Child was the first human rights treaty that contained a specific reference to disability. The General Comment 9 by the Committee on the Rights of the Child notes that measures taken for the implementation of the rights contained in the Convention should aim at the maximum inclusion of children with disabilities in society.

More specific to people with disabilities, the Convention on the Rights of Persons with Disabilities (CRPD) reinforces the rights of people with disabilities to the same health services as people without disabilities. Article 9 of the CRPD calls for accessibility, including to medical facilities and to information while Article 19 calls for community support services to ensure the living and inclusion of people with disabilities in communities. Article 22 asserts the equal rights of people with disabilities to privacy, including the privacy of personal health information. Article 25 requires State parties to ensure equal access to health services for people with disabilities, with specific mention of sexual and reproductive health services, population-based public health programmes and disability-related health services. Article 26 requires State parties to take measures to strengthen and extend habilitation and rehabilitation services, including promoting the use of assistive devices. The Convention on the Rights of the Child also requires State parties to provide specific assistance to ensure children with disabilities have effective access to health care services and rehabilitation services in a manner conducive to the child achieving the fullest possible social integration and individual development (Article 23).

Box 1: What is Universal Health Coverage?

Universal Health Coverage (UHC) means that all individuals and communities (not only people with disabilities, but everyone) receive the health services they need without suffering financial hardship. UHC includes the full spectrum of essential, quality health services from health promotion to prevention, treatment, rehabilitation and palliative care across the life course. The delivery of these services requires adequate and competent healthcare workers with the optimal skills mix at facility, outreach and community level, and who are equitably distributed, adequately supported and enjoy decent work.

UHC strategies enable everyone to access the services that address the most significant causes of disease and death and ensures that the quality of those services is good enough to improve the health of the people who receive them.

Taken from [https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-\(uhc\)](https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)).

The right to health itself means State parties must generate conditions in which everyone can attain the highest standard. Central to the right to health is timely, acceptable and affordable healthcare of appropriate quality. Services should be provided on an individual (person-centred) basis with regard to the range of support services required (including nursing, personal assistance and respite) and based on an individual's choice and informed consent.

In addition to Conventions like the CRPD, health also features in the global Sustainable Development Goals (SDGs). The SDGs (the current global development framework) place at their heart the principle to 'leave no-one behind'; they explicitly emphasise the importance of including people with disabilities in global development. SDG 3 (good health and well-being) commits to ensuring healthy lives and promotes well-being for all at every age, recognizing the importance of Universal Health Coverage (see Box 1) and underscoring the need for people-centred health services. SDG 5 (gender equality) reinforces commitments to ensure universal access to sexual and reproductive health and reproductive rights, as well as the elimination of violence against all women and girls. The Political Declaration of the High-level Meeting on Universal Health Coverage² also recognizes the importance of increasing access to health services for all people with disabilities.



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² <https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/09/UHC-HLM-silence-procedure.pdf>

1.4 Why is it important for health services to be inclusive of children and young people with disabilities?

Ensuring people with disabilities are purposefully included in health services is a requirement of international law and global health goals (see [Section 1.3](#)). State parties to the CRPD are required to promote, protect and ensure people with disabilities' right to health; signatories are also obligated to tackle discrimination concerning access to health services. In addition, to achieve the SDGs and UHC, health services must be disability-inclusive to ensure all people can access and receive the health services they need. Health services must be of sufficient quality to be effective and must also be affordable (so that healthcare costs do not cause financial hardship at the household level). UNICEF-supported health programmes can help to influence and directly contribute to national efforts to meet international law and global goals.

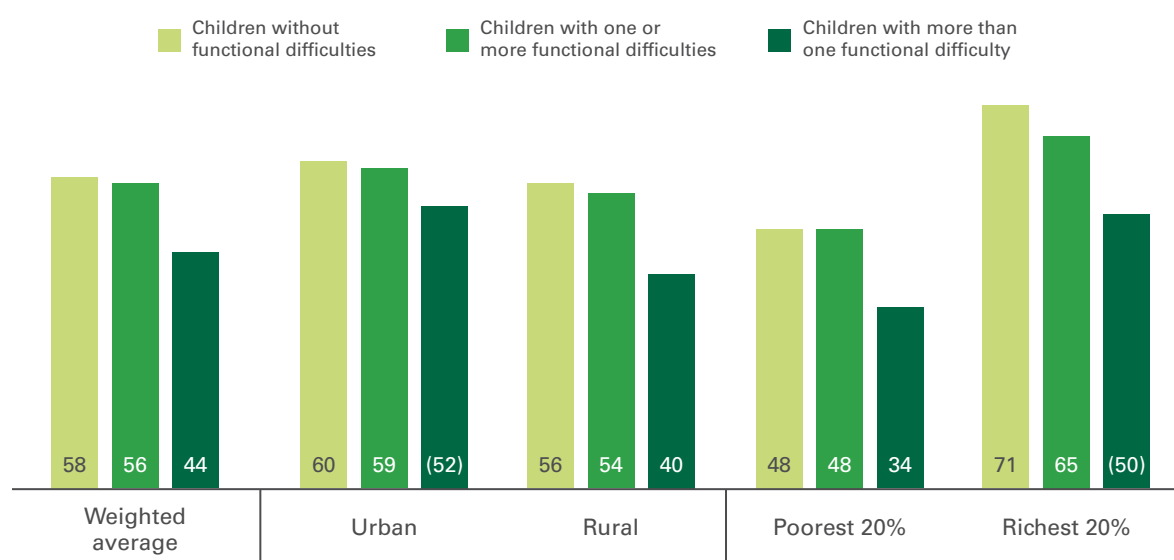
High quality and timely treatment or prevention measures will avoid the development of new health conditions or the deterioration of existing ones, improving health outcomes for children and young people with disabilities (see [Section 6.4](#) for more on early identification and early intervention). Staying healthy will also help these children and young people to access a good education, be included in the community and live on an equal basis with other children and families. For those families acting as sole carers for children and young people with disabilities, disability inclusive health services can facilitate work and income-generation. Healthy individuals also have greater capacity to contribute to their communities, socially, culturally and economically although many disease prevention and health promotion programmes require wide engagement within the community to help reduce transmission of infectious diseases.



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Existing health inequities (see Figure 1 and Figure 2) also make it essential, from a public health perspective, to ensure health services include and are equipped to serve children and young people with disabilities. People with disabilities are more likely to experience poor health (including mental health) because of underlying health conditions, higher levels of poverty, prevailing negative attitudes, stigma and discrimination as well as persistent societal barriers. Poorer health means many people with disabilities have a greater need for health services; children with disabilities are five times more likely to report having been seriously ill than children without disabilities.³ More broadly, people with disabilities in low- and middle-income countries tend to have poorer health service coverage and face greater expense.⁴ UNICEF's commitment to tackling inequality places a responsibility on UNICEF to ensure it addresses the health inequities that currently affect children and young people with disabilities.

Figure 1: Percentage of children aged 24–35 months who received all basic vaccinations at any time⁵



Differences in immunization coverage across different population subgroups can be due to both supply and demand factors and often reflect long-standing health and social disparities.

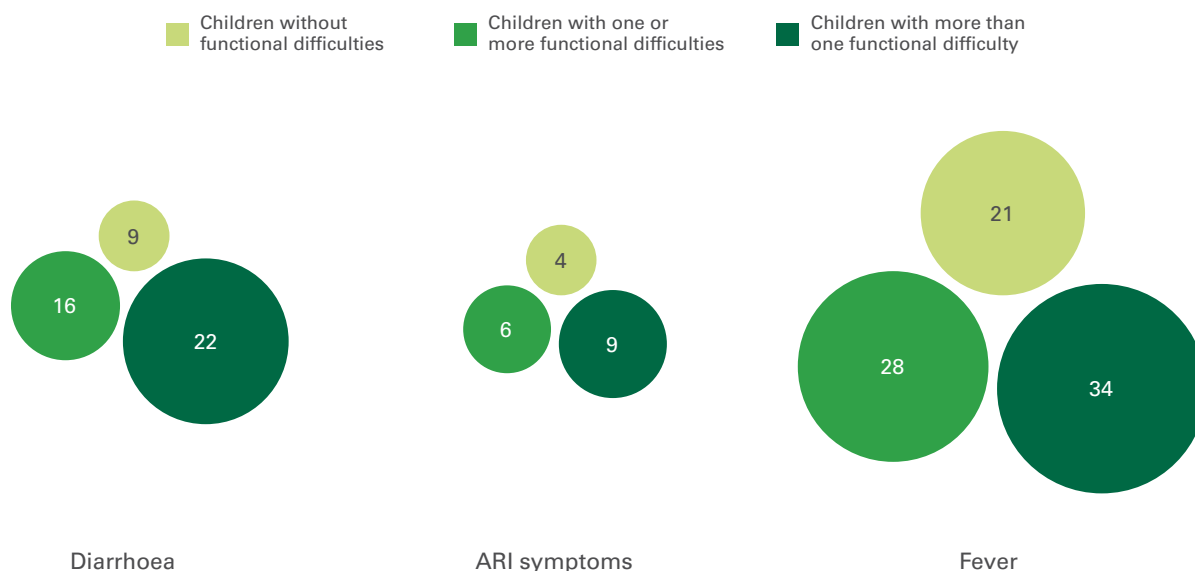
Disparities in immunization coverage exacerbate the risks for poor health in children in the most vulnerable and misunderstood groups, such as children with disabilities living in rural areas and the poorest households.

³ Kuper, H., et al., 'The Impact of Disability On The Lives of Children: Cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries,' *PLoS One*, vol. 9, no. 9:e107300, 9 September 2014.

⁴ Bright, T. and H. Kuper, 'A Systematic Review of Access to General Healthcare Services for People with Disabilities in Low and Middle Income Countries,' *International Journal of Environmental Research and Public Health*, vol. 15, no. 9: E2165, 30 August 2018.

⁵ United Nations Children's Fund, 'Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities', UNICEF, New York, 2021.

Figure 2: Percentage of children aged 24–59 months with a reported episode of diarrhoea, symptoms of acute respiratory infection⁶



Disability-inclusion is not about making health services work for ‘others’, it is about ensuring health services work for all of us throughout our life course (e.g., from pre-natal and newborn care to childhood vaccinations, sexual and reproductive health, rehabilitation and palliative care). It is likely that everyone will experience some form of disability – whether temporary or permanent – at some stage in their lives. By considering disability inclusion in health programmes it supports, UNICEF is contributing to a stronger healthcare system capable of delivering effective health services to many children and young people at some point in their lives and helping make UHC attainable.

Providing disability-inclusive health services will help to cut unnecessary health costs.⁷ Children and young people with disabilities are more likely to have unmet healthcare needs than those without disabilities. For example, adolescents with disabilities are less likely to be included in sex education programmes⁸ and girls with disabilities experience higher rates of violence but are often invisible in or excluded from responses to gender-based violence.⁹ Not providing health information (including to caregivers) or not including children and young people with disabilities in vaccination or health screening programmes risks them later presenting for more extensive, invasive and expensive treatment. Building disability inclusion into UNICEF’s health programmes from the outset will help to eliminate unnecessary and costly health interventions later in the life course.

⁶ Ibid.

⁷ McIntyre, D., et al., ‘What Are the Economic Consequences for Households of Illness and of Paying for Health Care in Low-and Middle-Income Country Contexts?’ *Social Science & Medicine*, vol. 62, no. 4, 2006, pp. 858-865.

⁸ Michielsen, K. and L. Brockschmidt, ‘Barriers to Sexuality Education for Children and Young People With Disabilities in the WHO European Region: A scoping review’, *Sex Education*, vol. 21, no. 6, 2021, pp. 674–692, DOI: [10.1080/14681811.2020.1851181](https://doi.org/10.1080/14681811.2020.1851181).

⁹ van Der Heijden, I. and K. Dunkle, ‘Evidence Review: Preventing violence against women and girls with disabilities in lower- and middle-income countries (LMICs), What Works, UKAid, London, September 2017.

Using this guide

2



2.1 What is this Practice Guide?

This Practice Guide supports UNICEF's work to achieve UHC and has been produced to help drive improvements in the accessibility, acceptability, quality and inclusiveness of UNICEF-supported programmes focused on routine general health care. This Practice Guide will also be relevant to health programmes delivered or supported by organizations other than UNICEF.

More specifically, this Practice Guide is intended to strengthen knowledge, attitudes and skills related to disability inclusion, including by providing:

- Entry points for addressing barriers that children and young people with different disabilities (and their families) experience when interacting with the health system;
- Examples of how disability inclusion can be applied in health care settings;
- Links to additional resources and materials.

This Practice Guide identifies what disability inclusion could look like across health services, from measures that could be adapted for systemic change to health service-specific measures (e.g., in regard to antenatal care or immunization programmes). This Practice Guide also presents key considerations for strengthening disability inclusion at each stage of the programme cycle.



Priorities for disability inclusion in every possible health programme are not set by this Guide as how to strengthen disability inclusion in different health programmes will hinge upon a thorough contextual analysis. Nor does this Practice Guide provide detail on how sectors other than health can utilize a disability inclusion lens (including education, water and sanitation and social protection) while still recognizing that a holistic multi-sectoral approach is so important to health and healthcare. This Practice Guide is not a prescriptive manual but presents key principles and ideas to help those delivering UNICEF-supported health programmes to get started. The starting point for disability will depend as much upon context as upon individual capacity and financial resources.

2.2 Why do we need a Practice Guide?

This Practice Guide responds to requests from countries, donors and partners working with UNICEF supported health programmes and the focus on the rights of persons with disabilities in UNICEF's Strategic Plan 2022–2025 (as well as the UN Disability Inclusion Strategy). A demand exists to better understand how to incorporate a disability-inclusion lens in health, to ensure barriers to routine general health services frequently faced by children and young people with disabilities are addressed in UNICEF's programming. A demand also exists to help strengthen the engagement and participation of this group of children and young people (and Organizations of Persons with Disabilities (OPDs)) in the design and implementation of health programmes and assistance to governments. The information in this Practice Guide is intended to inspire action and serves as a basis for individuals to present or seek further learning, illustrating practical steps individuals can take to strengthen disability inclusion in UNICEF supported health programmes.



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2.3 Who might use this Practice Guide?

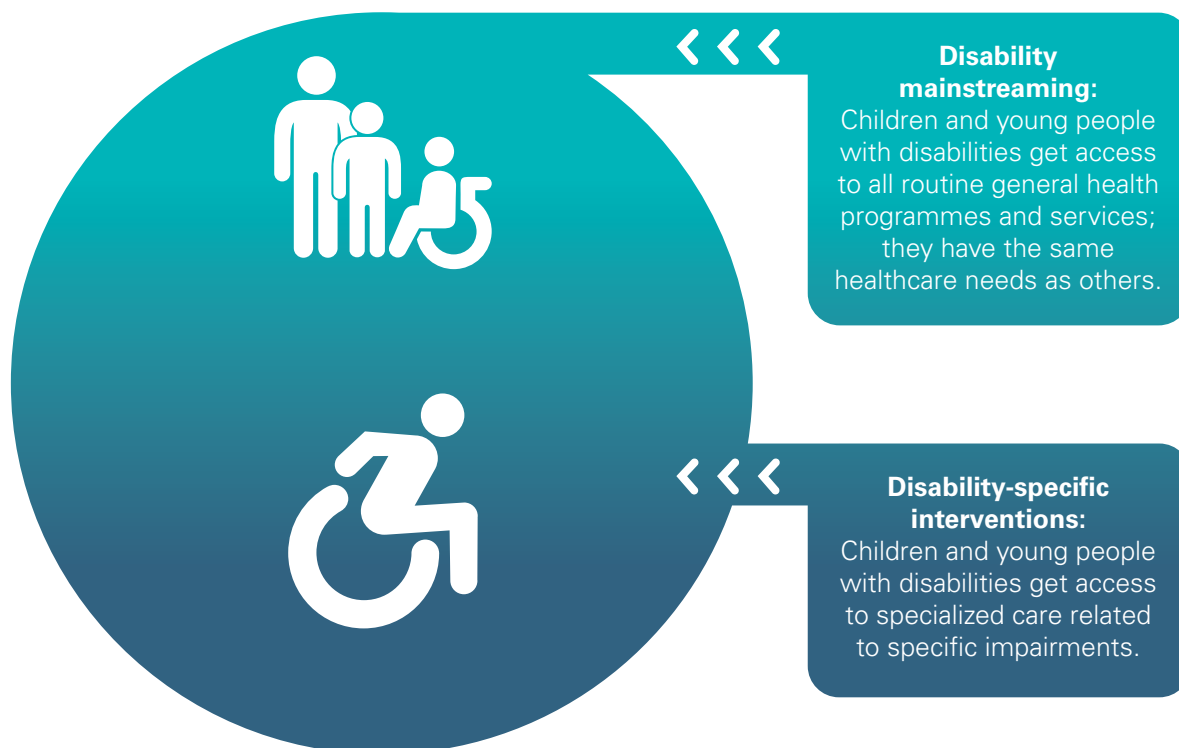
This Practice Guide is primarily for programme staff, implementing partners and the national and sub-national health authorities they are supporting (including those working in the mental health sector). We recognize that those involved in designing and delivering health services are often in the best position to facilitate and support practical changes to service delivery. Health managers and policy-makers may not have direct contact with children and young people with disabilities (and their families, parents and/or caregivers), but they are responsible for ensuring that health service sites and existing services are constructed or organized in a way that is inclusive of this group of children and young people.

