World Health
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Foreword

An estimated 1.3 billion people globally experience significant disability. This figure has grown over the last decade and will continue to rise due to demographic and epidemiological changes, underscoring the urgency for action.

Over a decade ago, WHO and the World Bank published the first World Report on Disability. Substantial progress has since been made in many countries, yet many people with disabilities are still being left behind. Due to persistent health inequities, they die earlier, they have poorer health and functioning, and they are more affected by health emergencies than the general population.

Doing nothing to address these health inequities for persons with disabilities means denying the realization of the universal right to the highest attainable standard of health. Each country has an obligation, under international human rights law and many domestic legal frameworks, to address these inequities.

The COVID-19 pandemic has unveiled and exacerbated the health inequities faced by many people around the world. Many persons with disabilities and their families have been disproportionately affected by social movement restrictions, physical distancing requirements and prioritization of certain health services – all of which have affected their access to essential services which are critical to maintaining health and functioning.

As the world continues to recover from the COVID-19 pandemic and prepare for future health emergencies, we have an opportunity to make health systems more inclusive for persons with disabilities through the primary health care approach. Doing so must be part of every country's journey towards universal health coverage and the other health-related targets in the Sustainable Development Goals.

The Global Report on Health Equity for Persons with Disabilities presents the evidence base for more systematic, comprehensive, and sustainable change in the health sector. It outlines key policy and programmatic actions and recommendations for Member States to strengthen and expand services for persons with disabilities.

We hope that governments, health partners and civil society, including organizations of persons with disabilities, will work together to implement the recommendations in this report, so that persons with disabilities can realize the highest attainable standard of health.

Dr Tedros Adhanom Ghebreyesus
Director-General, World Health Organization

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Acronyms and abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
DAT	digital and assistive technology
FDD11	Functioning and Disability Disaggregation Tool (WHO)
GDP	gross domestic product
GLAD	Global Action on Disability
HIS	health information systems
HPSR	health policy and systems research
HRQoL	health-related quality of life
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organization
ITU	International Telecommunication Union
LGBTQIA	lesbian, gay, bisexual, trans, queer or questioning, intersex, asexual
MDS	Model Disability Survey (WHO)
NCD	noncommunicable disease
NGO	nongovernmental organization
PAHO	Pan American Health Organization (WHO)
PHC	primary health care
RQ	research question
SDG	Sustainable Development Goal

SRH	sexual and reproductive health
UHC	universal health coverage
UN	United Nations
UNDIS	United Nations Disability Inclusion Strategy
UNFPA	United Nations Population Fund
UNPRPD	United Nations Partnership on the Rights of Persons with Disabilities
WASH	water, sanitation and hygiene
WCAG	Web Content Accessibility Guidelines
WHA	World Health Assembly
WHO	World Health Organization

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Introduction

Overview

- ✓ Disability is part of being human and integral to the human experience. It results from the interaction between health conditions and/or impairments that a person experiences, such as dementia, blindness or spinal cord injury, and a range of contextual factors related to different environmental and personal factors such as societal attitudes, access to infrastructure, discriminatory policies, age, or gender.
- ✓ As of 2021, approximately 1.3 billion people – about 16% of the global population – experience disability.
- ✓ Persons with disabilities are part of human diversity, and although often referred to as a single population, they are a very diverse group of people.
- ✓ Persons with disabilities have an equal right as any person to the highest attainable standard of health.
- ✓ Substantial progress has been made in many countries; however, the world is still far from realizing the right to the highest attainable standard of health for persons with disabilities. This is due to the persistent health inequities that persons with disabilities experience.
- ✓ The overarching aim of this report is to make health equity for persons with disabilities a global health priority. The specific objectives of the report are to:
  - bring health equity for persons with disability to the attention of decision-makers in the health sector;
  - document evidence on health inequities and country experiences on approaches in advancing health equity in the context of disability; and
  - make recommendations that stimulate country-level action.

Disability and persons with disabilities

Disability is part of being human and integral to the human experience. It results from the interaction between health conditions and/or impairments that a person experiences, such as dementia, blindness or spinal cord injury, and a range of contextual factors related to different environmental and personal factors including societal attitudes, access to infrastructure, discriminatory policies, age, and gender. This understanding of disability is grounded in the WHO International Classification of Functioning, Disability and Health (ICF), published in 2001 *(1)*. The ICF, adopted by WHO Member States, was the first document to set a new understanding of disability, based on the biopsychosocial model, and defining disability not only by the underlying health condition or impairment of a person, but also by the fundamental effect of their environment.

Disability is not the same as a health condition. For example, depression, cerebral palsy or having a retinopathy are not disabilities: they are health conditions which contribute to disability if the surrounding environment negatively impacts the person's life. A person with disability can be a child with blindness who cannot attend school because of a lack of vision-assistive products and educational materials that are not adapted to their needs. A person with disability can be a man in his forties with a diagnosis of schizophrenia, who does not have a job because of the stigmatization associated with mental health. A person with a disability can be a retired woman with dementia who does not have the means to afford health care or long-term care and lives isolated from society. Regardless of the health condition or impairment, persons with disabilities can enjoy healthy lives by realizing their aspirations, satisfying their needs and changing their environments *(2)*.

As of 2021, approximately 1.3 billion people – about 16% of the global population – have disability. This number has increased substantially during the past decade due to different demographic and epidemiological changes such as population rising and the increase in the number of people with noncommunicable diseases, who are living longer and ageing with limitations in functioning.

Persons with disabilities are part of human diversity; although often referred to as a single population, they are a very diverse group of people. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes persons with disabilities as "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" *(3)*. Persons with disabilities can be of any age, gender identity, race, or religion. Several factors contribute to this diversity including the substantial variety of underlying health conditions and impairments that determine the different health-care needs of the individual. For example, children with underlying conditions such as congenital heart disease or muscular dystrophy may require health interventions such as early identification and rehabilitation to optimize their development and functioning *(4)*. Adolescents with mental health conditions and psychosocial disabilities may benefit from health services in non-specialized care settings. Persons with chronic health conditions associated with high levels of disability, such as spinal cord injury, stroke, or rheumatoid arthritis often have long-term care needs delivered by specialized health professionals *(5)*. Older persons are likely to experience more health conditions and impairments which can result in elevated health-care use and the need for personal support services *(6)*.

The environment is an additional factor influencing the diversity of persons with disabilities. As described above, different environmental barriers such as inaccessible education, transportation, employment and health care, may hinder persons with disabilities from participating fully and effectively in society on an equal basis with others. Two people with the same type of impairment and health condition can have very different experiences of disability. For example, a person with a spinal cord injury living in a low-income setting without accessible transportation, health information and communication, or employment, will experience disability differently from a person with the same condition, who benefits from a good job, wide social network, family support and the health care they need.

The intersection of disability with factors such as sex, age, gender identity, sexual orientation, religion, race, ethnicity, and economic situation also affects the experiences and participation of persons with disabilities. While disability often correlates with disadvantage, not all persons with disabilities are disadvantaged equally. For example, women, children and older people with disabilities experience a combined disadvantage associated with sex, age, and disability *(7)*, which is evidenced in discrimination, limited access to health care or increased forms of violence *(8–11)*. Conversely, higher income and status often helps with overcoming activity limitations and participation restrictions *(12)*. Furthermore, persons with disabilities living in rural or remote areas have substantially reduced access to services and support compared to people living in metropolitan areas and thus can experience greater disadvantage *(13)*.

Persons with disabilities and the right to the highest attainable standard of health

The constitution of the World Health Organization sets out a range of principles and obligations, including that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" *(14)*. Persons with disabilities have an equal right to the highest attainable standard of health as anyone else. This right is inherent, universal, and inalienable, and is enshrined in international law through human rights treaties, and in domestic legal frameworks including national constitutions.

The CRPD is the core human rights treaty[1] that fostered a new era reframing disability with respect to human rights and establishing the norm of participation of persons with disabilities in society on an equal basis with others. The CRPD has 185 ratifications or accessions, and 164 signatories,[2] recognizing the broad global support for addressing the human rights of persons with disabilities everywhere. It provides an international framework that, among other things, promotes and protects the right of persons with disabilities to enjoy their highest attainable standard of health by making decisions about their own bodies and their own health care and without being discriminated against on the basis of their disability.

In addition to international law, various global development and health frameworks have recognized and promoted the right to health for persons with disabilities. Disability-specific international policy and guiding frameworks have evolved over time, starting with the World Programme of Action Concerning Disabled Persons in 1982 *(15)* which included a particular focus on rehabilitation and health services. This was followed in 1993 with the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the United Nation General Assembly, and provided policy guidance for governments around the world on actions to improve the experiences of persons with disabilities *(16)*. The WHO Global Disability Action Plan 2014–2021 was a significant step in achieving health and well-being and human rights for persons with disabilities *(17)*. In 2021, at the Seventy-fourth World Health Assembly, WHO Member States adopted resolution WHA74.8: "The highest attainable standard of health for persons with disabilities" *(18)* which reiterated the need for countries to ensure that persons with disabilities exercise their

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[1] https://www.ohchr.org/en/professionalinterest/pages/coreinstruments.aspx.

[2] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.

full right to health. The resolution aligns with broader international frameworks on health, such as the United Nations Political Declaration on Universal Health Coverage *(19)* which commits Member States to ensuring that all people can access the essential health services they need without financial hardship, thereby aligning with Sustainable Development Goal (SDG) target 3.8.

At the national level, various legal frameworks, health laws or disability laws support the realization of the right to health for persons with disabilities, with some constitutions specifically guaranteeing this. For example, the constitution of Montenegro states that "a person with disability shall have the right to health protection from public revenues, providing for free health care" *(20)*. In addition to national laws, some countries have national policies which set out an objective on health and well-being for persons with disabilities *(21)*. One example is Australia's Disability Strategy 2021–2031 which has the outcome that "people with disability attain the highest possible health and wellbeing outcomes throughout their lives" *(22)*. Arguably, as expressed by the CRPD Committee in its concluding observations to State reports, more needs to be done in all countries to harmonize existing laws related to disability *(23, 24)*.

Substantial progress has been made in many countries; nonetheless, the world is still far from realizing the right to the highest attainable standard of health for persons with disabilities. This report shows that persons with disabilities continue to experience a wide range of health inequities. Contributing factors to these inequities remain unchanged during the past decade, and many persons with disabilities continue to die prematurely, have poorer health, and experience more functioning limitations as a result. The COVID-19 pandemic revealed the disadvantaged position of persons with disabilities within and beyond the health sector[3], and the need for urgent action.

Why this report now?

The call for this report comes at an important time. Several factors and developments during the past decade have contributed to the need for such a report today.

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[3] The terms "health sector" and "health system" have the same meaning and are often used interchangeably. WHO defines "health system" as the "aggregate of all public and private organizations, institutions, and resources mandated to improve, maintain or restore health. This includes both personal and population services as well as activities to influence the policies and actions of other sectors to address the political, social, environmental, and economic determinants of health". However, the term "health system" is very often referred to exclusively as a composite of "building blocks" or components which work together to deliver health services; its other key roles, such as coordinating multisectoral action, are not considered. Therefore, for clarity, this report will use "health sector" as an overarching term, and "health system" when referring to the six building blocks.

More than 10 years have passed since the launch of the first ever *World report on disability*[4] produced jointly by WHO and the World Bank. In the previous report, health was one of many topics, together with others such as education and employment. This current report provides a more comprehensive analysis of challenges in the health sector, as well as the actions needed for ensuring the highest attainable standard of health for persons with disabilities.

In 2014, to implement the recommendations of the *World report on disability*, WHO Member States endorsed the WHO Global Disability Action Plan 2014–2021. The plan called on countries to remove barriers and improve access to health services and programmes; to strengthen and extend rehabilitation, assistive products and support services; and to enhance research on disability and related services, and the collection of relevant and internationally comparable data on disability. In 2021, the action plan expired but the need for global guidance to scale up the health sector response for persons with disabilities remained.

In 2015, all United Nations Member States adopted the 2030 Agenda for Sustainable Development which sets out 17 goals to transform the world. The agenda pledges to leave no one behind, including persons with disabilities, and recognizes disability as a cross-cutting issue to be considered in the implementation of all the goals.

In 2019, heads of state and government representatives adopted the political declaration: "Universal health coverage: moving together to build a healthier world", which includes a specific reference made to persons with disabilities, in terms of increasing "access to health services for all persons with disabilities". The call was also to remove "physical, attitudinal, social, structural, and financial barriers, provide quality standard of care and scale up efforts for their empowerment and inclusion, noting that persons with disabilities, representing 15% of the global population, continue to experience unmet health needs" *(19)*.

In 2019, the UN Secretary-General launched the United Nations Disability Inclusion Strategy (UNDIS) to implement the inclusion of disability through mainstreaming disability in both the programmatic areas and business operations of the United Nations. The strategy enables the UN system to support the implementation of the CRPD and other international human rights instruments, as well as the achievement of the SDGs, the Agenda for Humanity *(25)* and the Sendai Framework for Disaster Risk Reduction *(26)*. Aligning with the UNDIS, this report also provides insights in how to mainstream disability across WHO and UN programmatic areas.

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[4] World report on disability. World Health Organization. 2011

The landmark resolution, adopted in 2021 by the World Health Assembly, on "The highest attainable standard of health for persons with disabilities", aims to advance the agenda of disability inclusion in the health sector in countries, and focuses on three central areas: i) access to effective health services; ii) protection during health emergencies; and iii) access to cross-sectorial public health interventions. A specific request made to the WHO Director-General was to develop a global report on the highest attainable standard of health for persons with disabilities before the end of 2022. This report represents the response to that request.

Objectives of the report

This *Global report on health equity for persons with disabilities* identifies and analyses the contributing factors to systemic health inequities for persons with disabilities and outlines key policy and programmatic actions along with recommendations to reduce these health inequities.

The report calls on WHO Member States to take action to advance health equity for persons with disabilities. It also invites civil society, including organizations of persons with disabilities and other health partners, to collaborate and advocate for the implementation of the recommendations included in the report, so that persons with disabilities can achieve the highest attainable standard of health.

The overarching aim of the report is to make health equity for persons with disabilities a global health priority. The specific objectives are to:

- bring health equity for persons with disability to the attention of decision-makers in the health sector;
- document evidence on health inequities and country experiences on approaches to advance health equity from a disability lens; and
- make evidence-based recommendations that stimulate country-level action.

Development process

The *Global report on health equity for persons with disabilities* was prepared through an evidence-based and consultative process. After determining the structure of the report, WHO performed a series of reviews of the academic literature to inform and shape the content. In addition, a broader review of grey literature, human rights reports and civil society documents was carried out to ensure that the report was based on, and reflected, real-life experiences that are not always captured in peer-reviewed literature. Protocols for these reviews have not been published, but details of the methodology followed can be found in Annex 1. Through a series of regional and global consultations, WHO also engaged with Member States, civil society, including persons with disabilities and their representative organizations, academia, health service providers, and other developmental partners. Throughout the process, consultations were held between WHO and a technical expert group, a civil society group, sister UN entities and WHO units. More details on the consultation process can be found in Annex 2.