The general global health and development community may also find this Practice Guide useful for their own efforts in strengthening the provision of disability-inclusive health services.

2.4 What is the scope of this Practice Guide?

Disability inclusion requires a 'twin-track' approach in which disability mainstreaming and disability-specific interventions are both implemented (see [Box 2](#)).

While UNICEF applies the twin-track approach across its efforts to advance the rights of persons with disabilities, this Practice Guide focuses on disability mainstreaming; on steps that can be taken to ensure children and young people with disabilities benefit equally from routine general health services. Throughout this Practice Guide are principles and ideas of ways to adapt health facilities and services to serve children and young people with disabilities. UNICEF recognizes that with full inclusion, health services are better suited for all children, young people and their families. This Practice Guide does not provide guidance on specialized care related to specific impairments.

Box 2: Twin-track approach

2.5 How is the Practice Guide organized?

This Practice Guide includes the following sections:

- Section 3 outlines common barriers children and young people with different impairments (and their families) experience when interacting with the health system, as well as key inclusion principles that address those barriers.
- Section 4 identifies key considerations for strengthening disability inclusion at each stage of UNICEF's programme cycle.
- Section 5 identifies key considerations and opportunities for strengthening disability inclusion at a system-wide level.
- Section 6 identifies key considerations and opportunities for strengthening disability inclusion in selected health services.
- The Annexes include: 1) a list of resources for further reading on disability inclusion and health, and 2) tools and further practical guidance.

Common barriers to health services

3



Common barriers to health services



To improve the inclusion of children and young people with disabilities in routine general health services, it is important from the outset to understand the barriers they and their families and/or caregivers experience in accessing health services. These barriers can affect both the supply and quality of health services by health workers, service delivery sites and governments as well as the demand for, or the uptake of, health services by children and young people with disabilities (or their families and/or caregivers).

The following are barriers common to people with disabilities in multiple settings:

Attitudinal barriers

Stigma, discrimination and ableist views are among the biggest barriers to inclusion experienced by children and young people with disabilities, including:

- Experiences of prejudice, humiliation and bigotry by health service providers and other staff at health service delivery sites (including support staff such as receptionists and security guards);
- Limited knowledge and understanding of disability rights among health service providers, in part because of inadequate professional training and development regarding disability inclusion;
- Inaccurate assumptions and misconceptions by health workers, families or communities regarding children and young people with disabilities (compounded by other factors, including gender and age), including around their health status; sexual activity and resulting health requirements; mental capacity and their ability to provide consent; legal capacity and/or their responsibility as parents or caregivers;
- Health service providers subjectively prioritizing treatment services or critical care to children and young people without disabilities where availability is limited;
- Requests by health workers (not in consultation with individual patients or caregivers) for personal assistants or sign language interpreters, compromising an individual's privacy and confidentiality;
- Children and young people with disabilities (or their families/caregivers on their behalf) choosing not to access health services because of previous negative experiences.

Environmental barriers

The accessibility of physical infrastructure, information and communications can present environmental barriers that prevent access to service delivery sites and/or undermine health literacy, including:

- Health service delivery sites not serviced by accessible transport options;
- Entrances to hospitals, clinics or other sites having stairs but no ramps or accessible elevator;
- Toilets, doorways, passages or rooms within health service delivery sites unable to accommodate wheelchairs or difficult for children and young people with mobility or sensory impairments to navigate;
- Examination beds and chairs that are not height-adjustable and fixed-height furniture, including for child-related examination and treatment;
- Health service delivery sites that are lit in a way or that have signage that is inaccessible or damaging to children and young people with disabilities;
- Health information and/or prescriptions that are not provided in accessible formats (e.g., Braille or large print), or not presented in easy-to-follow formats, including plain language and pictures or other visual cues (further compromising informed consent to treatment).



Common barriers to health services

Institutional barriers

Legislation, health policies and standardized practices across the health sector can be the source of institutional barriers, including:

- Omission of children with disabilities (and their families) from decision-making processes within health systems or consultation processes;
- Exclusion of children and young people with disabilities from medical research and drug trials, contributing to less effective treatment regimens;
- No policies in place to accommodate the practical requirements of children and young people with disabilities, including longer and/or flexible appointment times, outreach services or subsidized services to reduce the cost of health care;
- Health staff and medical professionals not routinely trained in disability inclusion during pre-service nor in-service, in turn lacking awareness or understanding of disability rights;
- Laws prohibiting discrimination regarding health insurance do not exist, leading to the exclusion of people with disabilities from public and private health insurance and the unaffordability of healthcare for them;
- National health plans or sector-wide strategies overlooking access to healthcare for children and young people with disabilities, meaning that disability inclusion is not considered from the outset;
- Ministry of Health budgets not considering disability inclusion, causing it to be inadequately resourced;
- Triage protocols allowing disability status to be used as a proxy for poor health status, negatively affecting access to life-saving health services for children and young people with disabilities;
- Insufficient national- or local-level disability disaggregated data and evidence on health inequities; coverage; affordability and quality of healthcare for children and young people with disabilities, limiting health planning and preparedness;
- Legislation disqualifying some people with disabilities granting consent for selected health services.

As already highlighted, children and young people with disabilities are not a homogenous group, meaning the barriers individuals experience will differ based on their impairment and other key characteristics such as gender and gender identity, ethnicity, geographic location and language, religion, and others. Context analyses help to present a more detailed picture of barriers experienced in different settings.¹⁰ However, it is important that context analyses (conducted with children and young people with disabilities) pay close attention to various identity factors intersecting with disability that may create very specific experiences of simultaneous and compounding discrimination based on interlinking social norms. While the specific situation of women and girls with disabilities relative to men and boys with disabilities has received more attention, gender equity remains a challenge in healthcare. Furthermore, gender consideration often continues to be limited to the binary understanding. Non-binary and transgender persons with disabilities, especially young persons, have very specific interacting health needs related to both their impairment and their gender identity. Religion may have a different influence on permission-based help-seeking behaviour and accessibility for young women with disabilities than for young men with disabilities.

¹⁰ The AAAQ (Availability, Accessibility, Acceptability and Quality) provides a useful framework for a context analysis, to ensure that key categories of obstacles to inclusive health care for persons with disabilities are considered.

3.1 Enabling principles underpinning disability inclusion in health services

Key principles exist (based upon the CRPD and the Convention's rights-based approach to disability inclusion) that are central to addressing barriers to health experienced by children and young people with disabilities. The common barriers identified in **Section 3** are often the result of the following key principles not being applied; likewise, removing barriers often also starts with applying the following key principles:

Independence and autonomy

Ensuring individuals have the opportunity to make informed choices and to participate actively in decisions regarding their lives. Children and young people with disabilities have the right to receive support (e.g., accessible information) to help develop their autonomy and informed consent to treatment and/or other health interventions, irrespective of the type of disability.

Meaningful and effective participation

Disability inclusion across health services requires the input of people with disabilities. They are the most familiar with their barriers to health services and are therefore an important resource that health services and healthcare providers should draw upon when developing strategies. Their families and caregivers can also provide valuable input as they consistently witness the barriers experienced and are critical advocates for positive change. Organizations of people with disabilities (OPDs) representing different disability types can adopt a representative role. Care should be taken to deliberately involve organizations of women with disabilities and of youth with disabilities or – where they are not established – women's and youth 'departments' or 'wings' of OPDs.



Common barriers to health services



Non-discrimination and equality

Children and young people with disabilities should have access to health services 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 accommodations’ (see Box 3) are essential to help them have an equality of opportunity.

Box 3: Defining ‘Reasonable Accommodation’

According to Article 2 of the Convention on the Rights of Persons with Disabilities:

“‘Reasonable Accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed 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 freedoms.”

Comprehensive accessibility

‘Universal design’ (see [Section 5.7](#)) is an approach that ensures services and products are usable by all people to the greatest extent possible. Improving the health system to be accessible to people with disabilities will also help meet the needs of other vulnerable groups (e.g., older people or minority language speakers). However, increasing accessibility requires focus on more than just physical infrastructure. Accessibility of health information and communications is also essential, as well as tackling negative attitudes and perceptions.

Disability inclusion across UNICEF's programme cycle

4



UNICEF grounds the design of every Country Programme of Cooperation in high-quality situational analyses; extensive engagement with government and development partners; participative planning processes as well as result-oriented budgeting and implementation. Central to UNICEF's design of Country Programmes of Cooperation is a systematic and result-oriented approach.

Applying a disability rights lens at each stage of the programme cycle helps to ensure that disability inclusion is embedded within the design of UNICEF supported programmes. Figure 3 provides indicative actions that can be taken to consider and address disability inclusion at each stage of the programme cycle: evidence and analysis; strategic planning; implementation; monitoring; reporting and evaluation.



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Figure 3: Indicative actions for considering disability inclusion in the programme cycle

Evidence and analysis	1
• Conduct a barriers analysis to identify barriers to health information and services experienced by children and young people with disabilities, nationally and locally (also considering the effect of other key factors and characteristics on compounding barriers, including but not limited to gender, ethnicity, geographical location and language). • Conduct a context analysis (see Section 5.1) to identify the existing entry points and referral pathways used by children and young people with disabilities to access health information and services, the key actors and stakeholders involved in each stage of health delivery for them, and the current coverage of disability inclusive health services. • Conduct secondary statistical analysis to generate disability disaggregated data (including disaggregation by gender and impairment type), where possible; identify data gaps that should be filled/help add a disability lens to health surveys. • Engage children and young people with disabilities and their families/caregivers in the analysis of data collected. • Conduct a stakeholder analysis in the health facility/ies and local community/ies to identify key influencers, facilitators and potential partners for policy and advocacy work, to strengthen the inclusion of children and young people with disabilities in routine general health services. The analysis should include the views of those in urban and rural areas, male and female and those from various cultural backgrounds. • Utilize data from the barriers and context analyses to initiate advocacy with government and other key stakeholders around disability inclusion.	2 3 4
Strategic planning	5
• Prioritize addressing specific barriers to routine general health services and information experienced by children and young people with disabilities. • Engage these children and young people (and their families or caregivers) in planning and prioritization, engaging girls and boys with different types of disabilities. • Apply an intersectional lens, to ensure strategic planning considers the compounding effect of disability and other marginalizing factors (e.g., age, gender, ethnicity, socioeconomic status). • Conduct analysis of multisectoral integration on disability, to identify existing referral pathways and how to strengthen multisectoral integrated service delivery. • Set specific and measurable outcomes/outputs/indicators on children and young people with disabilities' access to health information and services and their resulting health and well-being; put in place appropriate monitoring and reporting systems. • Ensure health budgets consider costs for disability inclusion. • Ensure Universal Design principles are factored into project plans for new infrastructure or changes to the existing. • Ensure resourcing includes capacity around disability inclusion.	6 Annex 1 Annex 2

Implementation

- Establish a coordination mechanism within the UNICEF Country Office to facilitate comprehensive delivery across health programmes and/or an integrated focus on disability inclusion across sectors.
- Establish new referral pathways and effective networks to strengthen multisectoral integrated service delivery.
- Create mechanisms for the systematic engagement of people with disabilities in the design, implementation and review of UNICEF supported health programmes.
- Provide a platform for implementing partners to strengthen their understanding and awareness of disability inclusion.
- Regularly identify and put in place improvements to strengthen disability inclusion.

Monitoring and reporting

- Prepare a disability inclusive monitoring and evaluation framework, including the collection of data on health inequities, coverage, affordability and quality of health care.
- Develop disability disaggregated reporting systems; then collect disability disaggregated monitoring data (see **Section 5.4**).
- Support governments and partners to strengthen disability disaggregation in Health Management Information Systems.
- Conduct accessibility audits to ensure any construction and/or project design is appropriate for children and young people with disabilities.

Evaluation

- Implement evaluations that analyse trends in coverage, quality and access, including with the participation of children and young people with disabilities.

System-wide measures to ensure inclusion of children and young people with disabilities in health services

5



System-wide measures to ensure inclusion of children and young people with disabilities in health services

A range of broader, system-wide measures exist and can be taken to ensure routine general health services are inclusive of children and young people with disabilities. This section looks more closely at these system-wide measures, providing examples for each measure of entry points for UNICEF supported programmes based on three levels of impact and ambition:

- Respond to the rights of people with disabilities and ‘do no harm’ as a minimum requirement **(compliance)**;
- Going beyond ‘compliance’ to approaches that build individual assets, capabilities and opportunities for children and young people with disabilities **(empowerment)**;
- Going further to challenge and shift persistent structural barriers to equality and inclusion **(transformation)**.

Each level of impact and ambition reflects expectations set in the CRPD and the examples provided are intended to provide a lens through which UNICEF supported programmes can meet and continue to strengthen compliance with the CRPD. This would be dependent upon the local context (including socio-economic context) and UNICEF’s capacity of programme implementation (e.g., in high-income countries compared to low-income countries).



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5.1 Sector-wide planning, legislation and policy

Disability inclusion requires careful planning of all routine general health services and activities, as well as specific activities to target and improve disability inclusion. Planning for disability inclusive health services involves first understanding the situation experienced by children and young people with disabilities. Conducting a situation analysis helps to identify priority areas for improvement and facilitate planning (see **UNICEF's Toolkit: New Generation Situation Analysis** for more information on conducting a situation analysis focused on children with disabilities). All areas of health services should be considered when conducting a situation analysis of disability inclusion (with engagement from OPDs). This would include: demand for services among children and young people with disabilities and entry points; the current coverage of disability inclusive health services; referral pathways; existing health service monitoring and evaluation (see **Section 5.4**); service provider attitudes (see **Section 5.9**); and disability inclusive health in emergencies (see **Section 5.10**). Using information from the situation analysis, it is possible to begin planning what is required to deliver a more disability inclusive health service, identify relevant objectives and strategies to achieve this and strengthen CRPD compliance in health sector budgets (see **Section 5.3**).

Involving people with disabilities (including children and young people) in the situation analysis and in developing objectives and strategies to strengthen disability inclusion is essential. Input from people with disabilities will increase the relevance and appropriateness of subsequent actions. Further guidance on partnering with OPDs is available in **Annex 2**.

Underpinning efforts to strengthen disability inclusion in health services should be legislation and policies that recognize the right of people with disabilities to the highest attainable standard of health. Country governments have specific obligations under international law to respect, protect and ensure the right to health for people with disabilities. A comprehensive legal and policy framework should be in place to provide a firm foundation on which to strengthen disability inclusive health services. A review or scoping of relevant legislation or policy can identify where this firm foundation does not exist and/or where reforms are needed to improve the realization of disability rights at country-level.

Table 1: Example entry points for disability inclusive planning, legislation and policy

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
Ensure national health strategies, legislation and policies explicitly require and support health services to be equally available to all people, regardless of age, gender or disability.	Build the capacity of people with disabilities and OPDs to advocate for, monitor and/or support inclusive health services in their home and in the community.	Enable people with disabilities and OPDs to lead work with health authorities to ensure health planning explicitly considers disability inclusion.

5.2 Institutional structures to support children and young people with disabilities

At the national level, responsibility for disability inclusion is regularly spread across multiple government ministries, often including a Ministry for Social Affairs and a Ministry for Education. Ministries of Health have responsibility for mainstreaming disability inclusion across health services (and for delivering disability-specific health services). Coordination between government ministries is critical, given the importance of a multi-sectoral approach to health and healthcare (see **Section 1.2.1**). It is because disability can be present at any and all stages of the life cycle that coordination on disability inclusion across government ministries is critical (e.g., through a cross-Ministerial Council or Commission of Disability Affairs), to help governments apply a coherent disability lens across multiple sectors to encompass services throughout the life cycle.

Coordination within a Ministry of Health is also critical to ensure appropriate adjustments are made across health services and facilities (reinforced using quality assurance tools and standards) and not limited to only some health services or facilities. Consolidating responsibility for disability inclusion across the health sector (including by mandating one 'directorate' in a Ministry of Health to focus on disability inclusion or establishing a disability inclusion 'task force' with representatives from across Ministry of Health 'directorates' and health sector development partners) can improve coordination and planning.



Table 2: Example entry points for institutional structures to support people with disabilities

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
Establish a disability 'focal point' in a Ministry of Health, with responsibility for strengthening disability inclusion across the health sector.	Establish safe, inclusive and accessible mechanisms that enable people with disabilities (and/or their families) to communicate with government, ask questions, and raise concerns regarding discriminatory health services.	In collaboration with people with disabilities (including children and young people with disabilities) and/or OPDs, develop an action plan for government and health sector partners to strengthen disability inclusion across the health sector and then monitor its implementation.

5.3 CRPD-aligned health financing

National efforts to raise, pool and use funds to ensure the availability and use of quality health services differs considerably. Severe competing pressures often exist within health budgets. In many countries, current budgetary allocations are already not enough to deliver essential public health functions to the entire population to achieve UHC. Despite these limitations, existing health financing should still improve health outcomes for children and young people with disabilities. One critical element is to ensure that health spending is inclusive and fosters accessibility. For example, health spending should not replicate or exacerbate existing environmental barriers to health facilities already experienced by these children and young people (e.g., through regulations during procurement focused on accessibility of physical infrastructure).

Where national health budgets set aside funding specifically to strengthen disability inclusion, disability spend needs to carefully respond to the situation experienced by children and young people with disabilities (see **Section 5.1**). Administrative costs (e.g., workplace adaptations for health staff with disabilities and disability awareness staff training) as well as operational costs (e.g., pooling funding to provide sign language or improving the accessibility of existing buildings) must both be incorporated into health budgets.

Where health insurance is available, children and young people with disabilities are often excluded from coverage based on impairment type or subject to higher premiums than persons without disabilities. As a result, they may not be able to obtain health insurance and subsequently have unequal access to health services. By preventing disability-based discrimination regarding health insurance coverage or reducing out-of-pocket health-related expenses experienced by children and young people with disabilities (and/or their families) it is possible to make more equal the access these children and young people have to health services.



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Table 3: Example entry points for CRPD compliant health financing

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
Strengthen and support utilization of funds for and/or government decision making around inclusive health financing.	Build the capacity of OPDs to monitor and conduct advocacy around health financing; including by building partnerships and synergies with representative organizations of other marginalized groups.	Ensure national legislation protects people with disabilities from discrimination in the provision of health insurance.

5.4 Disability inclusive monitoring and evaluation

Accurate and timely national- or local-level quantitative and qualitative data and evidence on prevalence, health inequities, coverage, affordability and quality of health care related to children and young people with disabilities (disaggregated by sex and gender) are pivotal in the planning, development and maintenance of disability inclusive health services.

All health facilities collect information for internal reporting purposes and to support district and/or national level planning and monitoring (e.g., through patient health and medical records or routine surveys as well as client exit interviews or accessible feedback and complaint mechanisms). Intentionally collecting data on an individual's disability status can strengthen planning, management and decision-making around disability inclusion at facility-level. For example, identifying patterns in utilization of services by children and young people with disabilities of services at that facility and to strengthen the care provided to them at that facility.

Collecting disability data is usually based on self-reporting and focussed on an individual's functioning. The Washington Group Questions (see **Annex 2** for a summary of Washington Group modules) can be used to help disaggregate utilization of services by disability (e.g., the number of children and young people with different impairments attending health facilities); they do not provide clinical diagnosis. The World Health Organization's **Model Disability Survey** is a general population survey that provides comprehensive information about the distribution of disability in a country or region and is based on the International Classification of Functioning, Disability and Health.

In some cases, national legislation may define 'disability' more narrowly than the CRPD and include selected impairments, potentially impacting government-collected disability data. Identifying children with disabilities presents added complexities. Impairments may not be evident and questions are often directed at parents or caregivers who may not identify (or choose to identify) their child as having an impairment.

Aggregated facility-level data as well as more targeted or detailed methodologies (e.g., focus group discussions or knowledge, attitudes and practice surveys) can also facilitate regional or national analyses around disability inclusion, including: to guide national policies and decision-making; strengthen health messaging or health worker training; help review health planning and budgeting; and examine the success or impact of health strategies or services. Evaluations of health programmes should also be designed to assess the relevance, efficacy, sustainability and impact on persons with disabilities as disability inclusion in evaluations is one indicator of the **UNDIS Accountability Framework** (see **Annex 2** for key disability considerations for evaluations of health programmes).

Persons with disabilities (including children and young people) and OPDs can play an invaluable role in data collection, sharing their own experiences or capturing the experiences of the disability community. Engaging children and young people with disabilities (as well as their families/ caregivers) in data collection requires careful consideration to ensure the views of girls and boys with different impairment types are captured and that the resulting data can be disaggregated by impairment type and by age. It is important that data reflects the fact that these children and young people are not a homogenous group.

In some settings, it is necessary to build capacity in collecting disability disaggregated data and/or including children and young people with disabilities in data collection.

Table 4: Example entry points for inclusive monitoring and evaluation

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
Ensure disability data is collected in a way that is not stigmatizing (e.g., is based upon functioning, where possible).	Ensure Health Management Information Systems and other health-related data capture evidence that can be used for planning and monitoring purposes on health inequities, coverage, affordability and quality of health care regarding children and young people with disabilities, not just prevalence.	Engage people with disabilities (including children and young people) and their families in collecting health data and evidence, including the experiences and views of the disability community regarding health and health care.

5.5 Referral networks for people with disabilities

Health referrals are processes by which a health worker at one level of the health system, typically because of insufficient capacity or resources to respond to a clinical condition (e.g., diagnostics, drugs, equipment or skills), seeks a better or differently resourced health facility at the same or higher level of the health system for the management of an individual's health care needs. Referrals can be driven by the need to seek expert opinions (e.g., regarding mental health), for additional or specialist services (e.g., prosthesis or additional tests) or for admission to a health facility for diagnosis and/or treatment.

Effective referral networks require a close and functioning relationship between all levels of the health system; they enhance individuals' access to high quality health care, ensure service delivery is coordinated and easier for individuals to navigate, facilitate timely access to specialist services and ensure health facilities are optimally and cost-effectively used.

While referral systems differ between countries based upon factors within a health system (e.g., the capabilities of different health facilities, capacity of health care workers and availability of specialized health workers) and broader, societal factors (e.g., population size and density, pattern and burden of disease and distances between health facilities), key components common to referral networks exist. Relationships between service providers are typically formalized with referral procedures agreed in advance, to help put in place suitable transport, communication and conditions for patient care. Each individual referred is typically accompanied by a written record of clinical findings and specific reasons for making the referral, to help the individual receive appropriate care and timely attention upon arrival at the facility. A referral register is also often used to track referrals made and received, helping health facilities monitor referral patterns and trends as well to strengthen both the referring and the receiving facility.

Critically, it is important that any referrals are conducted in a way that limits any fear or anxiety individuals may experience. Relevant information about the referral should be provided and understood by children (and their families), confidentiality should be ensured and individuals (or their caregivers, depending upon the age of the child and the severity of the impairment) should be involved in the decision-making process.

System-wide measures to ensure inclusion of children and young people with disabilities in health services

Children and young people with disabilities require referrals for routine general health care and specialized medical care, just as do those without disabilities. Ensuring a person-centred approach to referrals for these children and young people can present unique challenges, including: ensuring that referral decisions are not clouded by stigma around disability or assumptions about the behaviours or health needs of children and young people with disabilities (e.g., their capacity to provide informed consent or their sexual activity); information regarding the referral is in an accessible format; the referral decision is made with the informed consent of the person with disabilities.

Table 5: Example entry points for inclusive referral networks

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
Ensure healthcare workers receive disability awareness and rights training to reduce the likelihood of stigma or discrimination impacting referral decisions.	Create a directory of disability-inclusive routine general health services (and specialized services) to aid decision-making by children and young people with disabilities (and/or their families).	Build the capacity of, or partner with, OPDs and parent groups for them to directly support routine general health services at community-level (including OPDs conducting targeted health campaigns).

5.6 Health sector's contribution to the birth registration of children with disabilities

Birth registration levels have increased globally, with about 3 in 4 children under the age of 5 years registered in 2019, compared to 6 in 10 children in around 2000.¹¹ While unregistered children are predominantly from poorer households, live in rural areas and have mothers with lower levels of education,¹² children with disabilities remain more likely to be unregistered than children without disabilities.¹³

Birth registration is not only a right of every child, (Article 7, Convention of the Rights of the Child) it is essential to the legal recognition of a child and closely linked to the realization of other rights (including access to health).¹⁴ Without birth registration (and subsequently, civil registration more broadly as well as disability registration), children and young people with disabilities are invisible and unable – alongside their families – to access essential resources, healthcare (e.g., routine vaccinations), entitlements or social support. The benefits of birth registration are not limited to the individual; the information collected can be compiled and analysed to underpin national and local policy and planning in the health sector (and other key sectors).

¹¹ United Nations Children's Fund, *Birth Registration for Every Child by 2030: Are we on track?* UNICEF, New York, 2019.

¹² Ibid.

¹³ United Nations Children's Fund, 'Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities', UNICEF, New York, 2021.

¹⁴ Todres, J., 'Birth Registration: An essential first step toward ensuring the rights of all children', *Human Rights Brief*, vol. 10, no. 3, 2003, pp. 32–35.

Non-registration or late registration can be the result of inaccessible registration facilities, a lack of knowledge about how to register a child, affordability and/or stigma. The perception that birth registration adds little value can also be the underlying reason for non-registration or late registration.

The health sector can be a powerful ally of children and young people with disabilities, to help them and their families overcome barriers to birth registration (as well as broader civil registration and disability registration). Health workers are in regular contact with these children and young people, providing care, and are central to early identification efforts (see **Section 6.4**). Health professionals can use these points of contact to provide information to children and young people with disabilities (and their families) about registration. Health professionals also record key information on births, deaths and disabilities and where permitted by law, health professionals could directly pass key information to the civil registrar. (See **'Health Sector Contributions Towards Improving the Civil Registration of Births and Deaths in Low-Income Countries: Guidance for health sector managers, civil registrars and development partners'** for further information and guidance).

Table 6: Example entry points for birth registration

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
Ensure health professionals can provide accessible information to families of children and young people with disabilities about birth registration and/or relevant information direct to the civil registrar.	Ensure birth registration systems are accessible and acceptable to children with disabilities and their families, including by training registrars on disability inclusion and eliminating registration fees.	Conduct targeted media campaigns showing the value and benefits of birth registration to children and young people with disabilities, to create greater demand for birth registration.

5.7 Accessible infrastructure, information and communications

Physical access to health service buildings and clinics, as well as hygiene facilities and outdoor on-site facilities, is critical. Accessibility needs to be considered in all health service delivery locations, including clinics, outreach activity centres, health centres, and hospitals but also anywhere health promotion, prevention or treatment is available. Physical accessibility is important for most patients, not only people with long-term disabilities. Injury, illness, surgical interventions and pregnancy can equally lead to children and young people experiencing barriers in terms of physical access. Accessibility is also important for the families and caregivers of many children and young people with disabilities, including those cared for by grandparents.

Physical accessibility extends beyond the infrastructure of health facilities to also include equipment used within health facilities as well as transportation to and/or from health facilities. In some locations, distances to health facilities may be greater than elsewhere or terrain more difficult. Transportation may also be unaffordable or inaccessible. Challenges around transportation underscore the importance of a multi-sectoral approach (see **Section 1.2.1**) including consideration of public transport.

System-wide measures to ensure inclusion of children and young people with disabilities in health services

Physical barriers to health can often be addressed at little or no cost. Examples include: clearing hallways and rooms of obstructions and excess furniture; providing clear signage; ensuring hygiene materials and drinking water are at heights accessible to all; carefully planning what services to make available on the ground floor of health facilities and utilizing ramps, grab bars and wider doorways. Alternative models of health care such as home visits, telehealth or outreach can also be used to address many physical barriers experienced by children and young people with disabilities.

Central to addressing physical barriers is the concept of ‘universal design’ (see Box 4 for key principles of universal design and **UNICEF’s Accessibility Toolkit**). Universal design involves “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Article 2, CRPD). The cost of incorporating universal design principles in health infrastructure (not including specialized medical equipment or some more extensive requirements) can be as little as 0.5 – 1 per cent, if incorporated into the planning and design phase from the outset.¹⁵ In comparison, retrofitting health infrastructure is often very expensive and, in some cases, impossible.

Box 4: Seven principles of ‘universal design’

- 1. Equitable use:** Design that is useful and marketable to persons with diverse abilities.
- 2. Flexibility in use:** Design that accommodates a wide range of individual preferences and abilities.
- 3. Simple and intuitive use:** Design that is easy to understand, regardless of the user’s experience, knowledge, language skills or concentration level and/or cognitive ability.
- 4. Perceptible information:** Design that communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory or cognitive abilities.
- 5. Tolerance for error:** Design that minimizes hazards and the adverse consequences of accidental or unintended actions.
- 6. Low physical effort:** Design that can be used efficiently and comfortably and with a minimum of fatigue.
- 7. Size and space for approach and use:** Design that provides appropriate size and space – for approach, reach, manipulation and use, regardless of the user’s body size, posture or mobility.

Source: [National Disability Authority, ‘What is Universal Design: The 7 principles’](#)

It is not solely physical accessibility that is critical; the accessibility of information and communications is also important. Health promotion materials are frequently not provided in formats accessible to children and young people with some disabilities (e.g., visual, hearing or cognitive disabilities), effectively excluding them from public health campaigns. Posters may not be in large print, braille-versions of pamphlets may be unavailable and people with cognitive impairments may find complex messaging inaccessible. In-person interactions with health workers and health facility staff (e.g., receptionists) also present communication barriers, often because of prevailing negative attitudes (see **Section 5.9**) and often because of limited methods or channels of communication (including limited availability of sign language interpreters or easy-to-read material). It is critical that families and caregivers of children with disabilities also have a good understanding of any diagnosis and of the treatment services being provided.

¹⁵ Metts R.L., ‘Disability Issues, Trends and Recommendations for the World Bank’, Social Protection Discussion Paper no.0007, World Bank, Washington, D.C., 2000.

Table 7: Example entry points for accessible infrastructure, information and communications

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
• Ensure public health campaigns and information is disseminated in formats and using channels accessible to children and young people with disabilities (see Annex 2 for an example communications audit).	• Engage people with different impairments in accessibility audits (see Annex 2 for example audit), to ensure infrastructure and communications are accessible to children and young people with disabilities.	• Ensure national legislation makes it a legal requirement for universal design principles to be part of health infrastructure projects.

5.8 Using assistive technologies to facilitate access to health services

Removing environmental barriers to routine general health services experienced by children and young people with disabilities is important (see **Section 5.7**), yet is often not sufficient. Assistive products and services can often be utilized in the short-term to facilitate access to routine general health services. Mobility aids (including wheelchairs and walkers) can help children and young people with mobility difficulties move around health facilities, and for those who need it, cushions and other posture supports can allow them to wait in relative comfort and with greater dignity.

In low-resource settings many hospitals might not be able to hire sign language interpreters (for children and young people with hearing impairments) or produce prescriptions in Braille (for those with visual impairments), but they may be able to work with OPDs to make such services available through smartphones. A video call can assist children and young people (and their families) with remote sign language interpretation, while audio messages can also provide access to crucial information for people with visual impairments.

For information on procedures or treatment, which are often needed, hospital administrators can work with sign language, closed captioning and other experts to pre-record the needed video and audio messages for periodic use. Information provided in video format will greatly assist those with hearing impairments, while information provided in audio format will not just assist children and young people with visual impairments, but also children and young people who are either illiterate or not fluent in the local language. Ultimately, having information provided in a variety of media will be beneficial to all patients, regardless of disability status.