Estimations of the prevalence of disability were made in collaboration with the Institute for Health Metrics and Evaluation. Economic analyses were also undertaken to demonstrate the importance of fostering a disability-inclusive health sector. Governmental and nongovernmental partners across the world contributed examples, case stories and photographs.

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1. Health equity for persons with disabilities matters

Personal story

Speaking out on stigma to fight it

When Dr Ahmed Hankir first experienced psychological distress as a medical student in the United Kingdom of Great Britain and Northern Ireland, he delayed seeking help due to the shame and stigmatization associated with having a mental health condition.

Compounding his situation was the stigmatization of being a man of colour, a Muslim and a migrant – a "triple whammy" which contributed towards an "identity crisis" – and the strain of surviving through low-paid jobs and a war in the country of his roots.

He felt the stigmatization of mental health most acutely within his own profession. He was "ridiculed" by fellow medical students and ostracized by his closest companions. When he sought help from the person in charge of student support, he was "psychologically tortured".

"Stigma is rampant in the medical profession. Unless we address it, it will continue," he said. "It takes strength to accept that you might be a source of stigma. There's ignorance and arrogance [from] providers. What we need is humility. I've met inspirational, humble doctors."

As a psychiatrist, he draws from his past. "My lived experience is my superpower. It makes me more insightful, and I can mobilize empathy."

Today, Hankir is renowned for his "Wounded Healer" presentation, which aims to debunk myths about mental illness through blending performing arts and psychiatry. He has won many awards for this, including the World Health Organization Director-General Award for Global Health in 2022.

"Speaking out on stigma challenges it. I try to engage and educate the audience," he explained. More than 100 000 people across 20 countries have heard him speak.

He continues to face negativity from some psychiatrists; some are "suspicious" of his success. "They think I can't function. I was miserable for many years. But now I am not just surviving, I'm thriving," he laughed.

Photo: © Dr Ahmed Hankir

Overview

- ✓ As of 2021, an estimated 1.3 billion people – or 16% of global population – experience significant disability. This number is growing driven by increased number of people with noncommunicable diseases, who are also living longer and ageing with limitations in functioning.
- ✓ Many of the differences in health outcomes between persons with disabilities and those without cannot be explained by the underlying health condition or impairment and are associated with avoidable unjust or unfair factors. These factors are called "health inequities".
- ✓ It is an obligation of the state, through their health sector in coordination with other sectors, to address existing health inequities so that persons with disabilities can enjoy their inherent right to the highest attainable standard of health. The obligation is an international law of human rights.
- ✓ Addressing health inequities for persons with disabilities will advance the achievement of global health priorities.
    - Health equity is inherent to the pursuance of UHC.
    - Countries can make faster progress in improving the health and well-being of their population through cross-sectoral public health interventions that are inclusive and provided in an equitable manner.
    - Advancing health equity for persons with disabilities is a central component of all efforts to protect populations in health emergencies.
- ✓ Addressing health inequities for persons with disabilities benefits everyone. Older people, persons with noncommunicable diseases, migrants and refugees, or frequently unreached populations, such as those from lower socioeconomic backgrounds can benefit from disability inclusive approaches that target persistent barriers to inclusion in the health sector.
- ✓ Advancing health equity for persons with disabilities contributes to their wider participation in society.
- ✓ Investing in health equity for persons with disabilities means investing in Health for All, which whilst would likely require additional investments for ensuring equitable access to people with disability still brings high economic and societal dividends. For example, there could be nearly US$ 10 return per US$ 1 spent on implementing disability inclusive prevention and care for noncommunicable diseases. Other population-wide interventions such as family planning and vaccination also remain highly cost-effective when provided in disability inclusive manner, despite the additional cost required.

1.1 Persons with disabilities and their experience of health inequity

> **Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”**
>
> Dr Martin Luther King, Jr

A wide range of differences in health outcomes exist between persons with disabilities and those without disabilities. These differences can be seen in three key health indicators: mortality, morbidity, and functioning.[5] For example, persons with intellectual disabilities die at a younger age than the general population – in persons with Down syndrome, 20 years younger, on average *(1)*. Compared to those without disabilities, persons with disabilities also have higher rates of limitations in functioning, and chronic health conditions such as diabetes, asthma, arthritis, cardiac disease, dental disease, osteoporosis or stroke *(2, 3)*.

Some of the differences in health outcomes are referred to as inequalities because they can be explained to some extent by the underlying health condition or impairment. For example, compared to the general population, persons with traumatic brain injury have a two-fold increased risk for mortality; the more severe the injury, the higher the probability of early death *(4)*. Evidence shows that persons with Down syndrome are more likely to develop earlier onset dementia than the general population and that dementia is the leading cause of death in this group of people. A study carried out in a community setting in England showed that, among 211 adults aged over 36 years with Down syndrome, 70% of deaths are caused by dementia, and mortality rates are five times higher in adults with Down syndrome who have dementia compared to those without dementia. In comparison, in the general population, mortality rates are slightly less than two-fold higher in those with dementia than those without *(5)*. Compared to younger adults with disabilities, older adults with disabilities have more functioning limitations and comorbid conditions which to some extent can be associated with the ageing process *(6)*.

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[5] “Mortality” is another term for death and is used to indicate the number of deaths due to an illness or a health condition among a certain group of people during a certain time period. “Morbidity” refers to having a disease or a symptom of disease. “Functioning” is a multidimensional concept, relating to the body functions and structures of a person (functioning at the level of the body); the activities of a person (functioning at the level of the individual); the participation or involvement of a person in areas of life (functioning of a person as a member of society); and environmental factors which affect the level of functioning as they can be facilitators or barriers.

A significant proportion of the differences in health outcomes between persons with and without disabilities are associated with unjust or unfair factors that are avoidable and cannot be explained by the underlying health condition or impairment. These differences are referred to as health inequities and are the focus of this report (Box 1). The existence and persistence of health inequities raise moral concerns and, from a human rights perspective, should be viewed as objectionable since they impede persons with disabilities to exercise their inherent right to the highest attainable standard of health. In terms of international law and domestic legal instruments they may also represent unlawful acts.

Distinguishing between health inequities and health inequalities can sometimes be difficult due to the lack of data and systematic research on these topics. Examples of health inequities demonstrate that their existence is pervasive and unacceptable (as explored in Chapter 2); with health inequalities, even when the differences can be explained by the underlying health condition or impairment, this does not mean that they are acceptable or that nothing can be done. As an example, the advances in health care and improvements in the overall health of individuals with Down syndrome led to a dramatic increase in the life expectancy of those with this condition. The life expectancy for persons with Down syndrome was only 10 years several decades ago, congenital heart defects being responsible for most deaths within the first year of life. Now for children with the condition who were born in 2010, the median life expectancy is estimated to be 65 years *(7)*. This longer life span, however, brings a considerable increase in the risk of dementia; therefore, research needs to be conducted and health interventions provided to close the gap in terms of delaying the onset of dementia in persons with Down syndrome.

Box 1

Health inequities

Health inequities are differences in health outcomes that are avoidable and unjust. In general, health equity is the absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically, or by other dimensions of inequality (e.g. age, sex, gender, ethnicity, disability, or sexual orientation). With health equity, every individual has a fair opportunity to realize their full health potential without being disadvantaged in achieving it.

A variety of health inequities lead to persons with disabilities dying prematurely. For example, people with vision impairment have a higher risk of dying prematurely compared to those who have mild or no vision impairment *(8)*; moreover, socioeconomic deprivation and poor access to health care are well documented risk factors for vision impairment and mortality, among other outcomes *(9)*. A six-fold discrepancy in deaths amenable to quality health care can be seen between persons with intellectual disabilities and the general population *(10)*. Contributing factors to premature mortality include problems in advanced care planning, inappropriate living accommodation, or adjusting care as needs change *(11)*. The higher rates in mortality escalated more markedly during the COVID-19 pandemic, during which persons with intellectual disabilities were eight times more likely to die from the disease than those without an intellectual disability *(12)*. They were also less likely to receive critical care support suggesting that quality of health care may be a contributing factor in the higher case fatality *(13)*. A mortality gap of 20 years for men, and 15 years for women, was experienced by persons with psychosocial disabilities in high-income countries, due to a combination of lifestyle risk factors, social determinants, and poorer health care *(14, 15)*.

In terms of inequities leading to poorer health, persons with disabilities have higher rates of acquiring new health conditions or increased morbidity, which are often driven by reduced access to health care, including rehabilitation services *(16, 17)*. Such conditions can include tuberculosis, diabetes, stroke, sexually transmitted infections or cardiovascular problems *(16, 18–22)*. Having multiple impairments increases the risk of a high prevalence of vision impairment among persons with disabilities *(23)*. Furthermore, persons with disabilities have an increased risk of poor oral health and developing mental health conditions such as depression or anxiety *(16, 19, 21, 24–27)*.

Differences in everyday functioning can also be attributed to unfair conditions such as barriers to economic life, transport, leisure activities, social contact, accessibility, and participation in employment *(28)*. The WHO Model Disability Survey reveals the impact of the surrounding environment on the levels of functioning of persons with disabilities. In Cambodia, for example, factors such as inaccessible transportation, the hindering aspects of places where persons with disabilities can take part in community activities, the lack of social support and of assistive products are detrimental to functioning *(29)*. In Cameroon, inaccessible physical environments, especially inside a person's home (e.g. the toilet or the dwelling itself), as well as negative attitudes and barriers to accessing health care, can increase limitations in functioning to a far greater extent than for those without disabilities *(30)*.

Advancing health equity for persons with disabilities can be achieved through addressing the contributing factors to health inequities which disadvantage persons with disabilities. These factors include: i) any structural conditions related to the social, economic, or political context, including stigmatization and discrimination against persons with disabilities; ii) the social determinants of health, such as poverty, education, employment, sex, or age; iii) a range of risk factors related to ill health that have an adverse impact on persons with disabilities, such as poor diet, physical inactivity *(31)*, the use of tobacco products *(32)*, alcohol consumption, drug use *(24)*, and sexually transmitted infections *(22)*; and iv) the broad set of barriers in the health system – prominently the lack of access to quality and affordable health care services, including for sexual and reproductive health.

The health inequities and contributing factors that lead to increased mortality, morbidity, and limitations in functioning are detailed in Chapter 2.

1.2 Health equity for persons with disabilities is a state obligation

It is a state obligation, through the health sector and in coordination with other sectors, to address existing health inequities so that persons with disabilities can enjoy their inherent right to the highest attainable standard of health. Obligations to address health inequities are created through international human rights treaties which are binding on the governments of States Parties. Governmental and nongovernmental actors in the health sector may also be bound under domestic policies and legislation. Addressing health inequities implies assuming obligations and duties to respect, protect and fulfil the right to health for every individual. The obligation "to respect" means that countries must refrain from interfering with, or curtailing, the enjoyment of this right. The obligation "to protect" requires countries to defend individuals and groups against human rights violations.[6] The obligation "to fulfil" means that the health sector must take positive action to facilitate the enjoyment of the basic human right for health through adopting a human rights-based approach to health and addressing existing health inequities. The practical implications of adopting this approach are elaborated in Chapter 3.

Countries have an obligation under international human rights law to ensure that their legal and policy frameworks do not discriminate on the basis of

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[6] https://www.un.org/en/about-us/udhr/foundation-of-international-human-rights-law.

disability. Since 2007, this obligation has been reaffirmed by the CRPD (see Box 2). The articles of the CRPD address non-discrimination as a cross-cutting issue. While Article 2 defines discrimination based on disability very broadly, Article 3 includes non-discrimination and equality of opportunity as general principles. Article 4 requires States that are party to the CRPD to repeal any legislation, regulations, customs and practices that constitute discrimination against persons with disabilities, including coercive and involuntary hospitalization and treatment of persons with disabilities, without their choice and informed consent. Article 5 calls on States to adopt strong anti-discrimination legal frameworks prohibiting any form of discrimination on the basis of disability. This will guarantee equal and effective legal protection against discrimination on all grounds to all persons with disabilities *(33)*.

Box 2

Article 25 of the Convention on the Rights of Persons with Disability (CRPD)

Article 25 of the CRPD lays down that States Parties must recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties must provide persons with disabilities with the same range, quality, standard of free or affordable health care and programmes as provided to other persons, including sexual and reproductive health services, population-based health programmes and other health services. It also prohibits discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law.

Furthermore, it is the obligation of each State to act upon the multiple and intersecting forms of discrimination faced by persons with disabilities. The CRPD recognizes the significance of such forms of discrimination, particularly in relation to women, girls and boys with disabilities, since these groups are at a higher risk of discrimination and exclusion. In domestic policies and programmes, States that are party to the CPRD or other relevant human rights treaties, are bound to address the different health inequities experienced by the most marginalized among persons with disabilities, such as women, children, young people, older persons, indigenous peoples, persons with psychosocial disabilities, sexual minorities groups, or persons with intellectual disabilities. In reality, however, while some countries have non-discrimination included in their legislation and constitutions, disability is often not mentioned as a basis for discrimination, or when included, is only considered in specific areas, such as education or employment *(34)*.

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The health sector has several available mechanisms to confront inequity, including directly reducing exposure to risk factors and vulnerability to ill health; improving equitable and non-discriminatory access to health services and health information; or promoting cross-sectoral action to address the wider social and environmental determinants of health and improve health status. Examples of the latter include water and sanitation policies for better hygiene, food supplements in collaboration with the food and agricultural sector, educational initiatives, or transport policies to address geographical barriers to access health services. Furthermore, the health sector can play a fundamental role in mediating the consequences of illness in the lives of persons with disabilities. For example, financial risk protection within countries' plans for universal health coverage (UHC) can support persons with disabilities from impoverishment or catastrophic health expenditures.

The World Health Assembly resolution, WHA74.8 *(35)*, reiterates the need for governments to commit to ensuring health equity for persons with disabilities. The resolution aligns with broader international frameworks on health. These include the 2030 Agenda for Sustainable Development, under which Member States have an obligation under Sustainable Development Goal 3 (SDG3) to ensure healthy lives and promote well-being for all at all ages; and the United Nations Political Declaration on Universal Health Coverage *(36)* which commits countries to ensuring that all people can access the essential health services they need without financial hardship (SDG 3.8).

1.3 A large proportion of the population has disability

Box 3

Prevalence estimates

To estimate the most recent prevalence of disability, WHO applied a similar approach to the 2011 World report on disability. This was done for consistency. The 2011 report relied on a combination of methods, using data from both the WHO World Health Survey of 2002–2004 and the 2004 Global Burden of Disease (GBD) study. In the absence of updated comparable WHO World Health Survey data, WHO used exclusively the 2021 data from the GBD for the current report.