Significant advances in assistive technologies continue to be made, presenting opportunities to trial additional ways in which to increase the access of children and young people with disabilities to routine general health services. Internet-based medical services can be extremely helpful for anyone with disabilities, as they have the potential of saving time and money spent physically getting to the medical facility. Internet-based accessible interfaces could strengthen referral networks (see **Section 5.5**), enabling healthcare workers to conduct remote consultations and helping children and young people with disabilities (and/or their families). However, it is essential that the digital interface design be accessible to all, including those with visual or hearing impairments, as well as those with limited experience using online tools.

System-wide measures to ensure inclusion of children and young people with disabilities in health services



Role of health systems in improving access to assistive devices

Assistive devices and technologies also facilitate habilitation (helping people with disabilities maintain or gain new skills, abilities and knowledge) and rehabilitation (regaining skills, abilities or knowledge that may have been lost or compromised due to a change in disability status). Healthcare systems are central to ensuring appropriate devices and technologies reach children and young people with disabilities in the right way and with positive impact. Strengthening the role of health systems in improving access to assistive technologies is an ongoing global focus (see the **Global Report on Assistive Technology**). UNICEF continues to help health systems improve access to assistive devices, directly supporting market shaping in some countries and providing direct procurement support to country governments, often led by UNICEF's Supply Division.

Table 8: Example entry points for using assistive technologies to facilitate access to health services

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
Conduct a facility-level barriers analysis; in turn, identify assistive technologies that could be deployed to address barriers experienced by children and young people with disabilities.	Create opportunities for children and young people with disabilities (and/or their families) to report problems with existing assistive technologies and suggest alternatives.	Establish a 'challenge fund' for OPDs to design and trial assistive technologies to ensure routine general health services are accessible to children and young people with disabilities.

5.9 Inclusive attitudes

Children and young people with disabilities (and/or their families) can be put off altogether from seeking health care or see their access to specific services curtailed because of negative and limiting attitudes of some health workers and health facility staff (including receptionists, cleaners or security personnel).

Negative attitudes that present barriers to children and people with disabilities include: stereotyping – that children and young people with disabilities are unhealthy or not sexually active; a sense of pity, leading to patronizing behaviour; ignorance of the abilities of children and young people with disabilities, including their ability to make their own decisions; denial of impairments that are not visible; fear of saying or doing the ‘wrong’ thing resulting in avoidance of a person.

Negative attitudes can impact the health services available to children and young people with disabilities in multiple ways. Health workers and staff working in health facilities may have little awareness of disability rights or policies (such as free or reduced-cost medical care) intended to facilitate access to health services. They may underestimate the quality of life of children and young people with disabilities, and in turn provide health advice and information that is inappropriate or less relevant. Health workers may have limited understanding of the factors undermining the health of children and young people with disabilities, leading to false diagnoses (including attributing health concerns to existing disabilities and overlooking underlying pathology) and in some cases, failure to detect violence or abuse. They may also provide inferior treatment or care, sometimes driven by facility-level policies limiting the duration of standard appointments as some children and young people with disabilities may require more time to communicate or to complete medical tests.

Social and behaviour change communication can improve awareness of disability rights among health workers, health facility staff and children with disabilities (and their families) and facilitate interpersonal dialogue to stimulate positive changes in attitudes. Not all children and young people with 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, social and behaviour change communication cannot treat children and young people with disabilities as a single homogeneous group. Instead, this kind of communication needs to consider the interplay between different characteristics to effectively influence the self-efficacy and attitudes of these children and young people toward accessing health services. It must also consider the attitudes of parents, caregivers and families of children and adolescents with disabilities toward their accessing different health services and the attitudes of health workers and health facility staff toward these children and young people.

Table 9: Example entry points for promoting inclusive attitudes

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
• Ensure training on disability rights (including a social behavioural change component) and inclusion is provided to health workers and health facility staff (in collaboration with OPDs), including as part of the curriculum for medical and nursing students.	• Facilitate dialogue between health workers, health facility staff and people with disabilities (including children and young people) to improve disability awareness.	• Deliver social and behaviour change communications to increase demand for quality health services among children and young people with disabilities (and their families/caregivers).

CASE STUDY

Disability and inclusion training for health care workers in Tanzania

The Tanzanian organization, Comprehensive Community Based Rehabilitation (CCBRT), is the country's largest provider of disability and rehabilitation services. Through its academy, CCBRT offers specialist training for healthcare professionals on disability inclusion in healthcare services. Based on a human-rights framework, a two-day training course provides trainees with an understanding of the concept of disability-inclusive health services and the barriers and benefits of such services for people with disabilities.

In 2019, 1,044 people were trained through the CCBRT academy. The healthcare professionals trained have since noted an increasing number of persons with disabilities coming to health facilities to access healthcare services. Improved access of physical infrastructure and initiatives by the Ministry of Health (and some partners) to produce accessible health information has also been reported to CCBRT.

Through its training, CCBRT has reinforced that, to ensure sustainability, it is crucial that there is continuous learning by healthcare providers about disability-inclusive approaches. People with disabilities also need to be empowered on their rights to healthcare services and be informed on availability of those services in their localities.

Source: 'The Good Practice Compendium', developed by Missing Billion:
www.themissingbillion.org/new-index



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5.10 Disability inclusion across health services in humanitarian action and public health emergencies

Children and young people with disabilities often experience additional barriers and/or heightened risks during humanitarian crises (from armed conflicts to natural disasters), disproportionately impacting their health and access to health services:

- People with disabilities (including children and young people) are frequently overlooked in disaster responses and health preparedness plans. Children and young people with disabilities are often not counted or identified prior to, during or after natural disasters; they are also rarely consulted in emergency risk management.
- Armed conflict and natural disasters can increase the number of children and young people with disabilities in a community because of injury or psychological trauma. Children and young people with existing disabilities may also be more vulnerable to injury, including because they are often left behind during an evacuation and/or are unaware of early warnings (if the early warning system is not in an accessible format). Injuries sustained during armed conflict or natural disasters and left untreated or inadequately treated can result in further increasing the number of individuals with severe and long-term impairments.
- Children and young people with disabilities (especially girls) frequently face increased risk of violence and sexual abuse during armed conflict and natural disasters, exacerbated by the breakdown of support networks.¹⁶
- Physical barriers to accessing health facilities by children and young people with disabilities may also increase during an armed conflict and natural disasters: buildings may be damaged; the physical layout of temporary settlements or health 'stations' may not be based on universal design principles (see **Section 5.7**), making them inaccessible; terrain may be impassable (e.g., due to flooding).

COVID-19 has demonstrated that many challenges experienced by children and young people with disabilities in humanitarian crises equally apply during public health emergencies. During the COVID-19 pandemic people with disabilities (including children and young people) have been at greater risk of death and serious illness; public health information on prevention measures is often inaccessible, as are water, sanitation and hygiene facilities; children and young people with disabilities are experiencing decreased access to repeat healthcare and medications due to pressure on the health system and supply chains, and increased psychosocial and mental health distress due to isolation and periods of remote education.¹⁷

The Core Commitments for Children in Humanitarian Action (see **Annex 1**) provide a framework to guide UNICEF's work with partners in delivering humanitarian assistance. They outline commitments and benchmarks related to health and HIV/AIDS interventions in humanitarian action that are equally applicable to children and young people with disabilities. Numerous other resources already exist to help protect disability rights in humanitarian crises and public health emergencies, including a Health Checklist focus on disability-inclusive humanitarian action (see **Annex 1**). Underpinning any efforts to improve the inclusion of people with disabilities in health services in humanitarian crises and public health emergencies must be the engagement of OPDs, to identify and/or provide appropriate health services to people with disabilities (including children and young people). Further guidance on partnering with OPDs is also available in **Annex 2**.

¹⁶ World Health Organization and United Nations Population Fund, 'Promoting Sexual and Reproductive Health for Persons With Disabilities', WHO/UNFPA Guidance Note, WHO, Geneva, 2009.

¹⁷ Meaney-Davis, J., H. Lee, and N. Corby, 'The Impacts of COVID-19 on People With Disabilities (No. 35)', Disability Inclusion Helpdesk, London, UK, 2020.

Table 10: Example entry points for disability inclusion in emergencies

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm' • Make all information accessible (e.g., sign language interpretation, audio and Braille) and use dissemination channels that will reach children and young people with disabilities (e.g., via OPDs and social media).	Build assets, capabilities, and opportunities for people with disabilities • Build the capacity of people with disabilities (including children and young people) and OPDs to contribute to the health emergency response.	Address unequal power relationships, seek legal, institutional and societal-level change • Ensure people with disabilities (including children and young people) and OPDs work with governments to incorporate disability inclusion in disaster response and preparedness plans.

CASE STUDY

Disability advisory groups for the COVID-19 response in Australia and Canada

Recognizing the profound impact the COVID-19 pandemic had on people with disabilities, the governments of Australia and Canada created advisory groups to guide national responses to the pandemic.

The Australian Government's Advisory Committee for the COVID-19 Response for People with Disability was established in April 2020. The Advisory Committee includes people with disabilities, parents and carers, Australian Government officials, state and territory government officials, experts from the health and research sectors and major disability advocacy groups. The Committee provides expert advice on the healthcare needs of people with disabilities, their families and the disability service sector, including access to COVID-19 screening, prevention and healthcare. The Advisory Committee reports to Australia's Chief Medical Officer and regularly informs the Australian Health Protection Principal Committee and Communicable Diseases Network Australia.

The Canadian Government's COVID-19 Disability Advisory Group (CDAG) is made up of people with disabilities, academics and leaders of civil society organizations who work on disability rights and empowerment. Housed within the Ministry of Employment and Social Development, the CDAG meets bi-monthly to advise the Minister on the specific issues people with disabilities are facing during the pandemic. Members of the CDAG have formed several informal working groups which also meet regularly to discuss how people with disabilities can be included in their respective pandemic response activities and reports back to the broader CDAG, the Minister, and other Ministers across the Government of Canada when appropriate.

Both advisory groups have helped to make their national COVID-19 response more inclusive of people with disabilities. The Australian Government's Advisory Committee developed a dedicated Management and Operational Plan for People with Disability, the first of its kind.

Source: Taken from the 'Good Practice Compendium', developed by Missing Billion:
www.themissingbillion.org/new-index

Service-specific measures to ensure inclusion of people with disabilities in health services

6



Service-specific measures to ensure inclusion of people with disabilities in health services

Service-specific measures also exist that can be taken to ensure particular aspects of healthcare and delivered services are inclusive of children and young people with disabilities. While broader system-wide measures (see **Section 5**) help underpin disability inclusion across health services, service-specific measures help ensure children and young people with disabilities are targeted by services and are a routine part of patient care. This section looks more closely at these service-specific measures, and on services and areas of healthcare UNICEF currently focuses on. Examples of entry points for UNICEF supported programmes based on the three levels of impact and ambition used in **Section 5** are provided:

- Respond to the rights of people with disabilities and ‘do no harm’ as a minimum requirement (compliance);
- Going beyond ‘compliance’ to approaches that build individual assets, capabilities and opportunities for children and young people with disabilities (empowerment);
- Going further to challenge and shift persistent structural barriers to equality and inclusion (transformation).

Each level of impact and ambition reflects expectations set in the CRPD. The examples provided are intended to provide a lens through which UNICEF supported programmes can meet and continue to strengthen compliance with the CRPD depending upon the local context (including socio-economic context) and UNICEF’s capacity of programme implementation (e.g., in high-income countries compared to low-income countries).



6.1 Antenatal care for women with disabilities

Antenatal care is essential for protecting the health of women and their unborn children, helping women to learn about healthy behaviours during pregnancy, including providing anti-malarial medications and insecticide-treated mosquito nets where malaria is endemic; understand warning signs during pregnancy and childbirth; receive social, emotional and psychological support; access micronutrient supplements; receive treatment for hypertension to prevent eclampsia and/or immunization against tetanus; access HIV testing and medications to help prevent mother-to-child-transmission of HIV.

Women with disabilities require the same standard of antenatal care as women without disabilities. Common barriers to antenatal care mirror those of health services more broadly, including inaccessible transport or health infrastructure (see [Section 3](#)). However, women with disabilities experience specific barriers to antenatal care that women without disabilities are less likely to experience. Women with impairments may find information provided at antenatal checks or by skilled health personnel (e.g., midwives) harder to digest unless provided in accessible formats and/or more time is devoted to individual checks. Women with disabilities are often less likely to be married or have a partner, in some settings causing further stigma.¹⁸ Those reliant on carers and family members may also find it difficult to attend antenatal care because of clinic opening times or (in some cases) the abuse, stigma or discrimination they are subjected to by their carers or family members.

At all stages, antenatal care and the services delivered must be underpinned by informed consent whereby women with disabilities make autonomous choices about their pregnancy and the birth of their child(ren). Some women with disabilities may be more likely to experience complications and health problems during childbirth (see [Section 6.2](#)). It is important that skilled health personnel understand the risks faced by these women and develop a birth plan tailored to each individual, regardless of impairment type.



Table 11: Example entry points for antenatal care for women with disabilities

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
Ensure birth plans are based on informed consent and autonomous choices by women with disabilities.	Create support networks and antenatal classes for women with disabilities, that include both women with and without disabilities.	Engage women with disabilities in the delivery of antenatal care as skilled health personnel (workers/ attendants such as a midwife, nurse or doctor).

¹⁸ Braathen, A., P. Rohleder and G. Azalde, 'Sexual and Reproductive Health and Rights of Girls with Disabilities: A review of the literature', Report, SINTEF and the University of East London, UK, 2017.

6.2 Intrapartum and postpartum care for young women with disabilities

Women with disabilities require the same standard of intrapartum and postpartum care as women without disabilities, including vis-à-vis communication, the attitudes they face from skilled health personnel and their choice and consent.

Intrapartum and postpartum care may need to be adapted for women with disabilities to maintain quality of care. During labour, delivery and immediate postpartum care, women with some disabilities may require communications to be provided in accessible formats to assist childbirth and allay anxieties. Some women with disabilities may have pre-existing medical conditions making it more likely than women without disabilities that they will experience complications and health problems during pregnancy and are more likely to be delivered by caesarean section.¹⁹ Early and teenage pregnancy is also associated with higher rates of symptoms of postpartum depression, likely to be exacerbated for young women with disabilities if they are not provided with appropriate support and awareness regarding their own mental health.²⁰

Postnatal care contacts, especially within the first few days following birth, are a critical opportunity for improving maternal and newborn health and survival, including to support breastfeeding and to provide information about birth spacing. Women with physical disabilities can experience difficulties with positioning or latching during breastfeeding that may require careful consideration and/or equipment (e.g., propping pillows or breast pumps) to help feeding. Young women with disabilities are less likely to have sufficient autonomy to make their own decisions on family planning and birth spacing (see **Section 6.9**). It is important that postnatal care contacts involving young women with disabilities counsel not just these women about their health and the health of their newborn child, but also their partners, to strengthen autonomy and choice around family planning.

Table 12: Example entry points for intrapartum and postpartum care for young women with disabilities

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
Ensure skilled health personnel (e.g., midwives, doctors, nurses) understand and can manage common health risks during pregnancy associated with pre-existing conditions among women with disabilities.	Provide information to young women with disabilities (in accessible formats) regarding exclusive breastfeeding, hygiene around continuing vaginal bleeding/discharge during early recovery, family planning and birth spacing.	Counsel the partners and families of women with disabilities to strengthen the womens' autonomy and choice around family planning and birth spacing.

¹⁹ Redshaw, M., et al., 'Women With Disability: The experience of maternity care during pregnancy, labour and birth and the postnatal period', *BMC Pregnancy Childbirth*, vol. 13, no. 174, 2013. <https://doi.org/10.1186/1471-2393-13-174>

²⁰ Lucas, G., et al., 'No Straight Lines – Young Women's Perceptions of Their Mental Health and Wellbeing During and After Pregnancy: A systematic review and meta-ethnography', *BMC Women's Health*, vol. 19, no. 152, 2019. <https://doi.org/10.1186/s12905-019-0848-5>

6.3 Newborn care for young women with disabilities

Deaths in the first month of life represent 47 per cent of all deaths among children under 5 years,²¹ most due to complications related to pre-term birth, intrapartum events such as birth asphyxia, or infections such as sepsis or pneumonia.

The vast majority of newborn deaths are preventable with high quality antenatal care (see **Section 6.1**); skilled care at birth and postnatal care for mother and baby (see **Section 6.2**); and high quality care of small and sick newborns. Midwife-led continuity of care can reduce preterm births by up to 24 per cent.²² Midwife-led continuity of care is a model of care in which a midwife or a team of midwives provide care to the same woman throughout her pregnancy, childbirth and the postnatal period, calling upon medical support if necessary. With facility-based births providing an opportunity to improve newborn care, it is important that common barriers to health services experienced by young people with disabilities (see **Section 3**) are removed. While more sick and small children survive, it is critical they have regular follow ups to monitor their growth, feeding, well-being (including any physical, cognitive and other impairment) and they they're kept warm.