Various factors, however, impede the direct comparisons between the prevalence estimates of the previous report and this report. This is because the Institute for Health Metrics and Evaluation (IHME), the organization behind the GBD data, has updated various details in the methodology over the years (for more details see Annex 3). In addition, IHME updates annually all data in the GBD study based on new epidemiological evidence from all around the world. This not only ensures more accurate prevalence estimates for health conditions, but also the possibility of considering data on new conditions or impairments for which information has lacked in the past. The prevalence estimates are updated retrospectively for all previous years up to 1990. This means, for example, that when the estimates of 2021 are published, the estimates for each health condition and impairment for every year since 1990 are also updated and published. Using the new estimates published every year, it is accordingly possible to observe trends over time with more valid and robust data.

To explore time trends, thus, we did not compare the estimates presented in the 2011 WHO and World Bank World Report on Disability, but the estimates of the GBD study produced by IHME in 2021 for the years 2010 and 2021.

The underlying health conditions and impairments included in the estimates are those that typically last longer than 6 months and are associated with significant (moderate or severe) levels of disability. All data is disaggregated by age and sex. There is no double counting of people who have more than one underlying health condition or impairment since an adjustment for comorbidity was made that considers the increased probability of having certain pairs of conditions. Full details on the methodology can be found in Annex 3.

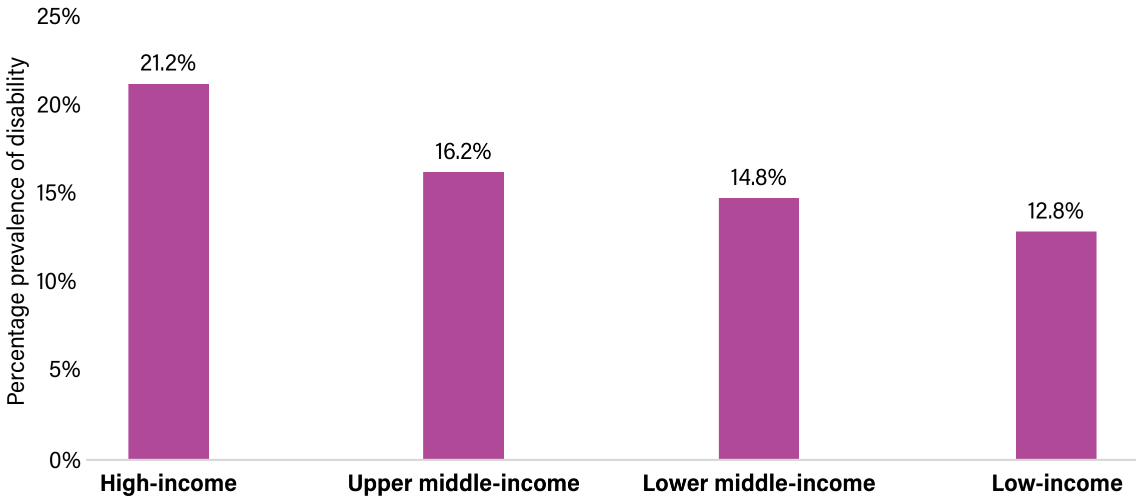
The estimates presented here are based on underlying health conditions and impairments associated with significant (moderate and severe) levels of disability, without considering the impact of the surrounding environment. This was also the case of the estimates presented in the World Report on Disability 2011. This is justifiable since there is little data on disability that measures the effect of different environmental factors. Even if the WHO Model Disability Survey, which considers the impact of the environment, has been conducted in 15 countries and there are other few studies that do the same using disability-specific tools, the data is not sufficient to obtain global or regional estimates. We acknowledge the limitations of this approach. As in most settings the environment presents more barriers than facilitators, if the impact of the environment is considered in estimating the prevalence of disability, the number of persons with disabilities is likely to be much higher due to the environmental impact.

1.3.1 2021 prevalence estimates of disability

As of 2021, an estimated 1.3 billion people – 16% of the global population – have significant disability. Of these people, around 142 million have severe levels of disability.

Nearly 80% of the 1.3 billion persons with disabilities live in low-income and middle-income countries of the world, as opposed to 20% in high-income countries. However, the prevalence of disability is highest in high-income countries (21.2%) and lowest in low-income countries (12.8%) (Figure 1). This difference can be explained by two factors. On the one hand, certain very prevalent health conditions such as musculoskeletal conditions or neurological conditions are more prevalent in high-income than in low-income countries. On the other hand, underdiagnosis and underreporting in low-income settings may lead to an underestimation of the number of persons with disabilities in many countries.

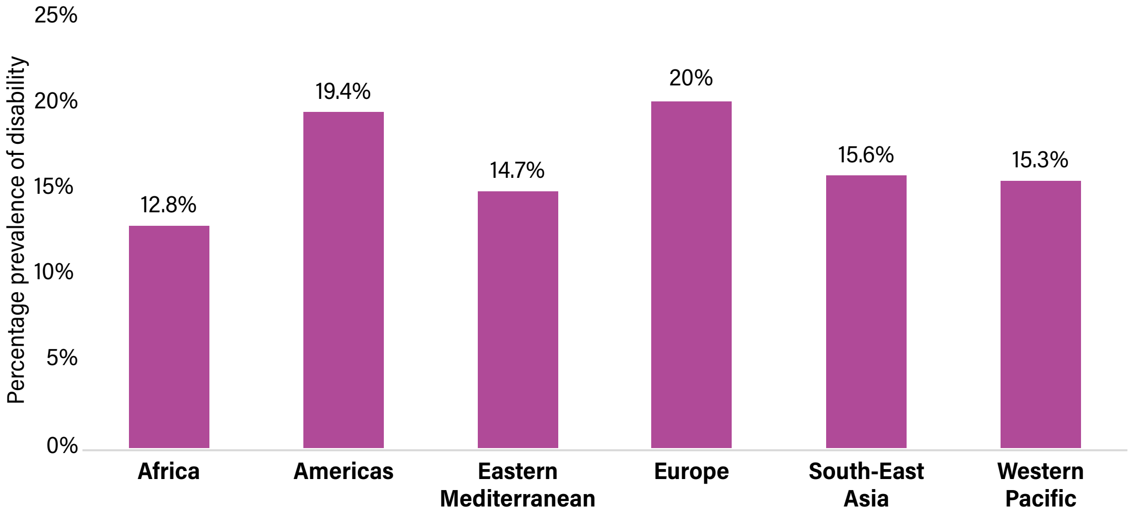
Figure 1. Prevalence of disability by World Bank country income group, 2021



Source: Global burden of disease data, 2021

The prevalence of disability varies across WHO regions with the European Region having the highest (20%), followed by the Region of the Americas (19.4%); the African Region has the lowest prevalence of disability with 12.8% (Figure 2). These results are in line with the findings per income group, with a substantial proportion of the countries in the European Region being in the high-income category, whereas in the African Region – there are more low- and middle-income countries.

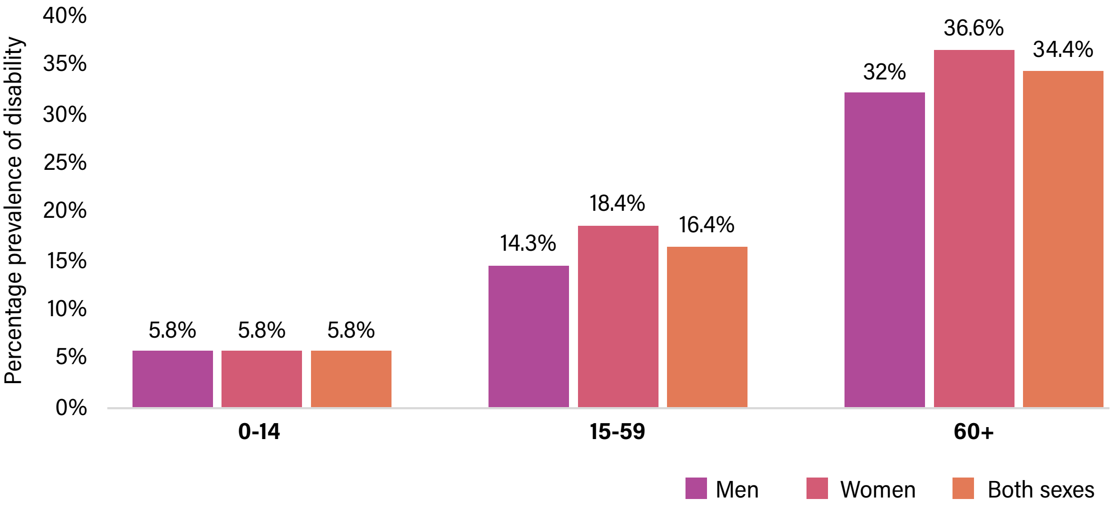
Figure 2. Prevalence of disability, by WHO region, 2021



Source: Global burden of disease data, 2021

The global prevalence of disability increases with age, rising from 5.8% in children and adolescents aged 0-14 years, to 34.4% among older adults aged >60 years (Figure 3). This indicates that 1 in 3 older adults is a person with a disability. In terms of differences by sex, women have higher prevalence of disability compared to men. Estimates show that 14.2% of the male population have disability compared to 18% of the female population.

Figure 3. Prevalence of disability, by age and sex, 2021



Source: Global burden of disease data, 2021

1.3.2 Time trends

The most recent GBD data for 2010 show that a decade ago, approximately 1 billion people had significant disability. This means that within only 10 years, there has been an increase globally of more than 270 million people who now have disability (see Box 3 for more information on data used to compare time trends).

This increase is due to demographic and epidemiological changes in the population. On the one hand, population numbers are rising, with almost 1 billion more people living today than in 2010. In addition, populations are ageing, with a 40% increase, during the past decade, in people aged >60 years *(37).* On the other hand, the number of people with noncommunicable diseases, who are living longer and ageing with limitations in functioning is increasing. Comparisons between 2021 and 2010 using the latest GBD estimates reveal a significant increase in the number of people with musculoskeletal, mental health and neurological conditions, as well as sense organ conditions such as hearing and vision loss. In addition, more people are living and ageing with chronic health conditions. GBD 2021 data used for this study show that the number of people aged >60 years with noncommunicable disease is significantly higher compared to 2010. More information on the changes between 2021 and 2010 are provided in Annex 3.

Alongside the increase due to demographic and epidemiological changes, health emergencies, including infectious disease outbreaks, natural disasters and conflicts, can result in many new impairments and an increase in disability in the affected population. For example, traumatic injuries may contribute to a higher prevalence of disability in conflict-affected communities *(38, 39).* According to a recent meta-analysis, of people living in conflict settings, 1 in 5 (22%) have a mental health condition, such as depression, anxiety, post-traumatic stress disorder, bipolar disorder, or schizophrenia *(40).* Furthermore, many people are experiencing post COVID-19 conditions. Initial studies demonstrate that 1 in 5 people will have a new disability when assessed six months after COVID-19 hospitalization *(41).* However, the evidence on how COVID-19 impacts disability prevalence in populations is still evolving.

1.3.3 How do the prevalence estimates relate to other studies?

A direct comparison between estimates is not possible due to the diverse nature of data collection tools to produce them. For example, some studies use a single item in their censuses or national surveys to identify those with disability, for example, “Do you have a disability?” *(42, 43)*. Others use instruments assessing functioning limitations that refer to a set of difficulties that people experience in undertaking specific activities such as walking, seeing, or hearing *(44, 45)*. While direct comparisons cannot be made, it is possible to provide some overview of how the trends presented in this report relate to data from other organizations and initiatives.

The United Nations Statistics Division maintains an international repository of disability statistics, which contains disability data from official statistics compiled from national population and housing censuses, household surveys, or administrative data. Data from the past decade show prevalence estimates varying from 1.5% in Guinea, based on the 2014 Population and Housing Census, to 32.5% in Sweden, derived from the Living Conditions Surveys 2014/2015 *(46)*. While country estimates vary from one country to another, the overall trends in disability prevalence are consistent to those described in this report. For example, the prevalence is higher among women compared to men in almost all countries, as well as in high-income countries compared to lower-income settings.

In a recent publication, UNICEF reported that approximately 1 in every 10 children aged between 0 and 17 has disability globally *(47)*. This estimate was derived from a harmonization of data from the Multiple Indicator Cluster Surveys, Demographic and Health Surveys (DHS), the European Health Interview Survey (EHIS) and the European Survey on Income and Living Conditions (EUSILC). A trend that is consistent with the data presented in this report is the similar prevalence estimates between boys and girls. UNICEF found that in most countries and areas, no statistically significant differences were found in the proportion of boys and girls with disabilities.

The WHO Model Disability Survey, which assesses difficulties in functioning which may arise due to a person’s health or their living environment, was implemented in 15 countries over the past 7 years. The survey allows for obtaining the distribution of disability in the population, reporting estimates for no, mild, moderate or severe disability. The trends that were found in the countries that have implemented the MDS, are similar to those presented in this report. For example, prevalence is higher in women compared to men, and increases with age, reaching the highest values in individuals aged >60 years *(48)*.

The recent Disability Data Initiative reported estimates of disability prevalence for 41 countries published from 2008 to 2019 *(49)*. Data showed that the median prevalence of adults aged >15 who have functioning difficulties was

12.6%. The authors acknowledge that the studies rely on instruments focusing on difficulties in selected functioning domains, that do not capture all persons with disabilities, particularly persons with psychosocial disabilities. As with the WHO estimates, the Disability Data Initiative reports higher estimates of functioning difficulties in older rather than younger age groups, and among women more than men.

1.4 Addressing health equity for persons with disabilities will advance the achievement of global health priorities

> **I firmly believe that inclusion is a prerequisite for sustainable development."**
>
> Honourable Mr Jonas Gahr Støre, Prime Minister, Norway

The estimates provided in this report reinforce the scale, the public health relevance, and the political importance of disability. The number of persons with disabilities has increased substantially over the last decade, and the continuous demographic and epidemiological changes suggest that it will continue to grow. This brings urgency to the need to advance health equity for persons with disabilities, as countries cannot meet their global health priorities if 1.3 billion people are left behind.

Based on the discussions taking place in international fora around health among heads of states, ministries of health and the general health policy community, including researchers, there is an agreement that to progress towards SDG3, countries need to concentrate on three key health priorities: i) achieving universal health coverage; ii) promoting healthier populations; and iii) addressing health emergencies.

For several years, these three health agendas have been a topic of discussion at high-level governmental meetings and events. At the annual G20 Health Ministerial meetings,[7] ministers have repeatedly discussed universal health coverage, addressing the diversity of determinants of health to improve population health, and health emergencies, especially in the context of the COVID-19 pandemic. Similarly, central topics for the 2022 World Health Summit include investment for health and well-being, climate change and

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[7] https://g20.org/about-the-g20/

planetary health, pandemic preparedness, and the resilience and equity of health systems.[8]

In addition to international fora, several important high-level declarations and resolutions made during the past decades highlight the importance of the three global health priorities. For universal health coverage, the Declaration of Alma-Ata on Primary Health Care from 1978, and the 2018 Declaration of Astana are central and guiding documents *(50)*. For improving the health of the population through addressing determinants of health, important documents include the Ottawa Charter for Health Promotion (1986) *(51)*; the Rio Political Declaration on Social Determinants of Health (2011) *(52)*; the Helsinki Statement on Health in All Policies (2013) *(53)*; and the Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development (2016) *(54)*. The importance of addressing health emergencies was emphasized in the International Health Regulations (2005) and the Sendai Framework for Disaster Risk Reduction *(55)*.

The COVID-19 pandemic has emphasized more strongly the need to focus on these three priorities in a consistent manner. Besides the consequences in terms of illness and mortality, the pandemic has also adversely impacted on countries' health systems and on society as a whole. The *Sustainable Development Goals Report 2021* documents how progress towards health goals has been derailed in the context of COVID-19, with 90% of countries reporting ongoing disruptions to essential health services and an exacerbation of health inequalities *(56)*.

The three global health priorities are interconnected and need to be tackled in a mutually reinforcing manner. Addressing health equity for persons with disabilities offers an important and unifying approach across all three priorities. Health equity can be advanced through building a fair health sector which provides opportunities for health for ALL members of society, regardless of their age, income level, gender, ethnic background, or any other social or economic reasons. This includes fair provision of health services without financial hardship (pursuing UHC); fair access to health promotion and prevention strategies to improve the health of the population; and fair response to health emergencies that protects everyone, including persons with disabilities. Advancing health equity across the three health priorities is a means of achieving SDG3 and progressing other related SDGs. The following sections explore the relation between health equity for persons with disabilities and the global health priorities.

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[8] https://www.conference.worldhealthsummit.org

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1.4.1 Achieving Universal health coverage

Health equity is inherent to the pursuance of UHC. The 2008 *World Health Report* defined UHC reforms as "reforms that ensure that health systems contribute to health equity, social justice and the end of exclusion, primarily by moving towards universal access and social health protection" *(57)*. By ensuring that financial barriers and service delivery models do not restrict access to the health services that any person needs, UHC provides an opportunity for health inequities to be addressed (Box 4).

Box 4

Universal health coverage

Universal health coverage (UHC) means that all people have access to the health services they need, when and where they need them, without financial hardship[9]. UHC must be understood in a comprehensive way, as it takes into consideration not only the delivery of quality services, but also the strengthening of the entire health system and intersectoral action. In terms of services, UHC includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course. These services respond to the needs of people and include those that are specialized and used most frequently by persons with disabilities. Quality is fundamental to all services *(58)*. The delivery of services depends on several factors. Financing functions of the health systems are a central component and include revenue collection, pooling of resources, and purchasing of services, all of which are critical to the realization of UHC. More details on financing in the context of UHC are provided in Chapter 3.

The means to achieve UHC is health system strengthening. More specifically, UHC progress is dependent on the wider health system strengthening approach of primary health care (PHC). For example, the delivery of services requires physical accessibility and adequate and competent health professionals with an optimal mix of skills at facility and community levels, who are equitably distributed and supported. Services, broadly, also include the provision of relevant health information, as well as universal access to drugs, products, and other goods. The realization of UHC requires intersectoral action *(59)* and needs to be understood as going beyond the health sector since some actions needed to improve access to health services lie in other sectors. For example, while affordability of health services is the primary responsibility of the health sector, certain barriers that lie outside the health sector can have an impact on the individuals' ability to receive services. For example transportation costs, which depend on other sectors' policies may impede people reaching health facilities.

To advance UHC, countries must progress in three dimensions making choices regarding equity: i) expand priority services, deciding which services to focus

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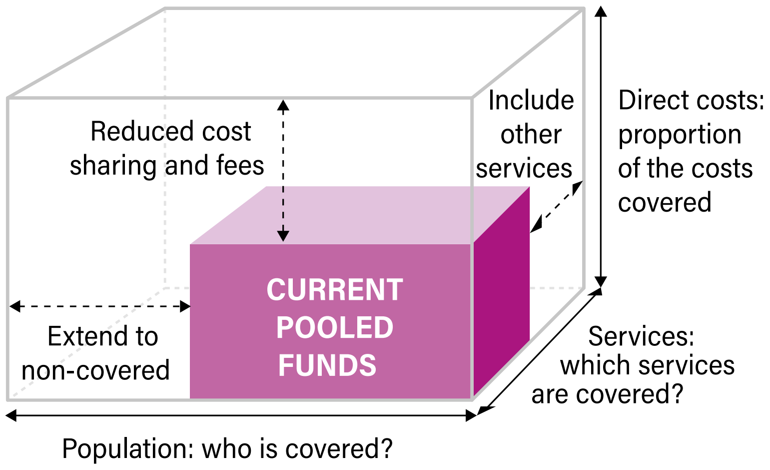
[9] https://www.who.int/health-topics/universal-health-coverage#tab=tab_1

on first; ii) include more people, deciding who to include first; and iii) address barriers to effective coverage, such as reducing out-of-pocket payments (see Figure 1 *(60)*). While choices are clear, the implementation of these choices requires good long-term planning and clear strategies that ensure inclusive and equitable progressive realization of UHC *(61)*. In terms of service expansion, packages of services can be prioritized, based on relevant criteria such as prioritizing the most disadvantaged, the most cost–effective services, or those that provide the most financial risk protection – or in reality, a balance amongst these and other criteria. Packages can include services specific to the underlying impairments and health conditions of persons with disabilities – such as vision rehabilitation or the provision of assistive technology – or mainstream services such as regular screening and examinations, or services for sexual and reproductive health. Health services need to be expanded as much as possible at community levels since much of the global population still lacks access to essential services close to where they live *(62)*. In terms of financing, equitable health budgeting and progressively reducing out-of-pocket payments can contribute to expanding coverage of high-priority services to everyone, including persons with disabilities, supported by pooled funds from compulsory sources (some form of taxation).

Figure 4: Universal Health Coverage Cube



Most countries are already taking steps and strengthening efforts to advance universal access to health care. However, inclusive actions are often not put into practice, which leaves out priority populations living in marginalized conditions, thus compromising the realization of UHC. It is important, therefore, that the disability considerations of all age groups are brought to the fore when UHC commitments are being framed at global, regional, and country level and in subsequent political and technical decisions regarding the content of packages of essential care.

The progress of UHC is dependent on the wider health system strengthening approach of Primary Health Care (PHC). PHC as a health-system strengthening approach entails three interrelated and synergistic components: i) integrated health services, with an emphasis on primary care and essential public health functions; ii) multisectoral policies and actions to address the wider determinants and risk factors for health; and iii) engaging and empowering individuals, families, and communities to increase social participation, and enhance self-care and self-reliance in health *(63)*. These three pillars are fundamental to addressing the factors contributing to health inequities in general, but particularly for persons with disabilities. The PHC approach is explained in more detail in Chapter 3.

1.4.2 Promoting healthier populations

Promoting the health of the population is a global public health priority that requires multisectoral policies and actions to effectively address the wider determinants and risk factors for health. Health system strengthening through the PHC approach is important because it encourages multisectoral action in delivering public health interventions. These interventions can be population-wide, such as tobacco taxation, water and sanitation infrastructure, or personal-level services, such as the provision of health advice. The most effective interventions for tackling determinants and risk factors for health are often led by, and require the engagement of, sectors other than the health sector. For example, reducing exposure to risks such as unhealthy diets, tobacco use, harmful consumption of alcohol or use of drugs, insufficient physical activity, violence and injuries, or unsafe roads, all require a multisectoral approach to influencing public policies across social development, transport, finance, education, entertainment and leisure, agriculture and other sectors. Frequently, public health actions require population-based policy, legislation or regulatory measures including fiscal measures, as well as government engagement with the private sector.

Health equity is at the core of this public health priority; however, the design, planning and implementation of multisectoral public health interventions frequently overlooks persons with disabilities who therefore do not benefit on an equal basis with others. For example, public health information is often not provided in accessible formats such as Braille, Easy Read *(64)*, sign language interpretation, and captioning; and information is frequently not tailored to the needs of persons with disabilities or their caregivers *(65)*. The physical environment is also a barrier for many persons with disabilities. A lack of ramps, ground cover that is appropriately surfaced, accessible bathrooms, changing spaces and fitness facilities and equipment can all create barriers to inclusion *(66)*. In addition, the actions of health-care workers themselves can be a barrier: by making assumptions about the appropriateness of referral or recommendations, workers can block access to public health interventions for persons with disabilities *(67)*. A key reason for these barriers is that responsibilities for public health and disability inclusion are often not clarified within governments, with some struggling to define whose role it is to provide inclusive public health interventions. This is particularly the case when considering cross-sectoral public health interventions, such as water sanitation and hygiene *(68–71)*.

By assuming its stewardship role and ensuring that cross-sectoral public health interventions are inclusive and provided in an equitable manner, the health sector can faster achieve improvements in the health and well-being of the population. The responsibility for public health policies and actions often spans departments or sits outside departments of health; with disability, this can result in a lack of cross-ministry and cross-sectoral coordination. Therefore, disability inclusion needs to be acknowledged and designed as a necessary component of public health initiatives, so that accessibility is in-built from the start. Consultation with persons with disabilities is critical to achieving this. The health sector, as a steward for intersectoral action, coordinates processes, which ensures three things: first, that a proper alignment across all stages of implementation of a public health intervention is established; second, that knowledge, expertise, reach, and resources can be leveraged from other sectors and partners, and thereby benefit from their combined and varied strengths; and third, that health equity is the driving force for achieving progress in improving population health. Recommended disability-inclusive actions to advance health equity in cross-sectoral public health interventions is provided in Chapter 3.

1.4.3 Addressing health emergencies

> **We are still invisible. But the pandemic has made us more invisible.”** ***(72)***
>
> Ana, a 57-year-old woman with disability in Panama during COVID-19

No country was fully prepared for a pandemic of the scope and scale of COVID-19 *(73)*. As a result, addressing health emergencies has become even more prominent as a global health priority and health equity more central to such emergencies. In relation to persons with disabilities, particularly women and girls, the evidence shows that during the pandemic they were, and continue to be, directly affected and disproportionately disadvantaged due to the increased risk of infection, morbidity, and mortality. There is evidence that COVID-19 infection rates are 4–5 times higher among persons with disabilities currently living in residential or long-term care facilities compared with the general population *(74)*, which is often due to the inability to provide basic services or ensure prevention measures are put in place.

Persons with intellectual disabilities are 4–5 times more likely to be admitted to hospital, and up to 8 times more likely to die from COVID-19 than those without an intellectual disability *(75)*. The disproportionate impact on persons with disabilities extends to a range of health emergencies. For example, children with disabilities are often more at risk of negative health outcomes in food security-related emergencies, with evidence that they are 1.5–2.7 times more likely to be underweight for age, stunted, and have low body mass index for age when compared to neighbour or family controls *(76)*.

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Persons with disabilities are also affected indirectly in emergencies, due to the impact of public health emergency response measures. Looking more closely at the substantial evidence relating to infectious disease outbreaks, such as COVID-19, persons with disabilities are at risk of new or worsening health conditions. Lockdowns, physical distancing requirements, school closures, disruptions to health services, and prioritization of health services have hampered access to regular health consultations, medication, psychosocial support, rehabilitation, including assistive technology provision, as well as personal assistant and home and school-based support services. All of these factors are critical to a person's independence and autonomy *(77, 78)*, and add pressure to families and informal care mechanisms *(79)*. Isolation due to physical distancing and movement restrictions has exacerbated the risk of violence against persons with disabilities, especially women, older persons, and transgender and non-binary persons with disabilities *(80–83)*. People who are deaf or hard-of-hearing also faced challenges with communication during the COVID-19 pandemic due to preventative measures such as use of face masks and physical distancing *(84)*. Furthermore, persons with disabilities are now facing greater economic impacts (e.g., due to job losses and reduced household income) compared to those without disabilities, adding to higher rates of poverty *(85–88)*.

Advancing health equity for persons with disabilities is central to all efforts to protect populations in health emergencies. There is widespread recognition that strengthening health systems and addressing the social determinants of health are critical to effective, sustainable, and equitable health emergency responses. Health systems strengthening and emergency preparedness have been described as "two sides of the same coin": functioning and effective health systems enable better preparedness and response to health emergencies *(89)*. WHO's *Health Emergency and Disaster Risk Management Framework* highlights how essential health service coverage and public health interventions improve the overall health status of affected populations, contributing to the prevention of outbreaks, mitigating risks and building community resilience to such hazards *(90)*. As social determinants of health and community engagement are still largely absent from wider health emergency frameworks, there are calls for a "unified Global Health Security – Universal Health Coverage Agenda [which] should be built with intersectional equity at the centre" *(91)*. Chapter 3 elaborates on targeted actions that can be integrated to the PHC approach to ensure disability inclusion in health emergencies *(92)*.

1.5 Addressing health inequities for persons with disabilities benefits everyone

> **Achieving health and well-being for all must include addressing the barriers that prevent people with disabilities from accessing the health services they need. Removing these barriers benefits everyone, especially vulnerable populations, older people, people with temporary limitations, or those living with chronic conditions."**
>
> Tedros Adhanom Ghebreyesus, WHO Director-General

In order to achieve good health outcomes for persons with disabilities, it is essential to address the health inequities they experience. Taking action on health inequities benefits everyone simultaneously by contributing to universality, people-centeredness, and non-discrimination in health services and public health promotion, thereby allowing health services to become more effective and responsive. Older people, persons with noncommunicable diseases, migrants and refugees, and frequently unreached populations, such as those from lower socioeconomic backgrounds, or people with limited literacy skills, often experience similar barriers. For example, inaccessible physical environments, stigmatization by health-care providers and community members, health information that is not in an understandable format, and financial barriers to accessing health services can discriminate against various groups of health service users. All of these groups can benefit from approaches that target the persistent barriers to inclusion of persons with disabilities in the health sector.

Older persons present a good example of a population that will benefit from disability-inclusive actions. Despite the predictability and accelerating pace of ageing populations, currently many older adults experience similar health inequities as persons with disabilities. This is also because a large percentage of the population of persons with disabilities are above 60 years of age. Older people often experience barriers when accessing the basic resources necessary for living a life with meaning and dignity, including daily barriers that prevent them from experiencing good health and well-being and fully participating in society *(93)*. These difficulties are exacerbated for people in emergencies, where resources are more limited and the barriers higher *(94)*. In addition, older adults are often subject to institutional or interpersonal ageism through the stereotypes, prejudice and discrimination directed towards them on the basis of their age. This very often intersects with the discrimination and stigmatization associated with the disability experienced by older people. For older people, ageism is associated with a shorter lifespan, poorer physical and mental health, cognitive decline, increased social isolation and loneliness, and increased risk of violence and abuse *(95)*.