The **Every Newborn Action Plan** calls for an increased focus on the time around birth, with targeted interventions for reducing newborn deaths. Women and newborns are frequently discharged early from hospital, increasing the risk of newborn deaths. Women with disabilities may require more time than women without disabilities prior to discharge from the hospital to assimilate information about newborn care. Home visits are also critical, to reinforce and further support newborn care by young women with disabilities.

While it is important that newborn care incorporates early detection of impairment as well as appropriate care for the child's optimal development and to avoid preventable impairments, this is not the focus of this Practice Guide. Numerous other resources provide information on appropriate newborn care, such as the World Health Organization's **Pregnancy, Childbirth, Postpartum and Newborn Care: A guide for essential practice (3rd edition)**.

Table 13: Example entry points for newborn care for young women with disabilities

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
Help governments adopt and implement non-discrimination policies to guarantee no discrimination of any kind against newborns in the provision of care, regardless of the health or disability status of the infant.	Develop community strategies to improve demand among young women with disabilities for services, birth preparedness and essential newborn care practices, (e.g., skin to skin contact or Kangaroo Mother Care) including home visits by community health workers.	Engage OPDs and women with disabilities to 'audit' and work with governments to improve newborn care services.

²¹ World Health Organization and Maternal and Child Epidemiology Estimation Group (MCEE), 2019 estimates.

²² <https://www.who.int/news-room/fact-sheets/detail/newborns-reducing-mortality>

6.4 Integrated Management of Newborn and Childhood Illnesses

Integrated Management of Newborn and Childhood Illnesses (IMNCI) is a comprehensive approach to preventing and managing the leading causes of morbidity and mortality (conditions and infectious diseases such as pneumonia, diarrhoea, malaria, measles and meningitis) in children under the age of 5 years. IMNCI recognizes that sick children often present with more than one symptom at a time. Under IMNCI sick children or young infants are treated not only for the symptoms or conditions they first present with, but are also assessed for additional symptoms, underlying conditions or impairments and may then be recipients of combined treatment. The families and carers of children or young infants are also counselled to strengthen care provided at home.

While childhood illnesses that are the focus of IMNCI (e.g., pneumonia and malaria) can be the cause of disabilities, this is not the focus of this Practice Guide; the focus is on the inclusion of children with disabilities in IMNCI. Existing data suggests that children and young infants with disabilities are more vulnerable to childhood illnesses that are the focus of IMNCI, making their inclusion in IMNCI critical. For example, children with learning and mobility impairments face greater risk of pneumonia than children without disabilities.²³

Developmental and growth monitoring

Central to IMNCI is children's healthy growth and development. Weight gain is the most important sign that a child is healthy, growing and developing well. From birth to the age of 2 years, children should be weighed regularly to assess growth. If regular weighing shows that the child is not gaining weight, or the parents or other caregivers see the child is not growing, the child needs to be seen by a trained health worker to identify any nutrition problems. Children and young infants with disabilities can be at greater risk of malnutrition because of delayed presentation at a health or nutrition facility, sub-optimal care or lack of follow-up after their discharge from the facility.²⁴

Good health and adequate nutrition lay the foundations for healthy growth and development from early childhood. UNICEF's Nurturing Care Practice Guide (forthcoming) provides practical approaches in health and nutrition services to strengthen caregivers' capacity to provide nurturing care to children and young infants (see **Section 6.13** for more on nutrition services).

Early identification and early intervention for children with disabilities

Early identification requires primary health care systems that are appropriately resourced and coordinated, including that mental health and psychosocial support options are available, inclusive, accessible and affordable for persons with disabilities (as well as their families and caregivers). Stigma and discrimination around disability may leave families reluctant to pursue early identification of their children's developmental delays or impairments. In connection to stigma and discrimination, early identification also requires health care providers with the capacity to be inclusive of children with disabilities, supportive of their families and not display any negative attitudes (see **Section 5.9**). Communication of developmental delays or impairments by health professionals should be non-judgemental, respectful and utilize 'person-first' language (see **Annex 2**).

²³ Seddon, P.C. and Y. Khan, 'Respiratory Problems in Children With Neurological Impairment', *Archives of Disease in Childhood*, vol. 88, 2003, pp. 75–78.

²⁴ Groce, N., et al., 'Malnutrition and disability: Unexplored opportunities for collaboration', *Paediatr. Int. Child Health*, vol. 34, no. 4, 2014, pp. 308–314.

Early identification is best integrated into other services such as maternity and immunization services, nutrition and well-baby clinics, mother-child groups, home visits for newborns and young child health care.²⁵ While many identification and screening tools exist, the majority of these were developed in very different cultural contexts and are not adequately suited for global use. Screening tools need to be brief; inexpensive; include developmentally appropriate items which are socially and culturally relevant to the local context; have strong psychometric properties; be available in local languages; validated on representative children of the particular population and require minimal training.

Early intervention services are designed to support families with young children who are at risk of, who are suspected to be, or who are experiencing a developmental delay or disability. The services and interventions are multisectoral, integrated and interdisciplinary. They are individualized and aim to strengthen family competencies and parenting skills to facilitate children's development and build resilience. They often also involve advocacy for the educational and social inclusion of these children and their families.²⁶ Interventions can be delivered in a range of settings including health services, rehabilitation centres, community centres, homes and preschools.

While not typically part of IMNCI, early identification of children with disabilities and early intervention is key in early childhood and complementary to IMNCI. In early childhood, a child's development in language, cognition, motor and socio-emotional domains is most critical. Early identification of developmental delays and impairments and early interventions dramatically improves children's opportunities to maximize their developmental potential, function and quality of life.²⁷ For example, early identification of cerebral palsy and the appropriate early intervention around stimulation and posture can have important positive effects on mobility, motor and cognitive functions as well as communication. Children with Down Syndrome can also significantly benefit from early intervention to expand their cognitive abilities and social development.²⁸



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²⁵ Lucas, J., L. Richter and B. Daelmans, 'Care for Child Development: An intervention in support of responsive caregiving and early child development', *Child: Care, health and development*, no. 44. 2018, pp. 41–49.

²⁶ Vargas-Barón, E., et al., 'Global Survey of Inclusive Early Childhood Development and Early Childhood Intervention Programs', RISE Institute, Washington, D.C., 2019.

²⁷ Smythe, T. et al., 'Early Intervention for Children With Developmental Disabilities in Low and Middle-Income Countries: The case for action', *International Health*, vol. 13, no. 3, May 2021, pp. 222–231. <https://doi.org/10.1093/inthealth/ihaa044>

²⁸ Mont, D., 'Combatting the Costs of Exclusion for Children with Disabilities and their Families', United Nations Children's Fund (UNICEF), New York, 2021.

CASE STUDY

Community health worker training in India to identify children with developmental delays and disabilities

Despite a high prevalence of disabilities in the mountainous state of Uttarakhand in India, evidence existed that children were not being referred to early intervention services as often or as early as they should. In response, the Latika Roy Foundation trained Accredited Social Health Activists (ASHA) in four blocks of the Dehradun district on early intervention for children with developmental delays and disabilities. ASHA are community health workers who visit homes for immunization and maternal health programmes and also check the health of young infants. Over four months (February to May 2013), 18 ASHA facilitators were trained as master trainers by parents of children with developmental delays and disabilities. From June onwards, these facilitators trained their own ASHA under supervision (320 in total). Follow-up workshops were then conducted on a monthly basis to identify and strengthen the knowledge and application in the field of the trained ASHA.

The training taught the ASHA to identify children with developmental delays and disabilities using a short interview and assessment with the parents during home visits. The ASHA were expected to refer any children identified as potentially having developmental delays and disabilities to the nearest primary health centre for further assessment and treatment.

The training successfully demonstrated that community health workers can be trained effectively to help identify children with disabilities and facilitate early intervention. The ASHA helped with the identification of hundreds of children with developmental disabilities who received early intervention.

Source: Taken from the Good Practice Compendium, developed by Missing Billion:
<https://www.themissingbillion.org/new-index>

Table 14: Example entry points for integrated management of newborn and childhood illnesses

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
Strengthen referral pathways to connect ‘early identification’ with integrated management of newborn and childhood illnesses.	Raise awareness and understanding among families of children with disabilities of appropriate home-based care and how/where to seek timely care from qualified health providers .	Help governments adopt policies on an integrated approach to the health and development of children with disabilities.

6.5 Immunizations and vaccinations

Considerable strides have been made in reducing vaccine-preventable deaths, disease and disabilities but global vaccine coverage has stagnated, driven by inequalities in vaccination coverage. In 2020, 23 million children worldwide missed out on the benefits of complete vaccination and many children received no vaccines at all (an increase from 19 million, driven by effects of the COVID-19 pandemic).²⁹ Children and young people with disabilities appear ‘under-immunized’ and evidence suggests they typically have lower rates of immunization across a range of different vaccines compared to those without disabilities.³⁰

UNICEF’s **Immunization Roadmap 2018–2030** articulates its vision for reaching global immunization targets, including ongoing eradication and elimination initiatives, with priority given to the most disadvantaged.

Children and young people with disabilities are, however, broadly absent from immunization strategies and vaccine action plans – where disability is mentioned, the focus is typically on preventing preventable impairments and not on delivering immunizations to these children and young people. The experience of children and young people with disabilities regarding immunization and their barriers to it is largely missing from research. Studies show that predictors of immunization in children with disabilities are regular health checks and recommendations to immunize by a health care provider.³¹ This underscores the importance of removing common barriers to health services for this group, such as negative attitudes and inaccessible information (see **Section 3**). Social and behaviour change interventions (see **Section 5.9**) are also important components to any immunization campaign, ensuring children with disabilities and their caregivers are included.

Table 15: Example entry points for immunizations and vaccinations

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
Provide regular health checks to children and young people with disabilities, training health professionals to raise awareness of vaccinations.	Engage OPDs to help deliver vaccination campaigns, targeting messaging to children and young people with disabilities (and their families).	Ensure immunization strategies or Vaccine Action Plans consider and monitor delivery to children and young people with disabilities.

²⁹ <https://data.unicef.org/topic/child-health/immunization/>

³⁰ O’Neill, J., et al., ‘Vaccination in People With Disability: A review’, *Hum. Vaccin. Immunother.*, vol. 16, No. 1, 2020, pp. 7–15. doi:10.1080/21645515.2019.1640556. See also: United Nations Children’s Fund and Leonard Cheshire Disability and Inclusive Development Centre, ‘Disability Prevention Efforts and Disability Rights: Finding common ground on immunization efforts’, working paper, undated, accessed 10 February 2020; Mactaggart, I., et al., ‘Assessing Health and Rehabilitation Needs of People with Disabilities in Cameroon and India’, *Disability and Rehabilitation*, vol. 38, no. 18, December 2016, pp. 1757–1764.

³¹ Yen C-F, et al., ‘Analysis of Seasonal Influenza Vaccine Uptake Among Children and Adolescents with an Intellectual Disability’, *Res. Dev. Disabil.*, vol. 33, 2012, pp. 704–710. doi:10.1016/j.ridd.2011.11.011 and Pandolfi, E., et al., ‘The Effect of Physician’s Recommendation on Seasonal Influenza Immunization in Children with Chronic Diseases’, *BMC Public Health*, vol. 15, no. 1, 2012, pp. 984–991. doi:10.1186/1471-2458-12-984.

6.6 Child and adolescent injury prevention

For the purposes of this Practice Guide, injury is defined as “the physical damage that results when a human body is suddenly subjected to energy in amounts that exceed the threshold of physiological tolerance – or else the result of a lack of one or more vital elements, such as oxygen”.³² The energy in question can be mechanical, thermal, chemical or radiated.

Injuries can be characterized as either ‘unintentional’ (e.g., road injury, drowning, falls, fire, poisonings, natural disasters) or ‘intentional’ (e.g., self-harm, interpersonal violence, war and conflict). Intentional injuries are outside the remit of this Practice Guide, but more information is available at www.unicef.org/protection.

Unintentional injuries are the third leading cause of death among children aged 1–4 years and the leading cause of death for children and adolescents aged 5–19 years.³³ More than 90 per cent of deaths from unintentional injuries occur in low- and middle-income countries.³⁴ Children and young people with disabilities are particularly vulnerable to injuries and are approximately twice as likely to sustain unintentional injuries than children without disabilities. Burn-related injuries and injuries from crashes involving motor vehicles or bicycles account for a high proportion of unintentional injuries among children and young people with disabilities.³⁵ Non-fatal unintentional injuries can also lead to new or additional disabilities; in 2019, injuries were the 10th leading cause of Years Lived with Disability among children and adolescents aged 0–19 years.³⁶

Developing healthy and safe environments that reduce the risk of fatal unintentional injuries requires careful delivery of evidence-based solutions across multiple sectors (see UNICEF’s Technical Guidance for Child and Adolescent Injury Prevention – forthcoming). Environmental modifications, such as traffic calming measures or improving spaces for pedestrians, benefits from urban planning strategies that utilize universal design principles (see **Section 5.7**). Education strategies at community-level or directed at individuals, including by reporting the burden of injuries experienced by children and young people with disabilities and raising awareness of risks, can prompt changes in behaviour. The health sector’s role in injury prevention is critical, including the provision of disaggregated data on child injuries to help shape national responses to injury prevention; strengthening paediatric trauma care to lower injury-related morbidity and mortality; and helping to educate local communities in injury prevention and first aid.

Table 16: Example entry points for injury prevention

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
Ensure paediatric trauma protocols and health professionals deliver trauma care in a standardized and consistent manner, irrespective of disability status.	Provide first aid education to children and young people with disabilities (and their families) to increase awareness of risk/prevention and understanding of immediate treatments for injuries.	Support people with disabilities (including children and young people) and OPDs to improve the safety of their environment, including by influencing government policies.

³² Baker, S.P., ed. *The Injury Fact Book*, 2nd ed. Oxford University Press, New York, 1991.

³³ World Health Organization, *Global Health Estimates*, 2019 data (made publicly available in 2021), WHO, Geneva, 2021.

³⁴ Ibid.

³⁵ Shi, X., et al., ‘Unintentional Injuries in Children with Disabilities: A systematic review and meta-analysis’, *Inj. Epidemiol.*, vol. 2, no. 1, 2015, p. 21.

³⁶ World Health Organization, *Global Health Estimates*, 2019 data).

6.7 Health of adolescents with disabilities

Adolescence is a critical period of development with rapid physical, psychosocial, cognitive and emotional growth as well as sexual and reproductive maturation. Adolescents' health and well-being is also influenced by multiple external factors. These include: social and cultural norms that, during adolescence, contribute to patterns of behaviour that can both enable and limit daily life;³⁷ families causing harm (e.g., abuse), enabling harmful practices (e.g., child marriage) or acting as powerful 'gatekeepers' to health services. These also include: new technology and social media providing opportunities for better access to information and services, but also reinforcing vulnerabilities (e.g., exposing adolescents to bullying, sexual abuse or depression).³⁸

Adolescent pregnancy is associated with poorer maternal health outcomes³⁹ and poor infant health and survival.⁴⁰ There are an estimated 1.2 million adolescent deaths annually,⁴¹ largely from preventable and treatable causes. Moreover, an estimated 70 per cent of preventable deaths from non-communicable diseases (NCDs) in adults have been linked to health risks and behaviours (including tobacco, alcohol and illicit drug use, physical inactivity and poor-quality diets) that are commonly established in adolescence (see **Section 6.10** for more on reducing NCD risk factors among children and young people with disabilities).⁴²

Adolescents with disabilities are at greater risk of poor health outcomes than adolescents without disabilities. They are also at higher risk of physical, sexual or emotional violence, including from their families.⁴³ Many lack essential health information, in some cases because wrong assumptions are made about their sexual activity and substance use.⁴⁴ Where adolescents with disabilities do have access to information, neither the content nor delivery may be accessible or acceptable (e.g., because of accompanying negative attitudes) and they are then less equipped with strategies for maximizing and maintaining their health and well-being.