Globally, the number of people aged 60 years and above is expected to double by 2050; this unprecedented demographic change will require a radical response from society and the health sector. Four main actions identified through the *Global strategy and action plan on ageing and health*,[10] and the related United Nations Decade of Healthy Ageing 2021−2030, include combating ageism; providing person-centred integrated care and long-term care; providing community-based services for people who need them; and creating age-friendly environments. Cross-cutting to these actions are four enablers: i) listening to diverse voices and enabling meaningful engagement of older people; ii) nurturing leadership and building capacity to take appropriate action integrated across sectors; iii) connecting various stakeholders worldwide to share and learn from the experiences of others; and iv) strengthening data, research and innovation to accelerate implementation *(94)*. Efforts towards the inclusion of disability in the health sector will contribute to the advancement of all the above actions for two reasons. First, commonly experienced health inequities can be addressed through inclusive actions; and second,

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[10] https://www.who.int/publications/i/item/9789241513500.

since a substantial proportion of older adults have disabilities, disability actions that address their needs can be set as good practices for the ageing population overall.

Addressing health equity for persons with disabilities can benefit people living with noncommunicable diseases (NCDs), communicable diseases or short-term injuries *(96)*. NCDs are increasing in magnitude globally because of population ageing and an epidemiological shift towards chronic conditions. Disability is strongly linked with NCDs. Persons with disabilities are more vulnerable to NCDs, often because of exclusion from health-care services or other unjust factors, and, as shown in section 1.3, the health condition underlying a disability is frequently a NCD. In addition, people living with NCDs may develop secondary impairments, which can cause restrictions in activity and participation when supportive personal and environmental factors are not in place *(96)*. Inclusive strategies and actions also benefit people with communicable diseases such as malaria, tuberculosis, or neglected tropical diseases, and those with short-term injuries due to accidents or other causes, or with reduced mobility from surgical procedures. People with these conditions can often experience limitations in their functioning when facilitating environmental factors are unavailable.

> “**We advocate for the meaningful involvement of people living with NCDs... so their lived experience is heard. I had to struggle to access healthcare and it took me nine years to get diagnosed. When I speak to health professionals and people in the government, then they understand there’s a lot of work to be done. If I don’t, who knows what will happen to the next person like me.”**
>
> Christopher Agbega, disability advocate for the Ghana NCD Alliance

Advancing disability inclusion can also benefit migrants, refugees, internally-displaced persons and asylum seekers in the context of conflicts or natural disasters. These populations very often experience similar barriers to those faced by persons with disabilities. Forced displacement often exacerbates the risk of violence, including sexual and domestic abuse, exploitation by family members, discrimination, and exclusion from health services. In contexts of forced displacement, persons with disabilities are more likely to be left behind in all aspects of humanitarian assistance due to a range of environmental barriers hindering access to health care, information, and human rights protection *(97)*. Persons with disabilities are often under-identified at reception, which negatively impacts their access to protection and assistance. Therefore, setting a disability-inclusive agenda within the health sector, which includes health emergency management, has multiple effects which not only can benefit populations of migrants and refugees and reduce the health inequities they face, but also support advancements in gender equality.


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Evidence shows that gender inequality contributes to poorer health outcomes for women and girls with disabilities; globally, they remain disadvantaged compared to men with disabilities in the social determinants of health, such as employment, education, and risk of violence *(98)*. Furthermore, women and girls disproportionately assume caregiving roles for persons with disabilities *(99–102)*, which has been linked to loss of opportunities *(103, 104)*, mental health concerns *(100, 105–107)*, and in some situations, an increased risk of violence for these groups *(104, 108)*. Addressing the contributing factors to health inequities for persons with disabilities will therefore facilitate advancements in gender equality – not only among persons with disabilities, but also within their wider support network. The opposite is also true: a firm focus on ensuring gender responsive and gender equitable approaches when meeting the needs of persons with disabilities, contributes to reducing the health inequities that they and their families experience. For example, confronting gender-based violence, abuse and marginalization is important to also improving health outcomes for women and girls with disabilities *(109)*.

1.6 Health equity and meaningful participation in society

Advancing health equity contributes to the wider participation of persons with disabilities in society. Having good health and well-being is important for people to build a good and meaningful life. Conversely, for persons with disabilities, a lack of access to health care on an equal basis as others hinders the realization of other fundamental rights, such as to education or employment. A study carried out in Nepal revealed that a major reason why children with disabilities do not go to school is because of poor health *(110)*. If persons with disabilities do not receive the required health services such as rehabilitation, including assistive products, they can be at a higher risk of exclusion from attending school, work and accessing livelihood opportunities, or participating in community life and society. Increased costs related to health care, personal care, equipment or other accommodations related to disability, can drive households further into poverty, thus also reducing opportunities to education or employment *(111)*. Advancing health equity for persons with disabilities can lead to larger societal benefits and facilitate the realization of other social and economic rights *(112)*.

Besides gains made at an individual level, addressing health inequities for persons with disabilities strengthens communities and society as a whole. The health of citizens contributes to a higher average level of education, a higher gross national product (GNP), higher productivity of workforce, and a more efficient economy *(113, 114)*. By addressing the health inequities of priority populations living in marginalized conditions, including persons with disabilities, a society can demonstrate its values and strengthen solidarity among the population, thereby creating equity in health.

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A fundamental factor for the meaningful participation of persons with disabilities in society is early childhood development which offers a critical window of opportunity to shape the trajectory of a child's holistic development and build a foundation for their future life. For children to achieve their full potential, they need different facilitators, ranging from good nutrition, protection from harm, opportunities for early learning, and the support of parents and caregivers, to access to timely and good quality health care. Investing in universal early identification systems such as newborn hearing screening, school-based eye care screening, and the early detection of congenital diseases, can impact the growth, development, and future prospects of children and their wider participation in society, as well as establishing a consistent life-course approach as part of UHC by ensuring good health care in the transitioning of different ages *(115, 116)*.

1.7 Health equity for persons with disabilities: an essential investment

The right to the highest attainable standard of health for persons with disabilities is a state obligation under which the health sector must take action to address health inequities that undermine the fulfillment of this right. As explained later in Chapter 2, persons with disabilities face a wide range of barriers to access health services. These barriers can often be associated with the health sector itself, but often lie outside the health sector, for example inaccessible transportation, or unequal educational and employment opportunities.

To demonstrate that the financial investment necessary to advance disability inclusion in the health sector is an investment with dividends, two published WHO-led cost-benefit analyses on NCDs and cancer prevention and control *(117,118)*, and a cost-effectiveness analysis on family planning and immunization *(119)*, for which there is evidence of lower access for persons with disabilities *(120-127)*, were adjusted to account for the higher costs of implementing the interventions in an way that would ensure accessibility to persons with disabilities. As there is currently very little information on the additional costs associated with making services accessible to persons with disabilities, a conservative assumption was made to increase the average cost of interventions with 10% to reach persons with disabilities. Full details on the methodology are described in Annex 4.

Results show that even if the average costs of interventions with a 95% coverage are increased by 10% to be delivered in a sustained disability-inclusive way, there is a good return on investment. For example, implementing cancer care with 10% increase in costs could bring an economic and societal return of nearly US$ 9 per US$ 1 spent. Similarly, there could be a return of nearly US$ 10 per US$ 1 spent in disability inclusive NCD prevention and care, assuming with a 10% increase in costs (See Boxes 5 and 6). In addition, family planning and vaccination interventions (*DPT, H. influenzae b, Pneumococcal, Rotavirus, Pentavalent DPT + Hep B + Hib, and Measles*) are cost-effective even when implemented with a 10% increase in costs (See Box 7).

Box 5

Return on investment for implementing disability inclusive cancer prevention and management interventions

A WHO-led study on prevention and management of cancer *(117)* was adapted to reflect an increase of 10% in the average cost of making services accessible to people with disability. Results show that investing US$ 1 on accessible cancer related interventions in low and middle-income countries could bring a return of US$ 8.7. In addition, we also explored only the gains in economic productivity. The results show that for every dollar invested, an economic return of US$ 2.1 could be expected (Table 1).

Table 1. Direct productivity related return on investment and return on investment

	Productivity related return on investment	Return on investment (economic and societal benefits)
Original study	US$ 2.3	US$ 9.5
Adjusted for accessibility*	US$ 2.1	US$ 8.7

** This scenario includes additional costs of making services accessible (+10%) for persons with disabilities.*

Box 6

Return on investment for implementing disability inclusive NCD prevention

The original study by Bertram et al. *(118)* was adapted to explore the economic and societal return on investment for making dietary, pharmaceutical and tobacco interventions for prevention of cardiovascular diseases with a 10% increase in average costs. Results show that return for every dollar invested could be US$ 9.9. This result suggests that even accounting for the 10% rise in costs to address barriers for those with disabilities, the return is still far more than the initial investment. If only economic gains are calculated the return on investment could be US$ 5.1 per every US$ 1 invested (Table 2).

Table 2. Productivity related return on investment and full return on investment

	Economic-only based return on investment	Economic and societal based return on investment
Original study	US$ 5.6	US$ 10.9
Adjusted for accessibility*	US$ 5.1	US$ 9.9

** This scenario includes additional costs of making services accessible (+10%) for persons with disabilities.*

Box 7

Cost-effectiveness of implementing disability inclusive immunization and family planning

The original analysis by Stenberg et al. for South East Asia and Sub Saharan Africa *(119)* was adapted to reflect additional 10% costs for removing the barriers for persons with disabilities in the delivery of interventions. Results show that family planning and vaccination interventions (*DPT, H. influenzae b, Pneumococcal, Rotavirus, Pentavalent DPT + Hep B + Hib, and Measles*) could be cost-effective when delivered in a disability inclusive manner. As shown in Table 3, the average cost-effectiveness ratios are marginally higher than in the original studies. For family planning, the average cost-effectiveness ratios are below I$ 1[11] in sub-Saharan Africa and between I$ 10–20 in South-East Asia, and vaccination ranges in the two regions, with the highest ratio being below I$ 1000.

Table 3. Cost-effectiveness for family planning and vaccination in sub- Saharan Africa and South-East Asian regions

Region	Intervention	General Population	Adjusted for accessibility with 10% increase in average costs
Sub Saharan Africa	Family planning	I$ 0.3	I$ 0.4
Sub Saharan Africa	Vaccination*	[I$ 10.1 – I$ 111.9]	[I$ 11.1 – I$ 123.1]
Southeast Asia	Family planning	I$ 11.2	I$ 12.4
Southeast Asia	Vaccination	[I$ 15.6 – I$ 557.1]	[I$ 17.1 – I$ 612.9]

** A range in cost-effectiveness ratio is provided for the six vaccination interventions included in the analysis.*

All ratios are in international dollars. An international dollar is an artificial currency used in economic analyses to eliminate purchasing power differences when comparing national economies.

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[11] International dollars

The returns of investing in disability inclusion presented above should be a strong argument for governments to advance health equity for persons with disabilities. These are the first analyses of its kind, and they place health equity as a key component in economic studies. When moving forward, there is an important question that needs further exploration by health economists: how considerations about equity of opportunity to access resources should be incorporated into quantitative analyses that are commonplace in health economics. Answers to this question can be facilitated by the implementation of a strong health policy and research agenda on disability inclusion, which is discussed in Chapter 3.

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2. Health inequities experienced by persons with disabilities, and their contributing factors

Personal story

Women with disabilities to give birth with dignity

"No, no, no! We don't want to take care of her!" These were the words that Coumba, from Dakar, Senegal, heard repeatedly when she sought care to deliver her baby. Four health centres refused her because her disability [polio from childhood] would make the delivery "too complicated".

She was finally referred to a hospital, where a midwife, without examining her, abruptly told her that she would be taken for a caesarean section. The midwife, Coumba said, equated disability with surgery. But a voice behind the midwife assured her: "I'm going to help you give birth in a regular way". It was a respectful health worker. The health worker later gave Coumba a bench so that she could climb onto the delivery bed, and then assisted her to give birth normally. An hour or so after the birth, a nurse came to move her, but did not help her off the bed. Coumba fell and started haemorrhaging. Two days later, she woke up in a resuscitation room. She was later told not to have another child.

Today, 22 years later, Coumba is an activist and town councillor striving to make health services more accessible for women with disability. "All these issues make women [with disability] scared to marry someone and get pregnant," she said. "Disabled people are afraid to go to the hospital. When they get sick, they stay at home, they take medicine bought in the street".

Coumba works with women's groups, the association of Senegalese midwives, female lawyers and community groups for her cause. "Health workers need better training on how to deal with people with disabilities," she said. "It's very important to communicate with disabled patients".

"Step by step, society will include people with disabilities. My dream is to make all delivery rooms accessible to disabled women... [and] to have medical staff [that are] both skilled and kind".

Photo: © Sightsavers/Sidy Camara

Overview

- ✓ Persons with disabilities face many health inequities: they die earlier, have poorer health and functioning, and are more affected by health emergencies than the general population.
- ✓ These inequities in health outcomes are unjust and largely cannot be explained in terms of the person's underlying health condition or impairment.
- ✓ Inequities arise from unfair conditions that affect persons with disabilities disproportionally and that are part of:
  - *Structural factors*: the socioeconomic and political context and the mechanisms that generate social stratification in society.
  - *Social determinants of health*: the conditions in which people are born, grow, live, work and age.
  - *Risk factors*: the factors associated with NCDs, including tobacco use, diet, alcohol consumption and amount of exercise; and environmental factors such as air pollution. The increased exposure to risk factors for persons with disabilities is due significantly to public health interventions often not being inclusive.
  - *Health systems*: the barriers across all building blocks – in service delivery, the health and care workforce, health information systems, and the financing and leadership of health systems.
- ✓ COVID-19 has uncovered structural, social and health system factors that drive health inequities for persons with disabilities. While these factors are prominent in other health emergencies, the unprecedented number of scientific publications relating to COVID-19 have helped unpack and better understand the contributing factors to health inequities experienced by persons with disabilities.
- ✓ The lessons learned from the COVID-19 pandemic can shape the way forward for achieving health equity for persons with disabilities. These include, for example, the importance of the provision of accessible health services close to where people live; the engagement and participation of persons with disabilities in the processes and decision-making of the health sector; and the delivery of public health interventions and information in an accessible format.

2.1 Health inequities faced by persons with disabilities

A wide range of differences in health outcomes exist between persons with disabilities and those without disabilities. Some of these differences are inequalities that can be explained by the underlying health conditions or impairments; however, others are associated with factors that are unjust or unfair. These factors align with the contextual factors of a person's environment, as described in the ICF and the description of disability in the CRPD.

Inequities are unacceptable and largely avoidable and, as introduced in Chapter 1, it is a state obligation to address them. Inequities for persons with disabilities exist in all three health outcomes: premature mortality, increased morbidity, and increased functioning limitations.

2.1.1 Mortality

Persons with disabilities have higher rates of premature mortality compared to persons without disabilities. For example, in persons with psychosocial disabilities in high-income countries, the mortality gap is 20 years for men, and 15 years for women *(1)*. In the United Kingdom of Great Britain and Northern Ireland, the crude annual death rate for persons with intellectual disabilities is double that of the general population *(2)*. The inequities in mortality of persons with intellectual disabilities are evident across all life stages: children are eight times more likely to die before the age of 17 years *(3)*, and in the older age range, more persons with intellectual and developmental disabilities die within 30 days of hospitalization than those without disabilities *(4)*. A major factor for the elevated levels of mortality is often poor quality health services *(2)*. For those with spinal injury, for example, the in-hospital mortality rate is nearly three times higher in low- and middle-income countries than in high-income countries *(5)*. Other factors that influence the levels of mortality are country and individual income. For persons with spinal cord injury, an increase of one standard deviation in the GDP of a country is associated with an increase of 5.5 years of life, whereas an increase of individual-level income is associated with an additional 0.5 years of life *(6)*. If, on average, persons with spinal cord injury in Romania live 10.8 years after an accident, those in Switzerland, live on average 26 years *(6)*.

Wider evidence on inequities in mortality is limited. Factors contributing to the inequity are frequently not well captured, making it difficult sometimes to explore the drivers of differences in mortality and whether these differences are indeed due to unjust or unfair factors. The collection of data on disability is often deprioritized in many countries, consequently the evidence of health inequities and their contributing factors is more limited than for other groups in marginalized situations. However, lack of evidence should not be interpreted as a lack of inequities. Evidence is often biased towards specific groups such as persons with intellectual disabilities, because investments for research largely concentrate on these groups. Furthermore, quality data are scarce, and the available evidence comes from a limited number of countries.

2.1.2 Morbidity

The health inequities in morbidity faced by persons with disabilities manifest in the higher rates of comorbid health conditions in persons with disabilities compared to those without disabilities. Evidence for this originates from a limited number of countries and focuses primarily on intellectual disabilities.

A higher incidence of communicable and noncommunicable diseases is found in persons with disabilities compared to persons without disabilities. This includes conditions such as tuberculosis, diabetes, stroke, sexually transmitted infections or cardiovascular problems *(7–12)*. A major factor for the increased morbidity among persons with disabilities is their limited or delayed access to health services. As regards comorbid health conditions, the differences in prevalence between persons with and without disabilities continue into older age *(13)*, and apply also to women's health issues. For example, more women with physical (32.9%), sensory (30%), intellectual (48.8%), or multiple (42%) impairments have a postpartum emergency visit compared to those without these impairments (23.5%) *(14)*.

Persons with disabilities have an increased risk for developing mental health conditions and often rate their mental health as being worse than those without disabilities. There is an increased diagnosis of mental health conditions such as depression or anxiety compared to individuals without disabilities *(7, 9, 11, 15–18)*; those with severe disabilities have a 2.5-fold higher likelihood of having depression *(19)*.

In addition, persons with disabilities have poorer oral health compared to persons without disabilities and present with systematically higher levels of untreated dental disease and higher levels of dental extractions rather than restorative treatment *(20, 21)*. Persons with psychosocial disabilities are three times more likely to have edentulous status, whereas this risk is even higher (at four times more likely) among those with multiple impairments *(22)*. Alongside poorer socioeconomic status among persons with disabilities, another important factor for the increased risk of poor oral health is the sometimes limited ability of their caregivers or health professionals to provide a proper diagnosis *(23)*.

In persons with intellectual disabilities, the rates of a range of secondary chronic conditions are higher than those without intellectual disabilities. These conditions may include thyroid dysfunction *(24)*, viral or infective diseases, neurological disorders, blood diseases, dental disease, decayed teeth and caries, eye diseases, respiratory system diseases, digestive system diseases, epilepsy, skin diseases, or diseases of the genitourinary system *(16) (3, 4, 14, 17, 21, 24–30)*. Similarly, adults with intellectual disabilities have higher rates of diabetes, asthma, arthritis, cardiac disease, hypertension, and mental health conditions *(4, 25, 31–35)*. These differences are visible from a very early age, since children with developmental disabilities are three times more likely to have diabetes *(3)*, and have higher rates of injury-related hospitalization, than children without disabilities *(17)*. Adolescents with intellectual disabilities are 1.5 and 1.8 times more at risk of overweight–obesity and obesity than adolescents without intellectual disabilities *(36)*.

2.1.3 Functioning

Persons with disabilities experience higher levels of functioning limitations due to barriers in the environment. Data from the WHO Model Disability Survey (MDS)[12] conducted in 11 countries, showcases that for persons with disabilities, various environmental factors appear to be hindering and limiting their functioning, especially in terms of day-to-day activities and participation in society, more than for those without disabilities. A brief snapshot of the available evidence shows that inaccessible health facilities are a factor affecting a larger proportion (up to six times greater) of persons with disabilities compared to those without disabilities. Non-existent, inaccessible or unaffordable transportation limits persons with disabilities up to 15 times more than the general population. Similar numbers can be seen for other factors, such as places to socialize that make it hard for persons with disabilities to engage in this activity, or joining community activities, where a striking 25-fold difference can be seen in some countries. Data show that women are more likely to experience limitations in functioning than men.

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[12] https://www.who.int/activities/collection-of-data-on-disability (some data are unpublished)

2.2 Contributing factors to health inequities for persons with disabilities

The mechanisms which cause health inequities are complex and "inescapably multidimensional" *(37)*. A range of factors, including structural factors, social determinants, risk factors, and the health system itself, all contribute to health inequities for persons with disabilities.

Structural factors include the socioeconomic and political context and the structural mechanisms that generate social stratification in society *(37)*. For the purposes of this report, this chapter considers structural factors that relate to the health sector, including cultural and societal values that manifest in ableism, stigmatization and discrimination against persons with disabilities, inequitable policies and processes, and governance and accountability.

Social determinants of health are the conditions in which people are born, grow, live, work and age *(38)*. There is a well-established link between several socioeconomic factors and health inequities *(39, 40)*. For the purposes of this report, the following interdependent social determinants which contribute to health inequity for persons with disabilities are explored: poverty; employment; education; added cost of living; poor living conditions and food insecurity; transportation; violence; climate impact, and a range of intersecting factors such as gender. Many determinants of health lie beyond the health sector; addressing them requires a multisectoral response.

Risk factors can include tobacco use, diet, alcohol consumption and amount of exercise, all of which are associated with NCDs, as well as environmental risk factors such as air pollution. Importantly, these factors are often the result of socioeconomic circumstances in which a person is born, lives and works, or they are due to exclusion in wider health activities such as public health interventions (e.g. campaigns for reducing tobacco use).

Health system characteristics are also a contributing factor to health inequities. The gaps and barriers across all building blocks – for example in service delivery, the health and care workforce, health information systems, and the financing and leadership of health systems – affect persons with disabilities and their families. In line with the conceptual framework of the social determinants of health *(37)*, the governance function of health systems (including accountability and policies) is considered under structural factors.

It is important to note that whereas all these factors affect the general population negatively, there is an incremental negative effect in persons with disabilities. For example, poverty is associated with poorer health across all populations; however, the additional costs of health care associated with disability can affect the financial state of individuals with disabilities more severely. In addition, all four categories of contributing factors are interdependent, feeding into and reinforcing each other, creating vicious cycles of poverty, exclusion, and poor health. Because persons with disabilities are less likely to access education and employment, they are more likely than those without disabilities to live in poverty; this in turn leads to poor living conditions, adds to their exposure to "health-damaging" conditions *(37)*, and ultimately increases their vulnerability to negative health outcomes.

The socioeconomic position of persons with disabilities also affects their access to, and control over, material resources, which is linked to differential access to health services. As such, addressing the contributing factors to health inequities faced by persons with disabilities requires "deliberate multi-layered analysis to understand, and innovative intersectoral and participatory solutions to tackle" *(37)*. The next sections present the available evidence on each of the four groups of contributing factors.

2.2.1 Structural factors

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Cultural and societal values that manifest in stigma and discrimination

> **When I became disabled my family disowned me. They were ashamed of me, which made me ashamed of myself. I lost all of my self-esteem, I felt like I had no value in my family or my community. Everyone abandoned me, and why? Because I was walking with a crutch? It didn't seem fair. They no longer saw me as a person who could be successful…" *(41)***
>
> Diane from Burundi, who works for an International Rescue Committee programme

Different cultural and societal values often manifest in ableism, stigmatization, and discrimination towards persons with disabilities in all facets of life. Ableism is a social prejudice that defines persons with disabilities by their disabilities and characterizes them as being inferior to those who do not have disabilities *(42)*. Conscious or unconscious ableism may be embedded in institutions, systems or the broader culture of a society and can limit the opportunities of persons with disabilities, reducing their inclusion in the health sector and communities *(43, 44)*. An "ableist" belief system that devalues and limits the potential of persons with disabilities often underlies negative attitudes, stigmatization and stereotyping towards them.

Compared to the general population, persons with disabilities are significantly more likely to experience stigmatizing behaviours and discrimination in the context of health *(45, 46)*. At the community level, the negative attitudes of community members can discourage health-seeking behaviours of persons with disabilities and their families. For example, the lack of community awareness on disability *(47–51)*, negative and discriminatory societal attitudes *(50–66)*, including stigmatization among family members *(51, 52, 54, 55, 58, 60, 62–64, 67–71)*, can lead to persons with disabilities being prevented from, or delayed in, accessing health care *(52, 71)*. Stigmatization can also lead to the abandonment of individuals with disabilities by families in inpatient facilities *(62)*, the uptake of traditional or alternative services against their will *(64)*, delayed diagnosis and care *(72)*, or hindered access to health care *(51, 54–56, 68, 73, 74)*. Very often, wider societal stigmatization leads to internalized stigmatization *(47, 50, 51, 64, 71, 75–80)*.

Persons with disabilities may have concerns about overburdening their family when accessing health care *(74)*, or have feelings of shame related to specific services, such as sexual and reproductive health, or mental health *(74, 75)* – both of which add to delayed seeking of, and access to care *(52, 55, 65, 68, 71, 78)*. Discrimination can be seen at a structural level through discriminatory policies and laws, as well as at an interpersonal level by health and care professionals. A wider discussion on both aspects of discrimination is provided later in this chapter.

Societal stigmatization and discrimination are further exacerbated at the intersection with gender in relation to the health care of women and girls with disabilities *(54, 57, 81)*. Women and girls with disabilities may be discouraged by their families from participating in community-based public health interventions *(82)*. This highlights the importance of considering and addressing wider social norms when designing health programmes and activities for persons with disabilities. Even though historically women are among the more disadvantaged groups, gender norms, roles and expectations can also have a negative impact on men, or people of diverse sexual orientation and gender identity.

Stigmatization and discrimination can directly or indirectly contribute to health inequities for persons with disabilities. Societal stigmatization and discrimination have been directly linked with increased suicidality, especially among persons with psychosocial disabilities *(83)*. Stigmatizing practices can also lead indirectly to increased mortality, morbidity and functioning limitations among persons with disabilities through delayed seeking of health care, hindered access to services, or even through discriminatory attitudes by health and care professionals *(51, 54–56, 68, 72–74)*. For example, for persons with albinism, deeply-rooted beliefs, myths and misconceptions about the condition can lead to stigmatization and discrimination, which can result in poverty and ultimately an increased risk of skin cancer and death *(84)*.

Examples of interventions that have been implemented to address stigmatization and discrimination include awareness raising initiatives and disability sensitization training for stakeholders *(85, 86)*, as well as wider social marketing campaigns (see Box 8) *(87, 88)*. There are also examples of disability-inclusive interventions led by civil society, particularly on sexual and reproductive health and rights, such as the Women's Integrated Sexual Health Access, Choice, Together, Innovation and Ownership, Now (WISH2ACTION) programme implemented in lower-income settings *(89)*. Very few of the interventions, however, have been evaluated for their effectiveness, and even fewer have been scaled up to institutional and societal levels.

Box 8

Time to Change

The Time to Change initiative was launched in England to improve public attitudes and tackle discriminatory behaviours against persons with mental health conditions *(90)*. One component of the initiative was the anti-stigmatization social marketing campaign that aimed to engage the public through media channels, calls to action, and active participation in mass social events. The campaign was developed by different stakeholders, including service users and people with experience of mental health conditions. Time to Change was found to be a potentially cost–effective and low-cost intervention for reducing the impact of stigmatization on people with psychosocial disabilities *(91)*. Evaluation of the campaign demonstrated that awareness and knowledge of Time to Change among the public, and an increase in the quantity and quality of social contacts with persons with psychosocial disabilities, led to better knowledge, attitudes, and intended behaviours. Furthermore, the evaluation found a significant increase in articles that were anti-stigmatizing, a decrease in articles that were stigmatizing, and an increased likelihood of people with psychosocial disabilities being quoted in the media *(92)*. Consequent analyses and evaluations of this and other anti-stigmatization campaigns highlighted the need to give attention to public understandings of mental distress, social inequalities, and power imbalances when implementing campaigns at the population level *(93)*.

Policies and processes

The lack of inclusive policies and processes very often disadvantage persons with disabilities. When policies and laws do not align with the CRPD, they can fundamentally undermine the rights of this group of people. For example, persons with autism, or intellectual or psychosocial disabilities, can be denied their rights to legal capacity, freedom from torture, violence exploitation and abuse, as well as the right to live independently and be included in the community. The risk is even greater for those living in institutions *(94)*. The violations of the rights of individuals are facilitated through provisions that allow involuntary admission and treatment, seclusion and restraint, and institutionalization, all of which can impact negatively on a person's health *(95)*. In extreme cases, persons with disabilities may be subject to forced sterilization. Research demonstrates that persons with disabilities, mostly women and girls, are sterilized for two principal reasons: prejudiced beliefs that they cannot and should not raise children; and as a precaution against unintended pregnancies from perceived inevitable sexual abuse *(96)*.

Policies can sometimes permit the transfer to a guardian of the authority to make decisions concerning the lives of persons with psychosocial and intellectual disabilities *(97)*. A guardian can make decisions in all areas of life: what treatment the person receives; where the person lives and with whom; the management of their personal finances; and other aspects of their daily life *(98)*. These decisions are often based on what is deemed to be in the "best interests" of persons with disabilities (i.e. what others think is the best decision or course of action) and not on the will and preferences of the person concerned *(99, 100)*. This extensive resort to approaches of substitute decision-making has been shown to have harmful effects on persons with disabilities, including a lowering of their self-esteem, and an increase in passive behaviours. Concerns have been raised regarding the potential abuses of power by those appointed as guardians *(101)*; nevertheless, the implementation of substitute decision-making models is rising, as is the use of coercive practices linked to the denial of legal capacity, such as involuntary detentions and mandatory treatments, even within well-resourced health-care systems *(102)*.