Adolescents with disabilities require health services and policies that promote enabling and safe environments and which protect and improve their health and development. Emotional health and well-being may particularly present key challenges for these adolescents in regard to self-esteem and body image, sexuality and sexual identity, social acceptance and interpersonal relationships. Persistent social stigma and stereotyping may amplify their concerns, with stronger effects on their mental health in turn requiring greater support to cope with that stress.⁴⁵

³⁷ Sawyer, S., et al., 'Adolescence: A foundation for future health', Lancet Series on Adolescent Health No. 1, *The Lancet*, vol. 379, 2012, pp. 1630–1640.

³⁸ Moreno, M., M. Standiford and P. Cody, 'Social Media and Adolescent Health', *Current Pediatric Report*, vol. 6, no. 2, 2018, pp. 132–138.

³⁹ Gibbs, C.M., et al., 'The Impact of Early Age at First Childbirth on Maternal and Infant Health', *Paediatr. Perinat. Epidemiol.*, supp. 1, July 2012, pp. 259–284. doi: 10.1111/j.1365-3016.2012.01290.x.

⁴⁰ Marvin-Dowle, K., et al., 'Impact of Adolescent Age on Maternal and Neonatal Outcomes in the Born in Bradford Cohort', *BMJ Open*, vol. 8:e016258, 2018. doi:10.1136/bmjopen-2017-016258.

⁴¹ World Health Organization, 'Global Accelerated Action for the Health of Adolescents (AAHA)', Guidance to Support Country Implementation, WHO, Geneva, 2017. Available at: <http://apps.who.int/iris/bitstream/handle/10665/255415/9789241512343-eng.pdf;jsessionid=1BC7566D91C86EA0B3BBE835B92DD>.

⁴² Kuruvilla, S., et al., 'A Life-Course Approach to Health: Synergy with sustainable development goals', *World Health Organization Bulletin*, vol. 96, 2018, pp. 42–50.

⁴³ United Nations Children's Fund, 'Hidden in Plain Sight. A statistical analysis of violence against children', UNICEF, New York, 2014.

⁴⁴ UNHR, WHO, UNAIDS, Disability and HIV Policy Brief, 2009. https://data.unaids.org/pub/manual/2009/jc1632_pol_brief_disability_long_en.pdf

⁴⁵ Horner-Johnson, W., and L. Sauv  , 'Applying Lessons of Optimal Adolescent Health to Improve Behavioural Outcomes for Youth with Disabilities', University Centre for Excellence in Development Disabilities, Oregon Health & Science University.

Table 17: Example entry points for the health of adolescents with disabilities

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
• Ensure adolescents with disabilities are included in health campaigns or education targets targeted at this age group, making adaptations to ensure accessibility.	• Engage adolescents with disabilities to deliver peer education on key health issues and to act as community-level 'health champions'.	• Support/strengthen adolescent-driven and led spaces and processes to ensure adolescents with disabilities help improve health services.

6.8 HIV/AIDS

Evidence suggests there is a higher prevalence of HIV among in people with disabilities than people without disabilities,⁴⁶ with women with disabilities at higher risk than men with disabilities.⁴⁷ Reliable data regarding the prevalence of HIV among children and young people with disabilities is not available. However, there is evidence that all people with disabilities (including children and young people) represent one of the largest and most underserved populations with regard to HIV services.⁴⁸ Mental health difficulties and mental disorders are common among adolescents living with HIV or who are affected by HIV (because of living in HIV-affected households in low- and middle-income countries), meaning it is essential HIV services consider mental health and psychosocial support.⁴⁹

There is often a misconception that young people with disabilities are sexually inactive or unlikely to use drugs, contributing to assumptions that their risk of HIV is limited.⁵⁰ As a result, these young people tend to be overlooked entirely by HIV programming and services, further compounding their risk. For example, young people with disabilities are less likely than young people without disabilities to feel able to negotiate and maintain safe sexual relationships.⁵¹ As people living with HIV survive longer with treatment, they are more likely to develop non-communicable diseases and disabilities due to the cumulative toxicity of lifelong antiretroviral medication. HIV treatment services consequently need to also consider disability inclusion.

Barriers to HIV treatment and services experienced by people with disabilities mirror common barriers experienced in accessing health services generally: inaccessible infrastructure, information and communications; poor planning; insufficient resourcing. The evidence base of 'what works' to address HIV

⁴⁶ Banks, L.M., et al, 'The relationship between HIV and Prevalence of Disabilities in sub-Saharan Africa: Systematic Review'. *Tropical Medicine & International Health*, vol. 20, no. 4, 2015, pp. 411–429. ISSN 1360-2276.

⁴⁷ De Beaudrap, P., M. Mac-Seing and E. Pasquier, 'Disability and HIV: A systematic review and a meta-analysis of the risk of HIV infection among adults with disabilities in Sub-Saharan Africa', *AIDS Care*, vol. 26, 2014, pp. 1467–1476.

⁴⁸ Joint United Nations Programme on HIV/AIDS, The Gap Report: People with Disabilities, UNAIDS, Geneva, 2014.

⁴⁹ Bhana, A., et al., 'Mental Health Interventions for Adolescents Living with HIV or Affected by HIV in Low- and Middle-Income Countries: A systematic review', *BJPsych Open*, vol. 6, no. 5, 2020, e104. <https://doi.org/10.1192/bjo.2020.67>

⁵⁰ UNHR, WHO, UNAIDS, Disability and HIV Policy Brief, 2019. https://data.unaids.org/pub/manual/2009/jc1632_pol_brief_disability_long_en.pdf

⁵¹ Maart, S. and J. Jelsma, 'The Sexual Behaviour of Physically Disabled Adolescents', *Disability and Rehabilitation*, vol. 32, 2010, pp. 438–443. 10.3109/09638280902846368.



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for people with disabilities (including children and young people) is limited. Evaluations of interventions to improve access to HIV treatment and services for people with different types of impairments (including children and young people) as well as evidence of harm reduction programmes that are disability inclusive is scarce. A lack of disability-disaggregated data and disability-focused metrics within mainstream HIV interventions also typically renders people with disabilities invisible.

Ensuring that HIV services include children and young people with disabilities is particularly pertinent in HIV-endemic countries, where poor understanding of HIV prevention and treatment may impact health and antiretroviral adherence.⁵²

Table 18: Example entry points for HIV/AIDS

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
Ensure mainstream HIV interventions routinely collect and utilize disability disaggregated data, to make children and young people with disabilities visible and to protect their rights.	Engage OPDs to strengthen disability inclusion across HIV interventions, including input from children and young people with disabilities.	Work with governments to require comprehensive sexuality education be routinely and consistently delivered to young people with disabilities, in accessible formats.

⁵² Hanass-Hancock. J. et al., ‘Disability and Living with HIV: Baseline from a cohort of people on long term ART in South Africa’, PlosOne, vol. 10.no. 12, 2015, e0143936.

6.9 Family planning and sexual reproductive health and rights

A fundamental right remains the right to decide, freely and for oneself, whether and when and how many children to have and to make informed and autonomous choices about sexual and reproductive health. Age, gender and disability often intersect to undermine and place this right at risk.

Exposure to abuse and violence can often undermine the sexual and reproductive health and rights of children and young people with disabilities. Those under 18 are almost four times more likely than young people without disabilities to experience abuse and young girls with intellectual disabilities are at greatest risk.⁵³ Children with disabilities are also nearly three times more likely to be subjected to sexual violence than children without disabilities,⁵⁴ also negatively affecting the individual's mental health. The inaccessibility of rehabilitative services (even where available) to young people with disabilities, including because of inaccessible information or the failure of health professionals to refer these young people, can directly or indirectly result in additional trauma.⁵⁵

A lack of understanding or knowledge of sexual reproductive health and rights also limits the capacity of many young people with disabilities to claim their rights. Low levels of sexual education can lead to higher-risk sexual behaviours. Studies show that young people with disabilities report low condom and contraceptive use but engage in casual and transactional sex.⁵⁶ In one study in Ethiopia, a minority of young people with disabilities (35 per cent) reported using contraceptives during their first sexual encounter while 63 per cent reported an unplanned pregnancy.⁵⁷

Where young people with disabilities have sufficient information to access family planning and sexual reproductive health services, inaccurate assumptions around sexual inactivity or disregard for disability rights can see these young people denied key services. They are often excluded or omitted from communications and education regarding family planning or sexual reproductive health, for example.⁵⁸ Negative attitudes have also resulted in choice being taken from them. Girls and young women with disabilities are sometimes infantilized or disempowered or lack voice, choice and control to make decisions about their own bodies and sexuality.⁵⁹ In some cases, these women and girls experience forced sterilization and abortions.⁶⁰

Annex 1 provides further resources focused on family planning and sexual reproductive health and rights, vis-à-vis young people with disabilities.

⁵³ Jones, L., et al., 'Prevalence and Risk of Violence against Children with Disabilities: A systematic review and meta-analysis of observational studies', *The Lancet*, no. 380, 2012, pp. 899–907.

⁵⁴ Ibid.

⁵⁵ AECID, We Decide, UNFPA and Women Enabled International, 'Women and Young Persons with Disabilities: Guidelines for providing rights-based and gender-responsive services to address gender-based violence and sexual and reproductive health and rights', United Nations Population Fund, New York, 2018.

⁵⁶ Kassa, T.A., et al., 'Sexuality and Sexual Reproductive Health of Disabled Young People in Ethiopia', *Sexually Transmitted Diseases*, vol. 41, no. 10, 2014, pp. 583–588; Oladunni, T.M., 'Access to Sexuality Information Among Adolescents with Disability', *Life Psychologia*, vol. 20, no. 20, 2012, pp. 142–149; Olaleye, A.O., et al., 'Sexual Behaviours and Reproductive Health Knowledge Among In-School Young People with Disabilities in Ibadan, Nigeria', *Health Education*, vol. 107, no. 2, 2007, pp. 208–218.

⁵⁷ Ibid. See also UNESCO and Humanity Inclusion, 'Seeing the Invisible: Sexuality-related knowledge, attitudes and behaviour of children and youth with disabilities in China', 2019.

⁵⁸ Ahumuza, S., et al., 'Challenges in Accessing Sexual and Reproductive Health Services by People with Physical Disabilities in Kampala, Uganda', *Reproductive Health*, vol. 11, 2014, pp. 59.

⁵⁹ Jones, N., E. Presler-Marshall and M. Stavropoulou, 'Adolescents with Disabilities: Enhancing resilience and delivering inclusive development', GAGE Programme, London, UK, 2018. <https://cdn.odi.org/media/documents/12323.pdf>

⁶⁰ Fraser, E., N. Corby, and J. Meaney-Davis, 'Family Planning for Women and girls with Disabilities', Disability Inclusion Helpdesk Research Report No. 60, Disability Inclusion Helpdesk, London, UK, 2021.

CASE STUDY

Health worker handbook on sexual and reproductive health care for people with disabilities in Ecuador

Ecuador's constitution acknowledges that persons with disabilities are a priority group with recognized rights of access to specialized health care, free medications, comprehensive rehabilitation and assistive technology. Building on this, Ecuador's Ministry of Health's National Plan for Sexual and Reproductive Health 2017–2021 promoted inclusion, equality and respect for human rights within the framework of sexual and reproductive health.

In 2017, a handbook on sexual and reproductive health services for people with disabilities was developed and distributed to healthcare professionals in Ecuador's national health system. With a special focus on primary care, the handbook aims to ensure quality services that respond to the particular needs of people with disabilities, including by strengthening sexual and reproductive health information and counselling for them. The handbook provides technical guidance, general recommendations and specific advice by type of disability on attitudinal, communicational and physical accommodations; autonomy, independence and informed consent; use of contraceptives; pregnancy, childbirth, postpartum and newborn care; and prevention of sexual violence.

The first national workshop in 2019 strengthened inter-sectoral coordination around implementation of the handbook and planned adaptations to it, including a booklet in Braille on the correct use of contraceptive methods.

Source: Taken from the Good Practice Compendium, developed by Missing Billion:
www.themissingbillion.org/new-index

Table 19: Example entry points for family planning and sexual reproductive health and rights

'Compliance'	'Empowerment'	'Transformation'
Address rights of people with disabilities; 'do no harm'	Build assets, capabilities, and opportunities for people with disabilities	Address unequal power relationships, seek legal, institutional and societal-level change
• Work to eliminate forced sterilization of children and young people with disabilities.	• Work with OPDs to build knowledge and understanding of sexual reproductive health and rights among young people with disabilities.	• Help governments to strengthen national legislation and policies protecting sexual reproductive health and rights of people with disabilities.

6.10 Reducing non-communicable disease risk factors among children and young people with disabilities

NCDs are often non-transmissible diseases, typically of a long duration (including cancer, chronic lung disease, diabetes, heart disease and mental health conditions).

There is a two-way association between NCDs and disability; NCDs can often lead to disabilities. For example, up to 4 per cent of blindness and visual impairment is caused by diabetes.⁶¹ Data from the Global Burden of Disease study show that 9 of the top 10 causes of Years Lived with Disability were NCDs.⁶² People with disabilities may also be more vulnerable to NCDs later in life meaning that children and young people with disabilities often require tailored support to reduce NCD risk factors and it is this association between NCDs and disability that is the focus of this Practice Guide.

Children and young people with some disabilities may be physically inactive (e.g., those with mobility impairments), increasing their risk as they age of cardiovascular disease, diabetes and dementia.⁶³ These children and young people are more likely than children without disabilities to become obese.⁶⁴ They are also more likely to have unmet health needs, risk factors for NCD incidence, progression and mortality. Barriers to screening services impact health seeking behaviours among children and young people with disabilities, meaning they may be less likely to access treatment or appropriate health services (e.g., nutrition services). Those who do seek healthcare may receive poorer quality services, including because of negative attitudes or assumptions held by health professionals (see **Section 3**).

Global strategies to combat NCDs focus significantly on the prevention and reduction mortality. Where the association between NCDs and disability is considered, the focus is often on preventing disabilities and not on reducing NCD risk factors among people with disabilities. NCD prevention and treatment strategies will miss a substantial and high-risk population if they are not explicitly designed to be accessible to and inclusive of all people with disabilities (including children and young people).

Table 20: Example entry points for reducing non-communicable disease risk factors among children and young people with disabilities

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
Collect and use disability-disaggregated data to strengthen data on NCD prevalence, burden of disease, risk factors and social determinants among children and young people with disabilities.	Include persons with disabilities in community-health worker cohorts tasked with the prevention and management of NCDs.	Engage OPDs and people with disabilities to review policies and laws targeting NCD-related risk factors using a disability lens.

⁶¹ Global Burden of Disease blindness and vision impairment collaborators on behalf of the Vision Loss Expert Group of the Global Burden of Disease Study, 'Causes of Blindness and Vision Impairment in 2020: Trends Over 30 Years and Prevalence of Avoidable Blindness in Relation to VISION 2020: The Right to Sight – an analysis for the Global Burden of Disease Study, *Lancet Glob. Health*, vol. 9, 2021: e144–60.

⁶² Global Burden of Disease Study 2013 Collaborators, 'Global, Regional and National Incidence, Prevalence and Years Lived with Disability for 301 Acute and Chronic Diseases and Injuries in 188 Countries, 1990–2013: A systematic analysis for the Global Burden of Disease Study 2013', *The Lancet*, vol. 386, 2015, pp. 743–800.

⁶³ Ko K.D., et al., 'Disparities in Health-Risk Behaviors, Preventive Health Care Utilizations and Chronic Health Conditions for People with Disabilities: The Korean national health and nutrition examination survey', *Arch. Phys. Med. Rehabil.*, vol. 92, 2011, pp. 1230–1237. doi: 10.1016/j.apmr.2011.03.004.

⁶⁴ Prynn J., et al., 'Self-Reported Disability in Rural Malawi: Prevalence, incidence, and relationship to chronic disease'.