Other common examples of non-inclusive policies are the social protection mechanisms in many low- and middle-income countries. Persons with disabilities are frequently not included in social protection schemes, and even when they are, they may encounter barriers to accessing them. Some of these schemes, such as those launched in response to COVID-19, fail to consider the added costs relating to disability, such as health care, personal care, and other costs *(103–105)*. Other barriers include requirements to apply in person; inaccessible information and communications; lack of accessible and available transportation; not having a bank account; difficulty communicating with staff; or the existence of a low-income cut-off point – all of which can result in many persons with disabilities being left behind *(103, 106–108)*. In addition, persons with disabilities often experience considerable difficulties navigating complicated bureaucratic systems to access health insurance and disability funding *(56, 109–111)*.

Unjust policies and processes in the health sector contribute to the persistence of health inequities experienced by persons with disabilities. Discriminatory or non-inclusive policies are very often factors that contribute to delayed care *(109)*, a lack of available and affordable health services *(112)*, and reduced quality of care *(61, 109, 113–116)*. Furthermore, some health policies and processes, particularly those established in pandemic responses, may lead to actions which inadvertently disadvantage persons with disabilities, adding to the risks they experience *(117, 118)*. All these factors increase the probability of worsened health outcomes. In addition, other sectors may establish public policies to reduce specific exposure to health damaging factors (e.g. improving conditions related to housing, water and sanitation, work, security, public spaces, restricting sales of tobacco and alcohol, food security, or elimination of environmental pollutants); these policies may not be inclusive and frequently do not reach persons with disabilities *(119, 120)*.

Examples exist of policy approaches that aim to advance health equity for persons with disabilities. The Government of Australia released the *National roadmap for improving the health of people with intellectual disability* to address serious health inequities faced by persons with intellectual disabilities *(121)*. The roadmap aims to improve support for persons with intellectual disabilities, their families and carers, develop better models of care, support health and care workers to deliver quality care for persons with intellectual disabilities, improve their oral health, and ensure that their needs are considered and met in emergency plans and responses. The roadmap was developed in close consultation with persons with intellectual disabilities, family members and carers.

Governance and accountability

Discrepancies often occur between the adoption of the CRPD and implementation of the convention through compliant disability legislation or guidelines in countries. One reason for this may be that when implementing the CRPD, an accountability mechanism with proper monitoring and enforcement is not put in place *(122–125)*. This can lead to a lack of compliance with existing legislation or health service guidance, including those relating to disability allowances, clinical protocols and reasonable accommodation in clinics, hospitals, and other health services *(123–126)*. In addition, limited accountability can be associated with acts of violence and abuse against persons with disabilities in health-care settings that are not properly reported or addressed *(127)*.

Persons with disabilities and their representative organizations are good sources to hold the health sector accountable for the implementation of disability policies. However, they are generally not engaged in governance processes, such as health sector planning, programme development and implementation. For example, women and girls with disabilities are rarely consulted on issues such as maternal and child health *(128)* and wider sexual and reproductive health and rights *(129)*. Persons with intellectual disabilities are often excluded from consultation processes due to negative assumptions about their capacity to contribute *(130)*. Even when community groups are created with representation from persons with disabilities, they express concerns that when asked, their inputs are not fully considered by implementers *(131–133)*.

> **“Rules are being made without taking into consideration the perspective of persons with disabilities. This makes societies unequal and unfair” *(134)***
>
> Melokuhle, wheelchair user from South Africa

There are examples of initiatives that have actively involved persons with disabilities and civil society organizations in their design and implementation. Studies on disability inclusion in water, sanitation and hygiene (WASH) activities in low- and middle-income countries have incorporated training for WASH stakeholders at all levels, designed and delivered by persons with disabilities *(119, 135, 136)*. Persons with disabilities have also been integral to decision-making processes and involved in the planning, funding, design, management, and monitoring of new WASH facilities. Local organizations of persons with disabilities have appointed focal persons in each region who receive appropriate training and capacity-building. At the grass-roots level, in the absence of local organizations, project implementers have worked with persons with disabilities living in the area to find positive role models and make visible the practical problems faced by some in their daily lives *(132, 133)*.

2.2.2 Social determinants

Personal story

Fighting a dearth of information with a foundation for parents

Nguyen Phuong Ha, a biology researcher, set up the Cerebral Palsy Family Association in Viet Nam, to provide support and information for parents of children with cerebral palsy (CP).

"My daughter Pika was born premature. I felt right away something was wrong. She was not responsive. I took her to many doctors, but I didn't get a diagnosis. I researched many things. I began to suspect she had CP. At 11 months, I told the doctor that she had CP. He agreed. There was no information on CP then in Viet Nam".

"In 2014, I decided to go overseas with my daughter to learn more. I found there were many systems to support parents – equipment, therapy, information. I learnt a lot. Because I didn't get any support or information in Viet Nam, I thought that I could help other parents, so I started the "Superhero Family Club" group on Facebook. Within two weeks, it had 200 members. It became a community for parents".

"I learnt English by myself because of my daughter. I went to YouTube. I read a lot. Now I can read documents very fast. I translate this information into Vietnamese for parents. We have 3000 members now and 1000 volunteers, who provide all kinds of support for the children. We work with doctors and I am now a spokesperson on CP".

"My daughter has severe CP. I found no school for her. So I decided to start a special education class for children with CP. At the hospital, I was told that children with CP cry a lot, but in our class, the children do not cry. My daughter is very happy there – she's 10 now and very talkative! The parents are happy too. It is just amazing, I planted a small seed and now the tree has grown up".

Photo: © Nguyen Phuong Ha

Poverty and added costs

Already more likely to live in poverty, persons with disabilities and their households also carry extra costs associated with disability. A higher proportion of persons with disabilities (in some countries double) compared to those without disabilities live under the national or international poverty line *(137)*. In the United States of America, for example, nearly 50% of adults with disabilities are living in or near poverty levels, compared to 28% of those without disabilities *(138)*. The additional costs of living associated with disability *(139)* represent an increase of around a third of the average income for those with moderate disability, and by more than 40% of an average income for those with significant disability *(137)*. These include costs associated with health care, housing, transportation, personal assistance, and assistive products. When broken down into different groups, persons with cognitive impairments and persons with physical impairments have up to five times more medical expenditures than those without disabilities *(140)*.

> **The cost of registration at a nearby privately-owned hospital is [too] much, so I have to travel a long distance to the state hospital because it is cheaper there, but I still have to take an interpreter with me to every antenatal visit. So, the additional cost of [a] sign language interpreter, transportation, ultrasound scans, and all other requirements for antenatal registration is too much for me" *(141)*.**
>
> Deaf woman, 27 years, Nigeria

Higher health-care costs deepen health inequities for persons with disabilities. Because of these higher costs, persons with disabilities experience clear unmet needs for health services *(142)*; reduced access to timely care and support *(13, 25, 52, 55, 68, 110, 140, 142, 143)*; interrupted treatment *(52, 53, 75)*; inability to pay for necessary devices or delayed repairs *(52, 53, 143)*; and stress and increased reliance on support from family members *(57, 110)*. All these factors have an inevitable negative effect on their health resulting in increased mortality and morbidity, and decreased functioning.

The strategy most commonly used in countries to address poverty and additional health-care costs for persons with disabilities is social protection. Social protection is effective in reducing the vulnerability experienced by persons with disabilities, improving health status, and supporting economic empowerment and participation. Even though some countries may provide some level of financial benefits to persons with disabilities, either through specific disability-targeted programmes, or more commonly through general social protection mechanisms, most low- and middle-income countries are far from providing disability-inclusive social protection. Recent estimates from the International Labour Organization show that, globally, only one third of persons with severe disabilities receive a disability benefit. Substantial regional variation is reported; while coverage of social protection in eastern Europe appears to be almost universal, estimates for Southern Asia and sub-Saharan Africa show a coverage rate of below 7%. Coverage in high-income countries is 85.6%, compared to 11.3% in lower-middle-income countries and 8.6% in low-income countries *(144)*. The reach of these mechanisms varies across countries; some intend to cover all persons with disabilities, whereas others target specific groups only, such as children with disabilities *(145)*. Inclusive social protection for persons with disabilities entails not only providing income security but supporting participation and inclusion in social and economic life.

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Education and employment levels

The lower socioeconomic status of persons with disabilities is evidenced through widespread disparities in the rates of education and employment. Data from UNICEF reveal that globally one in three children with disabilities are not attending school, compared with one in seven children without disabilities. More specifically, children with disabilities at different ages are 25% less likely to attend early childhood education; 16% less likely to read or be read to at home; 42% less likely to have foundational reading and numeracy skills; 49% more likely to have never attended school; and 47% more likely to not attend primary school *(146)*. As such, it is unsurprising that adults with disabilities have low literacy rates *(137)*, which is one of many factors hindering access to health information, tools, and resources. These disparities extend to all levels of the educational system *(10, 32, 147)*, affecting longer-term employment and opportunities to generate income.

Similar trends can be seen in for employment. In many countries, the rates of unemployment for persons with disabilities are higher than for those without disabilities, and the employment-to-population ratio is, on average, almost twice less for persons without disabilities *(9, 137, 138, 148, 149)*. In addition, in all regions, women with disabilities are less likely to be employed than men with disabilities or persons without disabilities. The employment-to-population ratios for women with disabilities are lowest in northern Africa and western Asia (14%), where women are five times less likely to be employed as men without disabilities *(137)*.

The links between health inequities and lower educational and employment levels are well established. Lack of education and unemployment are associated with lower life expectancy at birth and premature mortality *(150)*. Lower levels of education are also directly linked with lower health literacy. This leads to poor vaccination rates of children or unhealthy behaviours among adults, thus compromising their life expectancy and health outcomes *(151)*.

Countries have adopted different strategies to address the disparities and make educational environments and workplaces more inclusive. An educational system inclusive of children and young persons with disabilities is a vehicle to achieving SDG Goal 4; the provision of support is fundamental to ensuring a transition to inclusive tertiary education and employment *(152)*. An example of an inclusive educational strategy is the creation of disability inclusive community-based schools to ensure that children with disabilities living in rural areas receive education *(153)*. In the classroom, ensuring diversity of seating options such as floor pillows, seats and ball seats that fit various body sizes and shapes has made learning environments more inclusive. Educating teachers on how to incorporate universal design and other inclusive principles into the classroom can make educational environments enabling for all students *(154)*. In the workplace, it has been shown that even the smallest accommodations such as buying equipment and changing work schedules lead to substantial benefits for both persons with disabilities and employers *(155)*. Nonetheless, despite these examples of practices, there is little evidence of their effectiveness and upscaling at national level.

Living conditions

Several factors contribute to the poorer living conditions of persons with disabilities compared to persons without disabilities. Inadequate housing is a principal factor. In many countries, levels of access to managed water supplies and electricity and decent housing conditions are lower for persons with disabilities and their households than persons without disabilities *(137, 156, 157)*. In addition, a disproportionate number of persons with disabilities have no accommodation and are homeless *(158)*, and evidence shows that an estimated 30% of this homeless population have psychosocial disabilities *(159)*. Rates of homelessness among persons with intellectual disabilities ranges from 10% to 40%, with men more likely to become homeless at an older age than women *(160)*. Lack of community-based housing options for persons with disabilities (in particular persons with psychosocial, intellectual and cognitive disabilities) contributes to their institutionalization which is associated with human rights violations and poor health outcomes *(161)*. Very often deinstitutionalization can contribute to homelessness among persons with disabilities, if conducted without a smooth, regulated and systematic process, appropriate support, or access to affordable accommodation *(159)*. For example, in Gauteng, South Africa in 2017 at least 144 people died – including from starvation and neglect – after being discharged from hospitals to underfunded and underskilled community care as part of a rushed and poorly planned programme to deinstitutionalize mental health care *(161)*.

Many persons with disabilities live in institutions. Data from low- and middle-income countries indicate that 4–15% of persons with disabilities currently live in institutions or special homes *(137)*. Persons with disabilities frequently enter these institutions as children or adolescents – at times against the expressed wishes of their parents *(162, 163)* – and remain for their entire lives. The living conditions of institutional settings are often inadequate, with unregulated or poor-quality services being provided *(164)*. Persons with autism or learning disabilities can experience intolerable treatment in institutions and inpatient facilities; they may be subject to abusive restrictive practices, detained for long periods of time in facilities that do not meet their needs, or kept long distances away from their families and friends *(165)*. In many countries, the health care of individuals with psychosocial disabilities is still predominantly provided in psychiatric or social care institutions *(166, 167)*, where these individuals are often exposed to a wide range of human rights violations, including forced treatment and coercive practices, and psychological, physical, and sexual abuses or violence *(168, 169)*. Even where living conditions in institutions are adequate, these settings can contribute to loneliness and isolation from families and exclusion from the community *(147)*.

Social isolation and loneliness associated with the place to live are a strong determinant of poor health and well-being in persons with disabilities. Compared to the general population, persons with disability have fewer friends, less social support and are more socially isolated *(170–173)*. The place to live has an enormous impact on the levels of isolation and loneliness. Alongside other important factors such as unemployment, the type of accommodation, living alone or having low levels of access to environmental assets contribute to the higher rates of loneliness among persons with disabilities *(174, 175)*. A large nationwide survey conducted in Germany demonstrated that living in institutions is associated with lower levels of satisfaction compared to living in private households *(147)*; conversely, living in the community have a positive effect for persons with disabilities in terms of social connectedness.

Finally, household food insecurity has a disproportionate impact on the living conditions of persons with disabilities *(176)*. A far larger percentage of households of persons with disabilities "do not always have food to eat" compared to households without persons with disabilities *(137)*. UNICEF data show that children with disabilities are 34% more likely to be stunted and 25% more likely to be wasted compared to their peers without disabilities; stunting and underweight are more prevalent among those living in the poorest and rural households *(146)*. Risk of household food insecurity predominantly results from reduced financial resources or high household expenses *(177)*. However, while persons with disabilities are more likely to experience food insecurity and report not being able to access food *(178)*, they still face challenges in enrolling in food and nutrition assistance programmes *(179, 180)*.

Poor living conditions contribute to negative health outcomes among persons with disabilities. Homelessness is directly linked to poor quality health care and follow-up among persons with psychosocial disabilities, thus negatively affecting their health *(61, 181)*. In food security emergencies, children with disabilities have poorer health outcomes, including being underweight, having stunted growth and a lower body mass index that those without disabilities *(182)*. In long-term care facilities, poor living conditions can be directly linked to high mortality among persons with disabilities, especially during health emergencies *(183)*.