6.11 Mental health and psychosocial support

Children and adolescents constitute 44 per cent of the world's population and it is estimated that 10-20 per cent experience mental health problems.⁶⁵ Mental health for children and adolescents refers to the ability to achieve and maintain optimal psychological and social functioning and well-being. Self-identity; a sense of worth; relationships within the family and with peers; being able to learn; the capacity to cope with developmental challenges and build resilience are important elements of psychosocial well-being.⁶⁶ Children and adolescents in low-resources settings, and especially in humanitarian contexts, are often disproportionately affected by risk factors and social determinants such as socio-economic and political instability, social inequalities, violence, malnutrition and ill-health. Exposure to these risks, especially over a long period of time and without a buffer of family and social support, is likely to have a significant cumulative effect on their development, mental health and psychosocial well-being with a higher risk of life-long mental health problems.^{67, 68}

In low- and middle-income countries, despite research identifying an increasing need and demand for mental health and community-based support services child and adolescent mental health policy and services are severely lacking.⁶⁹ The very low mental health expenditure currently in place prioritizes psychiatric diagnoses and pharmacological responses over other, more holistic interventions and allocates 80 per cent of funds to long-term institutional care and psychiatric hospitals.⁷⁰

The inclusion of people with mental health difficulties and psychosocial disabilities in routine, general health services is often also limited. Stigma remains a significant barrier to inclusion. Negative attitudes and distorted beliefs about persons (including children and adolescents) with psychosocial disabilities often leads to intersecting forms of discrimination and human rights violations, including medical or scientific experimentation without free and informed consent; forced medication; seclusion/isolation and restraint; forced sterilization; non-consensual electroconvulsive therapy; and psychosurgery. Children and adolescents with disabilities are particularly vulnerable to long-term institutionalization with a high risk of experiencing patterns of coercion and sexual abuse.^{71, 72, 73}

Efforts that target self-esteem and self-stigma can help address discrimination among children and young people. With these efforts, the optimism and faith of a caregiver in a child's abilities can also serve as a protective measure against self-stigma.⁷⁴

⁶⁵ Zhou, W. et al., 'Child and Adolescent Mental Health Policy in Low- and Middle-Income Countries: Challenges and lessons for policy development and implementation', *Frontiers in Psychiatry*, vol. 11, 2020, p. 150. 10.3389/fpsy.2020.00150.

⁶⁶ United Nations Children's Fund, 'A Rights-Based Approach to Disability in the Context of Mental Health', Discussion paper, UNICEF, New York, 2021.

⁶⁷ Yoder, H.N.C., et al., 'Child Mental Health in Sierra Leone: A survey and exploratory qualitative study', *Int. J. Ment. Health Syst.*, vol. 10, no. 48, 2016.

⁶⁸ United Nations Children's Fund, 'A Rights-Based Approach to Disability in the Context of Mental Health'.

⁶⁹ O'Raw, L.E. and Z. Tariq, 'Breaking the Silence: A discussion on child mental health in the developing world', *Muslim Hands*, 2020.

⁷⁰ United Nations Children's Fund, 'A Rights-Based Approach to Disability in the Context of Mental Health', Discussion paper, UNICEF, New York, 2021.

⁷¹ Haegeman, E., V. Ahlenbäck, and C. Mills, 'Rapid Evidence Review on Mental Health to Inform a DFID Theory of Change', Disability Inclusion Helpdesk, London, UK, 2019.

⁷² Vasquez, A., 'A Rights-Based Approach to Disability in the Context of Mental Health', Discussion paper, UNICEF, New York 2019.

⁷³ A Rights-Based Approach to Disability in the Context of Mental Health.

⁷⁴ United Nations Children's Fund, 'The State of the World's Children 2021: On My Mind – Promoting, protecting and caring for children's mental health', UNICEF, New York, October 2021. See also Kaushik, A., et al., 'The Stigma of Mental Illness in Children and Adolescents: A systematic review', *Psychiatry Research*, vol. 243, 2016, pp. 469–294.

Service-specific measures to ensure inclusion of people with disabilities in health services

The right to health covers physical, mental and social well-being and includes the right to non-discrimination; the right to control one's health and body and participate in all health-related decision-making; and the right to be free from non-consensual medical treatment and experimentation.⁷⁵ Mental health policy and practice requires a life-course approach that begins with child and family services and early childhood development and fosters intersectoral collaboration encompassing education, protection and prevention against violence, community support, housing and social protection. The mental health of an individual's caregivers is equally important. Mental health and psychosocial support options and respite services are available, inclusive, accessible and affordable for family members and caregivers of persons with disabilities. See **UNICEF's 2021 Discussion Paper, 'A Rights-Based Approach to Disability in the Context of Mental Health'** for a more detailed framework of this issue.

Table 21: Example entry points for a rights-based approach to disability and mental health

'Compliance' Address rights of people with disabilities; 'do no harm'	'Empowerment' Build assets, capabilities, and opportunities for people with disabilities	'Transformation' Address unequal power relationships, seek legal, institutional and societal-level change
• Work with governments on legislation and policy reform processes for deinstitutionalization of stand-alone mental health hospitals and long-stay institutions and ending coercion in mental health provision.	• Consult with children and adolescents with disabilities and actively involve them in decisions affecting the implementation of mental health services (including planning, monitoring and evaluation and research).	• Conduct campaigns in multiple and accessible formats to promote positive perceptions and increase awareness of children and adolescents with psychosocial disabilities, combating stereotypes and eliminating coercion.



⁷⁵ Ibid.

6.12 Improving rehabilitation services for children and young people with disabilities

Rehabilitation services include interventions designed to optimize functioning and reduce disability amongst individuals with health conditions in the interaction with their environment.⁷⁶ Rehabilitation helps a child, adult or older person be as independent as possible in everyday activities, by addressing underlying conditions (such as pain) and supporting individuals to regain skills, abilities or knowledge that may have been lost or compromised. For example, rehabilitation services may include increasing physical strength to improve mobility and balance and/or cognitive training to maintain or improve memory and quality of life. Habilitation services differ insofar as the focus is on children and young people with disabilities attaining, maintaining or improving autonomy, skills, abilities and knowledge. Assistive devices and technologies can be critical to rehabilitation (and habilitation) (see **Section 5.8**).

Rehabilitation and habilitation services have wide scope and relevance; most people require these services during their lifetime and for multiple reasons. Children and young people with disabilities require rehabilitation and habilitation services, for example, in response to new injuries (see **Section 6.6**) or NCDs (see **Section 6.10**).

There is growing recognition of the need to scale up rehabilitation services. The **Rehabilitation 2030** initiative spotlights the profound unmet need for accessible rehabilitation worldwide and the importance of increasing availability. Scaling up rehabilitation services for children and young people with disabilities requires an increase in specialist healthcare professionals, task shifting and building the capacity of non-specialists (including health staff, community workers, family members and caregivers). Innovation to provide remote rehabilitation services will help increase coverage to children and young people with disabilities, but it is critical that innovations incorporate universal design principles (see **Box 4**).

A multi-sectoral approach to rehabilitation is critical, to ensure that the health and well-being of children and young people with disabilities is improved more broadly as these children and young people will, for example, fall behind their peers in terms of education outcomes.

Table 22: Example entry points for improving rehabilitation services for children and young people with disabilities

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
Conduct accessibility audits and measure quality of existing rehabilitation services to identify gaps, barriers and facilitators to then help strengthen inclusion of children and young people with disabilities.	Help establish and engage OPDs and parent and peer support groups to help tailor and target rehabilitation services to children and young people with disabilities, including at community level.	Help governments to develop and implement national plans to strengthen rehabilitation services, ensuring the services are accessible to and inclusive of children and young people with disabilities.

⁷⁶ See <https://www.who.int/news-room/fact-sheets/detail/rehabilitation>

6.13 Nutrition services for children and young people with disabilities

Children and young people with disabilities are at heightened risk of undernutrition. For example, an infant with a cleft palate may not be able to breastfeed or consume food effectively. Children with cerebral palsy may have difficulty chewing or swallowing. Certain conditions, such as cystic fibrosis, may impede nutrient absorption. Some infants and children with disabilities may also need specific diets or increased calorie intake in order to maintain a healthy weight. These children are three times more likely to be malnourished than children without disabilities, and twice as likely to die from malnutrition during childhood.⁷⁷ Compared to children without disabilities, children with disabilities are 34 per cent more likely to be stunted and 25 per cent more likely to be wasted.⁷⁸ While not a focus of this Practice Guide, it is important to acknowledge that nutrient deficiencies during pregnancy or at a young age may also lead to disabilities.

While many children and young people with disabilities require nutrition services, they are often hidden from community screening and nutrition interventions. Those who do not attend school miss out on school feeding and micronutrient supplementation programmes. This is further exacerbated in emergencies where children with disabilities are at high risk of being wasted but also less likely to be identified for treatment through mass screening exercises. In humanitarian contexts, standard food rations and supplies are rarely adapted for children with disabilities who may require a modified food consistency such as pureed food that is easier to swallow, additional nutrients and adapted utensils.⁷⁹ As a result, consultation with children and young people with disabilities and their families is essential to providing inclusive, equitable and quality nutrition services in the community, including in humanitarian contexts.

The specific effects of poor nutrition on children and young people with disabilities is broadly unknown. It is often assumed that these children and young people do not grow and thrive because of their disability, whereas it is probable that in some cases, what is assumed to be disability-associated ill health and malnutrition may actually be connected with feeding problems or the withholding of adequate nutrition. This is particularly so in households with scarce resources when it is assumed children and young people with disabilities will not live to adulthood in any case or when mothers may be pressured not to breastfeed their



⁷⁷ Kuper, H. and P. Heydt, 'The Missing Billion: Access to health services for 1 billion people with disabilities', 2019.

⁷⁸ United Nations Children's Fund, 'Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities', UNICEF, New York, 2021.

⁷⁹ See generally, Women's Refugee Commission, 'Disability among Refugees and Conflict Affected Populations: Resource kit for field workers', New York, 2008.

babies with disabilities, denying them food or providing less nutritious food than to their siblings without disabilities.⁸⁰ Proper nutrition, safe feeding, and nurturing care during early childhood lay the foundation for lifelong health and well-being, including for children and young people with disabilities.

Access to enough and sufficiently nutritious food is also an issue of concern to adults with disabilities, often because of poverty and unequal distribution of resources within the household. The issue of access to nutritious food for women with disabilities and their children is consistently overlooked by many in both the nutrition and disability sectors, placing women and their children at increased risk.

Table 23: Example entry points for nutrition services for children and young people with disabilities

‘Compliance’ Address rights of people with disabilities; ‘do no harm’	‘Empowerment’ Build assets, capabilities, and opportunities for people with disabilities	‘Transformation’ Address unequal power relationships, seek legal, institutional and societal-level change
• Ensure global and national nutritional plans and policies are explicit about disability-related links, risks and interactions, and provide disability-specific guidance.	• Promote inclusive nutrition interventions (including school feeding and micronutrient supplementation) through institutions and networks supporting families of children with disabilities, ensuring nutrition information and education materials are accessible for the different types of disabilities.	• Actively partner with the health system at all levels and OPDs to ensure nutrition strategies are flexible and responsive to the context-specific needs of children and young people with disabilities.

⁸⁰ United Nations Children’s Fund, The State of The World’s Children 2013, UNICEF, New York, 2013.

Further reading on disability inclusion and health

Annex 1

AECID, We Decide, UNFPA and Women Enabled International, 'Women and Young Persons with Disabilities: Guidelines for providing rights-based and gender-responsive services to address gender-based violence and Sexual and reproductive health and rights, UNFPA, New York, 2018.

Bell, E. and N. Corby, 'HIV Prevention, Treatment and Care Programming for People with Disabilities', Research Report No. 7. Disability Inclusion Helpdesk, London, UK, 2019.

Fraser, E., N. Corby, and J. Meaney-Davis, J., 'Family Planning for Women and Girls with Disabilities', Research Report No. 60, Disability Inclusion Helpdesk, London, UK, 2021.

Inter-Agency Standing Committee Mental Health and Psychosocial Support (MHPSS) Reference Group, Disability and Inclusion Working Group, 'Information Note on Disability and Inclusion in MHPSS (field guide)', IASC, Geneva, 2022.

IASC Mental Health and Psychosocial Support (MHPSS) Reference Group, Disability and Inclusion Working Group, 'Advocacy Brief: A supplementary document to the information note on disability and inclusion in MHPSS (field guide)', Geneva, 2022.

Kaloyan, K. et al., 'Needs and Unmet Needs for Rehabilitation Services: A scoping review', Disability and Rehabilitation, vol. 41, no. 10, 2019, pp. 1227-1237. DOI: [10.1080/09638288.2017.1422036](https://doi.org/10.1080/09638288.2017.1422036)

Kuper, H. and P. Heydt, *The Missing Billion: Access to health services for 1 billion people with disabilities*, 2019.

Office of the United Nations High Commissioner for Human Rights, *Policy Guidelines for Inclusive Sustainable Development Goals: Good health and well-being*, OHCHR, UN, New York, 2020.

Pathfinder International and Humanity & Inclusion, 'Developing an Adolescent Competent Health Workforce: Training service providers in adolescent sexual and reproductive health, Unit 16: Adolescents with Disabilities', Pathfinder International, Watertown, MA., 2020.

United Nations Population Fund, 'Young Persons with Disabilities: Global study on ending gender-based violence and realising sexual and reproductive health and rights', UNFPA, New York, 2018.

United Nations Children's Fund, 'Health Checklist: Essential actions for disability-inclusive humanitarian action', UNICEF, New York, 2022.

United Nations Children's Fund, 'A Rights-Based Approach to Disability in the Context of Mental Health', Discussion Paper, UNICEF, New York, 2021.

United Nations Children's Fund, 'Social and Behavioural Change Interventions to Strengthen Disability-Inclusive Programming: A synthesis of the evidence', UNICEF, New York, 2020.

United Nations Children's Fund, 'Core Commitments for Children in Humanitarian Action', UNICEF, New York, 2020.

United Nations Children's Fund, 'Mental Health and Psychosocial: Technical note', UNICEF, New York, 2019.

United Nations Children's Fund, 'Global Survey on Inclusive ECD and ECI', UNICEF, New York, 2019.

United Nations Children's Fund, 'Guidance: Including children with disabilities in humanitarian action, Health and HIV/AIDS', UNICEF, New York, 2017.

World Health Organization, video presenting the views of people with disabilities on accessible health information: www.youtube.com/watch?v=LFzBcwC2qqg, WHO, Geneva, 2021.

Tools and further guidance

Annex 2

1. Guidance on partnering with OPDs

OPDs are representative membership-based non-governmental organizations led, directed and governed by people with disabilities, who constitute the majority of their membership in all levels of the organization.⁸¹ OPDs may represent impairment-specific groups or have a cross-disability focus. They may represent a particular group of people with disabilities with intersecting identity factors; for example, young people with disabilities, or indigenous persons with disabilities. OPDs may be organized by family members/relatives of people with specific disabilities and/or children with disabilities. Their primary aim is empowerment and growth of self-advocacy of people with disabilities.⁸²

OPDs play a critical role in representing the viewpoints and lived experiences of people with disabilities and constitute an important link and intermediary between policy makers/duty bearers and people with disabilities. Article 4.3 of the CRPD calls on State Parties to engage with people with disabilities through their representative organizations, highlighting the human right of participation.

In practice, this means:

- Consulting OPDs on the barriers to and solutions for service provisions. Consultation must be meaningful; that is, building a dynamic and equitable relationship based on genuine interest to learn from and act upon the inputs and concerns of children and young people with disabilities, not just extracting information. The UN Disability Inclusion Strategy dedicates a specific indicator to the consultation of people with disabilities.⁸³
- Establishing informal or formal partnerships with OPDs; for example, ongoing working relationships or formal agreements around allocated responsibilities and resource commitments.

⁸¹ UN Disability Inclusion Strategy, 'Guidelines Consulting Persons with Disabilities'.

⁸² Disability Rights Fund.

⁸³ UN Disability Inclusion Strategy.

Before you do, it is crucial to

- Check if selected OPDs are representative of diverse children and young people with disabilities related to, for example, gender; impairment type; location and other identity factors that might intersect with disability and account for situations and experiences of simultaneous and compounding discrimination. If not, additional relevant OPDs should be considered. Where such OPDs are not established, individual activists or groups of people with disabilities and intersecting experiences should be identified and included in meaningful consultations (see **UNICEF's 'Take us Seriously! Engaging children with disabilities in decisions affecting their lives'** for guidance on enhancing the participation of children with disabilities in policies and interventions).
- Organize consultations under the principle **'do no harm'**, taking every precaution to ensure children and young people with disabilities are not at risk or adversely affected by their participation in consultation processes or partnerships. This includes maintaining confidentiality, anticipating and managing power dynamics, and preparing for the availability of support services and resources should, for example, issues of emotional distress or the risk of backlash and/or violence arise.⁸⁴

Recommended activities:	
Getting started	• Invite diverse children and young people with disabilities and OPDs to be involved in identifying barriers and solutions to routine general health care.
Institutional barriers	• Involve OPDs in the review of service provision policies for disability inclusion.
Attitudinal barriers	• Involve diverse children and young people with disabilities in developing and delivering awareness-raising activities and training to service providers that: a) ensure an intersectional perspective, and b) include respectful communication strategies for all staff, including reception and security staff.
Environmental barriers	• Involve children and young people with different types of disabilities in a gender-sensitive accessibility audit (see below) of health services to identify any physical and communication barriers to access health service facilities and information. • Involve people with different disabilities (including children and young people) in identifying inaccessible health information, developing new accessible health promotion material, and disseminating the material to children and young people with disabilities (and/ or their families).

⁸⁴ UN Disability Inclusion Strategy.

Recommended activities:	
Health information systems for planning, monitoring and evaluation	- Involve diverse children and young people with disabilities in the planning, design and implementation of data collection processes for planning, monitoring and evaluation activities. - Ensure the data collection includes, at minimum, gender and age disaggregation along with disability; where possible expand gender to include non-binary option(s).
Rehabilitation services	- Involve OPDs in service mapping for referral pathways, drawing on their knowledge of disability-specific services, ensuring a gender and age perspective. - Seek input from OPDs as well as children and young people with disabilities, to assist in training on basic rehabilitation approaches.
Inclusive health in emergencies	- Involve diverse people with disabilities (including children and young people) in disaster preparedness planning and anticipating access barriers to health services during emergencies. - Ensure a gender and age perspective to barriers and specifically health services related to mental health/psychosocial support and (gender-based) violence.
Important considerations for action: - Search for and contact OPDs in your local area with a view to establishing partnerships. If none exist, help facilitate setting up OPDs or inclusive community groups. - Allocate budgets to cover travel and participation expenses along with attendance time for people with disabilities (and/or their family members/caregivers) and OPDs to be actively involved in consultations. Be sure to address gender and age-specific factors that may influence opportunities to travel and participate (e.g., domestic responsibilities, freedom of movement, assistance, distance, etc.). - Ensure people with disabilities (and caregivers) and OPDs are paid and acknowledged appropriately for their time and expertise. - Employ people with disabilities within the health service. - Promote diverse people with disabilities as health workers to demonstrate their skills and capacities and improve representation and visibility of people with disabilities with different intersecting identities. - Work with OPDs to consider specific opportunities (in addition to those listed above) for involving people with disabilities (including children and young people) in decision-making about health service provision. An intersectional lens is particularly important to identify relevant opportunities for people with disabilities from diverse backgrounds and life situations.	

Source: Adapted from 'Disability-Inclusive Health Services Toolkit: A resource for health facilities in the Western Pacific Region', World Health Organization Regional Office for the Western Pacific, Geneva, 2020.

2. Data tools for identifying persons with disabilities and disaggregated data by disability status

Data collection module	Designed for	Recommended use	Tool
WG Short Set of Questions (WG-SS)	Adults (over 18 years)	Designed for use in censuses or household surveys where there are space constraints or where the purpose is focused on counting.	Six questions covering difficulties functioning across six domains. Does not capture all domains, so some persons with disabilities will not be counted.
WG Short Set – Enhanced (WG-SS Enhanced)	Adults (over 18 years)	Designed for use in surveys (multi-topic surveys or disability surveys) where extensive information is collected on adult household members. Recommended for programmes with outcomes and outputs on persons with disabilities.	Twelve questions cover difficulties functioning across eight domains. Designed to capture additional domains not in the WG-SS, so will capture data on more persons with disabilities.
WG Extended Set of Questions (WG-ES)	Adults (over 18 years)	Designed for use in surveys (multi-topic surveys or disability surveys) where extensive information is collected on adult household members.	Thirty-five questions covering additional functional domains. Provides greater granularity as well as questions on assistive devices and personal assistance.
Module on Child Functioning	Children (aged 2–17 years). Two sets of questionnaires: one for children aged 2–4 and one for children aged 5–17.	Designed for use in surveys (multi-topic surveys or disability surveys) where extensive information is collected on children. Recommended for programmes with outcomes and outputs on children with disabilities	Developed in collaboration with UNICEF; identifies children who have difficulty functioning across 14 domains. The module is available in multiple languages.

Table based on: Data collection tools developed by the Washington Group on Disability Statistics and their recommended use, Washington Group, International, Boise, ID., 2020.

3. Key disability considerations for evaluations of health programmes

Engage OPDs and children and young people with disabilities in evaluations (see guidance on partnering with OPDs, above). Along with other community members, children and young people with disabilities can be involved in:

- Identification of criteria for the evaluation;
- Data collection;
- Analysis and validation of findings;
- Formulation of recommendations.

Evaluate, document and share:

- If and how barriers to health care for children and young people with disabilities were overcome.
- Whether children and young people with disabilities benefited from the programme on an equal basis to others.
- The relevance of general healthcare to children and young people with disabilities.
- The intersection of disability, age, gender and other factors to determine whether particular groups of people were excluded.
- The accessibility of health infrastructure and information.
- The affordability of healthcare for households with persons with disabilities.
- The participation of children and young people with disabilities in all stages of the programme, including as decision-makers; also considering gender representation in the participation.
- Changes in awareness, capacity and attitudes related to disability.
- Sustainability of disability-inclusive and accessible general healthcare.
- Impact stories from persons with different types of disabilities.

Use findings from health evaluations to formulate and share recommendations on strengthening disability inclusion and accessibility in strategies, programmes and policies.

4. Sample physical accessibility audit

Physical accessibility audits provide a practical way to identify environmental barriers experienced by children and young people with disabilities in regard to routine general healthcare. A physical accessibility audit involves systematically moving through a health facility to identify the physical accessibility of all areas, including the surrounding location. Audits should be undertaken by (or with) a local OPD and people with different disabilities. Findings must be discussed with the facility's leadership team and an accessibility improvement plan developed.

An example of a physical accessibility audit is available below (adapted from **Disability-Inclusive Health Services Toolkit: A resource for health facilities in the Western Pacific Region**).

Focus area	Key component	Yes	No	Comment
Access to the health facility	Are parking spaces strictly observed for people with disabilities?			
	Are the reserved parking spaces close to the building entrance?			
	Is accessible public transportation available to the facility?			
	Is there a pathway to the facility that is flat, firm, non-slippery and clear of any obstacles and hazards at ground and higher level?			
	Is there any tactile paving of contrasting colour?			
	Are kerb ramps built into the footpath, especially for access from the parking area/road to public transport?			
	Are road crossings clearly signed and safe for passage?			
Entrance to the health facility	Does the building have a ramp at the entrance? If YES: - Is the ramp at least 1.2 metres wide? - Is the ramp gentle enough for wheelchair users to self-propel or be pushed easily by a carer? - Is the ramp surface non-slippery? - Is there a landing at least every 9 metres? - Are there handrails on either side of the ramp?			
	Is the door width wide enough to fit a wheelchair?			
	Is the door handle at a height that can be reached from a wheelchair?			

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Focus area	Key component	Yes	No	Comment
Entrance to the health facility	Can the door be opened easily without much effort?			
	Is the entrance clear of any obstacles and hazards at ground and higher level?			
	Is there a map of the building and signage near the entrance, with tactile information?			
	Are door staff/security staff aware of any policies regarding priority of treatment for people with disabilities?			
	Are assistive devices available near the entrance for patients who need them?			
Reception and waiting areas	Is the pathway from entrance to reception/triage clearly signed and clear of obstacles?			
	Is the reception counter at a height that is accessible to people in wheelchairs?			
	Are the reception and waiting areas clear of any obstacles and hazards at ground and higher level?			
	Is there space for wheelchairs in the reception and waiting area?			
	Are the reception and waiting areas well-illuminated, well-ventilated and free from loud background noises?			
	Is drinking water available at a height/location accessible for all people?			
Internal environment	Is there level access to all relevant areas where health service provision takes place?			
	If there are any steps inside the facility: - Is there a ramp or lift that can also be used? - Do steps have contrast strips for people with vision impairments? - Are there handrails beside steps and ramps? - Are there handrails along corridor walls?			
	Are corridors free from obstacles?			
	Are floor coverings non-slip?			
	Are all areas well-lit to support people with low vision to see visual cues and people who are hard of hearing to lip read?			

Focus area	Key component	Yes	No	Comment
Internal environment	Is there clear signage with tactile information, including indicating accessible escape routes and safe refuge points?			
	Are doorways to examination/treatment rooms wide enough to fit a wheelchair?			
	Are examination tables height- adjustable or of a height that allows a person to transfer easily from a wheelchair?			
Toilet and hygiene facilities	Is there clear signage indicating the location of the toilets?			
	Is the doorway wide enough to fit a wheelchair?			
	Do doorways slide or swing outwards?			
	Can the door be operated by people with limited strength or manual dexterity (for example, using a closed fist)?			
	Is there turning space inside the toilet cubicle for a wheelchair?			
	Are there grab rails near the toilet?			
	Are bins available for disposal of menstrual hygiene products?			
	Are hand basins, taps and soap at a height that can be reached from a wheelchair?			
	If the toilet is a squat style is there any adaptive seating device?			
	Is the floor surface well-drained, waterproof, non-slippery and non-glare?			
	Can the tap be easily operated by people with limited strength or manual dexterity (for example, using a closed fist)?			
	Are toilets clear of any obstructions or hazards at ground and higher level?			
	Can the toilets be locked from inside and released from outside by authorized staff in an emergency?			
Service provider information	Is health information available in accessible formats, e.g., large print, Braille, sign language interpreters, simplified for people with intellectual disabilities?			
	Are people with communication difficulties requiring assistance able to access support and/or sign interpreters?			

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Focus area	Key component	Yes	No	Comment
Emergency evacuation	Is information about what to do in an emergency available in accessible formats?			
	Are emergency evacuation routes clearly signed and in Braille for people with vision impairments?			
	Are emergency warning systems implemented using a number of formats, e.g., flags or lights, sirens, large print for people with vision and hearing impairments?			
	Have health facility staff responsible in emergencies been trained in providing additional assistance for people with disabilities during an emergency?			
	Are emergency exits clear from obstacles?			
	Are escape routes accessible for people with a mobility impairment or vision impairment?			
	Are assembly points accessible for people with mobility impairments?			

5. Checklist for making communications accessible to people with disabilities

Communication audits provide a practical way to identify barriers experienced by children and young people with disabilities in accessing health information. Removing these barriers will help these children and young people receive equitable healthcare. Communication audits should be undertaken by (or with) a local OPD and people with different disabilities and the findings discussed with health leaders and an accessibility improvement plan developed.

A checklist of key considerations for any communications audit is available below (adapted from **Disability-Inclusive Health Services Toolkit: A resource for health facilities in the Western Pacific Region**).

Considerations	Recommended actions	Impairment-specific considerations
Are children and young people with disabilities (and their families) aware of different health services in the community, including: • How to find (including directions) and contact the service(s)? • Appointment costs and how to pay? Are insurance or concessions available? • How to make appointments? • What to bring? • The reputation of the health service(s) in how they treat diverse persons, including children and young people with disabilities, or the experience of diverse children and young people with disabilities with the service(s)?	Contact local OPDs and rehabilitation services to promote health services to children and young people with disabilities. Develop materials promoting the health service(s) for distribution to children and young people with disabilities: • Use a variety of formats. • Include positive representation of children and young people with disabilities as part of the general community. • Consider a range of dissemination channels: OPDs; schools; religious leaders; carer/ family networks.	Check with OPDs if information is accessible for different disability types and relevance: • Ensure written material is available in large print, Braille, easy-read versions. • Representation of children and young people with disabilities includes different types of disabilities, and also references those disabilities that are less visible. • Make sure to link with organizations of youth and women with disabilities.
Is the location of the health service clearly signposted and easy to find? Are reception staff able to provide appropriate information about the appointment (including fees, waiting times, paperwork) to people with different types of impairment?	As part of an accessibility walk-through, review whether all signs relating to the location of health service(s) can be understood by children and young people with different types of disabilities. Organize disability- inclusion awareness training for reception staff and other staff (security personnel, health workers); involve OPDs in training.	• Use clear images/symbols that are easy to understand. • Use good colour contrast on signs. • Consider how to communicate with children and young people with different types of disabilities. • Use basic sign language.

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Considerations	Recommended actions	Impairment-specific considerations
Consider whether children and young people with different disabilities can understand information about: • What the health appointment involves. • Providing informed consent. • Their own health needs and issues. • Relevant health promotion and preventive health information. • What a treatment or physical examination involves. • How to stop any treatment or physical examination if they are uncomfortable. • Providing immediate feedback on the treatment or examination. • What the follow-up course of action is/any next steps in managing health issues. • Instructions/prescriptions for any medications/ongoing treatment. • Requirements for any follow-up appointments.	Review how information is communicated to children and young people with different disabilities, and if formats are available and/or adapted to be accessible. Consider and source, if necessary, alternative communication options. Discuss options and gaps in information provision with OPDs. Organize training for health workers on: • How to identify preferred methods of communication for children and young people with diverse disabilities. • Using different methods to communicate health information to children and young people with different types of disabilities. • Ensure health workers are sensitive and responsive to gender, age and other identity factors in their interaction with children and young people with disabilities.	• Is there health information other than in written form so that children and young people with visual disabilities can access, or can the written material be provided in large print or Braille? • Is health information provided in easy-language and picture form to help children and young people with intellectual disabilities and/or learning disabilities process the information (which is also helpful for individuals with low or no literacy or different languages etc.)? • Can children and young people who are deaf access health information that is usually communicated verbally? • Do children and young people with hearing impairments prefer to sign or lip read, or write down communication? • Do children and young people with disabilities prefer to communicate with assistance of a family member or friend or other assistant (consider implications for confidentiality)?

Considerations	Recommended actions	Impairment-specific considerations
Be mindful of the varied requirements of children and young people with different disabilities in one-on-one interaction and when doing a physical examination.	General key actions relevant for all disability types include: • Scheduling extra time for appointments. • Speaking to children and young people with disabilities directly, even if they need communication assistance. • Having communication aids available, e.g., pen and paper, or gadgets to write/type with, talking mats with photos, words and/or images. • Asking children and young people with disabilities if they need assistance with mobility (positioning, transfers) before touching them, being respectful of their personal space. • Being respectful of their mobility aids, e.g., do not lean on or touch/move wheelchair or white cane. • Being patient.	Examples of engaging with children and young with specific impairments: Visual impairment: • Introduce yourself and anyone else who may be in the room; use the name of the individual with the visual impairment to ensure they are aware that/when you are talking to them. • Orient the individual within the room and offer to describe it. • Provide a verbal description of your actions and visual information to the individual during the examination and explain each procedure before touching any part of their body. Hearing impairment: • Confirm with the individual their preferred way of communication. • Face the individual when speaking and do not cover/obstruct your mouth (if using face masks, try to use one with a transparent shield). • Raise the head of the examination table (in particular, during gynaecological examinations with women and girls who are deaf or hard of hearing). • When demonstrating something, allow the individual to focus on the speaker and then interpreter so they can process information; do not demonstrate and talk at the same time. • Have a list of terminology and definitions available (especially when medical terms have no assigned sign) and use diagrams, visual 3D models.

Considerations	Recommended actions	Impairment-specific considerations
Be mindful of the varied requirements of children and young people with different disabilities in one-on-one interaction and when doing a physical examination.		Intellectual/cognitive disabilities: • Be patient and allow extra time for the individual to respond. • Take time to find out how the individual communicates. • Repeat yourself as often as necessary and check if you have been understood before moving on; use signs, gestures, and facial expressions to supplement communication. • Break up information into smaller bits, one idea at a time, with short sentences and simple words. • Pay attention to the individual's reaction to physical contact during examination; they may be anxious or need more time and some may need more explanation.

6. Examples of 'people first' language

Say:	Instead of:
Persons with disabilities; disabled people; people with impairments; children with disabilities	The disabled; the handicapped; PWDs
Person(s) without disability; non-disabled person(s); sighted person; hearing person; neurotypical person	Normal person/people
Lives with/has/experiences a disability or impairment	Suffers with/from
Person(s) with psychosocial disability or impairment	'Mad'; 'mental'; mentally handicapped
Person who is deaf; person who is hard of hearing; deaf person; user of sign language	The deaf; deaf and dumb; deaf mute
Person who is blind; visually impaired person; person who has low vision; partially-sighted person	The blind; person who cannot see
Person who uses a wheelchair; wheelchair user	Confined or restricted to a wheelchair; wheelchair-bound
Person with a physical disability; physically disabled person	Invalid; cripple; handicapped
Person with cognitive disability; person with autism; person with Down syndrome	Mentally handicapped; retarded
Person with epilepsy	An epileptic