Even though evidence is scarce, examples exist of public interventions to address the poor living conditions of persons with disabilities. One such example is in Rwanda where there is a demobilization and reintegration commission housing scheme for ex-combatants with disabilities *(184)*. This governmental programme, supported by the World Bank and Multi-donor Trust Funds, instigated the building of hundreds of residential houses and provided a monthly stipend to cover the costs of basic needs for those eligible. The housing units were designed with the support of international disability experts and standards for accessibility and reconstruction *(185)*, based on low-cost housing design. As a result, the beneficiaries of the programme recognized the improvement in their living conditions. The model adopted in Rwanda was later implemented in Burundi.

Transportation

The lack of available or accessible transportation represents an additional barrier for persons with disabilities to access health services. Factors such as unavailability or unreliability *(47, 52–54, 67, 75, 76, 109, 142, 143, 147, 186–192)*, lack of accommodation *(54, 76, 193, 194)* or costs of transportation, hinder the access to health services for persons with disabilities *(47, 52, 54–57, 67, 68, 75, 109, 112, 186, 190, 193, 195–198)*. High costs can be prohibitive for persons with disabilities when accessing services, as they may have to pay for more expensive modes of transportation, such as taxis or the hiring of specialized vehicles *(57)*, cover transport fares for caregivers and support people *(196, 197)*, or be charged additional fees for wheelchair use *(198)*. Other barriers related to time constraints affect every person but present an incremental burden for persons with disabilities unique to their impairments. *(189, 199)*. Persons with disabilities may also experience discrimination and safety concerns when travelling to health facilities; parents of children with intellectual disabilities, for example, have reported that public transport is unsafe due to the risk of violence *(186)*. In addition to health services, inaccessible transportation can also hinder access of persons with disabilities to necessities such as food, water, or sanitation *(157)*.

> **Buses don’t stop if they see you are in a wheelchair because they say you waste too much time... There is only one accessible bus but it’s far away from my house and the way to get there is not accessible”.**
>
> Angelica, 25, Venezuelan refugee living in a rural area
> of Santander department, Colombia ***(200)***

These transportation barriers have been linked to poorer health outcomes for persons with disabilities. Delayed access to care *(110)*, reduced attendance to health care appointments *(67)*, or increased dependence on caregivers and other family members *(47, 52, 75, 112, 201)* have all been associated with worse health outcomes in terms of morbidity and functioning. Complex or multistep transportation services can be limiting to use for persons with cognitive impairments and can also result in a far lower percentage of women with a learning disability being screened for breast cancer compared to women without a learning disability *(202)*.

Evidence is limited on effective interventions to address transportation barriers to health care for persons with disabilities, and mostly focuses on the provision of financial support to overcome added costs. In Tanzania, an intervention called “TransportMYpatient” utilized mobile phone technology to transfer funds covering transport costs for persons with obstetric fistulae or with cleft lip or palate. The transportMYpatient initiative saw a 65% increase in the number of fistulae repairs performed in 2010 (203). Making transportation accessible to everyone – as is often the case in high-income countries – improves access but does not substitute the need for more targeted interventions for certain populations.

Violence

Persons with disabilities are 1.5 times at greater risk of violence than persons without disabilities. The risks are even higher for persons with intellectual or psychosocial disabilities *(204, 205)*. In low-income countries, one in five persons with disabilities has been physically or verbally abused because of their disability *(32, 137)*; similar trends are also seen in high-income countries. The latest report by the U.S. Bureau of Justice Statistics showed that persons with disabilities were victims of 26% of all nonfatal violent crime; the rate of violent victimization against them was 4 times the rate for persons without disabilities, with one in three robbery victims being a person with a disability *(206)*. Persons with disabilities who live in health and social care settings, particularly older persons and those with psychosocial and intellectual disabilities, may also experience neglect, physical and mental abuse, and sexual violence *(127, 207, 208)*.

Women and children with disabilities are at higher risk of violence. For example, nearly one in three women will experience physical or sexual violence in their lifetime *(209)*, with women with disabilities being 2–4 times more likely to experience intimate partner violence than those without disabilities *(210)*. Worldwide, one in six older women experience abuse, with disability being a major risk factor *(211)*. In some conflict-affected contexts, the proportion of women with disabilities reporting experiencing physical or sexual intimate partner violence is as high as 85% *(212)*. Furthermore, forced sterilization of women and girls with disabilities is a practice often legitimized through claims of "medical necessity" or "best interests" in the health sector when in the framework of human rights, it is an act of violence *(96, 127, 207, 213, 214)*. Children with disabilities also experience higher levels of violence than children without disabilities (a nearly three-fold increased risk) *(215, 216)*, including higher rates of sexual violence *(205)*. This risk is highest among children from socioeconomically disadvantaged groups *(217)* or in displacement and refugee settings *(218)*. There is also evidence that 37% of poorer mental health in adolescents with disabilities is explained by exposure to peer-bullying *(219)*.

> **I have 'attacks' ['crises' in French] – and people take advantage of me during these attacks. This is when men come to rape me – I don't know any of the fathers of my children."** ***(220)***
>
> Refugee woman with disability, Burundi

There is a clear link between violence, poorer health and increased mortality among persons with disabilities. Victims of violence often experience injuries or sexually transmitted diseases that cause their health to deteriorate. With these situations, women with disabilities, often are less likely to disclose violence or seek healthcare or help. This can be due to different factors: women with disabilities can be unaware that they are being abused or experiencing ill treatment; they may be dependent on the perpetrator, or fear losing their partner or children; they may fear discrimination and stigmatization by family members, service providers and the wider community, or fear institutionalization. Furthermore, there may be a lack of screening for violence, or lack of access to information on prevention or protection services; or they may not be aware of their rights and the laws for their protection. Women with disabilities also face a range of physical, resource and attitudinal barriers when they do seek support, including not being listened to or believed when disclosing their experience *(220, 221)*. Not accessing health care can often lead to worsened health outcomes including contemplated or attempted suicide *(222)*. They may experience post-traumatic stress following the act of violence; care for this condition is often hindered by the lack of accessibility to diagnostic tools; it may go unrecognized by health-care professionals and therefore not be addressed *(223)*.

Many of the interventions to prevent abuse or violence against women with disabilities lack evaluation of effectiveness. Generally, they focus on awareness and skills-building, and are primarily designed for women with intellectual disabilities, their support persons and service providers. The programmes aim to increase awareness of abuse, educate participants on how to avoid dangerous situations, provide safety promoting information, and increase empowerment and self-determination *(221)*. However, without proper evaluation, there is no robust evidence that these interventions impact the incidence or perpetration of violence against women and girls with disabilities.

Climate impact

Hazards related to climate change exacerbate the vulnerabilities of persons with disabilities. During climate-driven disasters persons with disabilities may be less able to escape from hazards, lose essential medications or assistive products such as spectacles or prostheses, be left behind when a community is forced to evacuate, or experience greater difficulty accessing basic needs, including food, water, shelter, and health services *(224)*. Recent findings from Kiribati, Solomon Islands and Tuvalu showed that following disaster events, such as cyclones, floods, king tides, and severe storms, persons with disabilities can face additional barriers in migration, such as not being granted visas, not being allowed to cross borders, and barriers in enrolling in social protection programmes or health care *(225)*. In addition, following an event, persons with disabilities often tend to encounter greater difficulty in securing additional resources or recovering from their losses compared to persons without disabilities *(226)*.


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Adverse climate events directly impact the health of persons with disabilities. Due to their general exclusion from disaster risk reduction policies, plans and programmes, persons with disabilities are often at greater risk of death, injury and additional impairments *(227)*. Furthermore, in encountering difficulties in accessing basic water facilities, shelter or health care following a disaster, persons with disabilities are likely to experience health complications that are unique to their disability and detrimental to their health. These could include additional health complications related to their underlying health condition or impairment *(226)*, loss or damage of assistive products that are essential for their functioning, or disrupted access to both mainstream and specialized health care *(228)*. Evidence shows that climate-driven disasters, such as heat waves, puts persons with disabilities at increased risk for heat-related mortality and morbidity *(229)*.

There are some examples of interventions to prevent or mitigate the impact of climate on persons with disabilities. Most of these interventions are driven by NGOs. These could include community trainings with a special emphasis on empowering persons with disabilities to actively participate in the disaster risk management process in their community. Awareness-raising campaigns, the development of training materials and other initiatives that support the inclusion of persons with disabilities have been implemented in several countries. In terms of mitigation, practices which address climate-related hazards tend to emphasize adjustments to infrastructure and increasing community and individual resilience through sustainable livelihood and financial security initiatives *(230)*. Nonetheless, despite these examples, few countries make provisions for the requirements of persons with disabilities when planning for adapting to the effects of climate change. To date, no country includes persons with disabilities in their programmes to reduce greenhouse gas emissions *(231)*.

Intersecting factors

In addition to the determinants described above, different intersecting factors contribute to health inequities in persons with disabilities. Such factors include aspects of individuals' social identities, such as race, gender identity, sexual orientation and refugee or migrant status, which in interaction with different structural factors – for example those set by laws and policies – shape the health of persons with disabilities. The section below provides examples of some of the more prominent intersecting factors.

Gender inequality contributes to poorer health outcomes experienced by women with disabilities. Globally, across all social determinants of health, women with disabilities remain disadvantaged compared to men with disabilities. Disaggregated data from the United Nations highlights that women are three times more likely to be illiterate; two times less likely to be employed; two times less likely to use the Internet; and therefore unsurprisingly, are also three times more likely to have unmet needs for health care *(137)*. Gender inequality adds to the risk of violence in persons with disabilities, especially women and girls with disabilities and gender non-conforming persons with disabilities *(218, 232)*. There are also gender gaps in access to health services; a good example of this is eye care, where women are significantly less likely to undergo cataract surgery than men *(233, 234)*. This gender inequality in the use of eye care services could be explained by a range of socioeconomic and cultural factors, including greater challenges for women in travelling to health services due to limited financial decision-making power or minimal experience in travelling outside of their community *(235, 236)*.

Persons with disabilities from sexual and gender minority groups experience additional barriers in accessing health care. This is very often a result of their multiple identities and the many layers of discrimination they face *(237)*. Young persons with disabilities who identify as lesbian, gay, bisexual, trans, queer or questioning, intersex, asexual, or non-binary (LGBTQIA+) are at increased risk for several outcomes. Compared with their peers, they are more than twice as likely to experience depression; more than four times as likely to attempt suicide; two to five times more likely to abuse substances; experience bullying twice as often; and have a three times greater risk of being assaulted sexually *(238)*. The stigmatization and discrimination experienced by persons of disability who identify as LGBTQIA+ when they access health services, can negatively affect their quality of care and consequently their health-seeking behaviours *(239)*. Sexual health needs are often not considered by service providers, with persons with intellectual disabilities reporting that they are made to "'feel invisible' in terms of their gay identity" *(240)*.


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Ageism is also an intersecting factor that requires attention. Childhood and disability can constitute a double vulnerability, particularly early childhood when young children are dependent on adults for care. Evidence shows that this vulnerability is increased for children with disabilities who are more disadvantaged than children without disabilities in terms of access to health services, rehabilitation, nutritional status, and education. Children with disabilities are also likely to experience higher rates of corporal punishment, perceive that they are being discriminated against, and have feelings of unhappiness *(146)*.

For older people with a disability, ageism is an intersecting factor that can result in discrimination and human rights violations. Older persons with disabilities are often denied their autonomy, and their role in the community is dismissed as irrelevant and burdensome *(241)*. They are more at risk for developing NCDs due to underlying health conditions, unmet health needs, greater levels of poverty and exclusion from services. This is an important issue given the anticipated increase in population ageing in the coming decades.

Race is another intersecting factor with racial discrimination affecting health outcomes for persons with disabilities. In the United States, persons with intellectual or developmental disabilities from Black and Latino populations have less income and education and are more likely to be uninsured medically compared to white persons with intellectual and developmental disabilities *(242)*. This compromises their access to health services and the quality of care they receive. Racial bias has also been found to influence the care provided to persons with mental health conditions and psychosocial disabilities, with reports showing higher rates of involuntary admissions among those who are from Black African and Black Caribbean ethnic origins *(243)*.

Indigenous peoples with disabilities often experience multiple discrimination and face barriers to the full enjoyment of their health, based on their indigenous status and on disability. Currently there is limited information on indigenous populations with disabilities; however the available evidence shows that indigenous children are more than twice as likely to have a disability as non-indigenous children, with the ratio being even higher among adults *(244)*. Indigenous peoples may face challenges in their day-to-day lives, such as accessing health-care services due to the fact that they often live in remote areas where health care is unavailable or communication with health and care workers is an obstacle. These challenges are compounded by additional layers of discrimination in relation to their indigenous origin and disability *(245)*.

Being an immigrant, a refugee, an internally-displaced person or an asylum seeker with disability adds to the experience of health inequities. These groups may face added social isolation in their new community *(74)*. Language, communication and cultural barriers *(71, 73, 74)* and a lack of linguistic and cultural training among health and care providers *(73)*, all negatively influence the health-seeking behaviours and quality of care for refugees and migrants with disabilities. They often report a fear of not being understood by health and care professionals *(71)* or feel that they should not ask for health services *(73)*, all of which lead to poorer health outcomes compared to the general population. In addition, refugees, asylum seekers and stateless persons with disabilities are often excluded in national health systems and plans and cannot receive the rehabilitative services or assistive products they require *(246)*. Conflict-related displacement, when people are forced to flee, has significant effects on access to essential services including food, water, sanitation, shelter and health care during the different phases of the displacement. It is important to note that populations who are more at risk, such as persons with disabilities, may be unable to flee or may choose to stay behind; if on the move, they will struggle to meet their immediate and ongoing needs *(247)*.

2.2.3 Risk factors

Different risk factors for health disproportionately affect persons with disabilities. Risk factors such as physical inactivity, overweight and obesity, poor diet, tobacco and drug use, and alcohol consumption often start at very early age and are critical factors for developing NCDs in adulthood *(248)*. In terms of physical inactivity, adults with disabilities are significantly more likely to be physically inactive compared to persons without disabilities *(7, 9, 10)*; this is observed from a very early age as children and adolescents with disabilities participate far less in sporting activities, compared to those without disabilities *(249)*. Poor diet is often associated with lack of financial means and evidence suggests that persons with disabilities, particularly children with disabilities, often have higher rates of poor nutrition *(146, 176)* which can manifest sometimes in higher levels of obesity *(138, 250)*. Special Olympics has found higher rates of obesity among Special Olympics participants with intellectual disabilities and the general population globally *(251)*.

> **My right to practice sports, to engage in physical activity, has greatly helped both my physical and mental health.”**
>
> Special Olympics Athlete at CRPD Conference for States Parties Side Event

Persons with disabilities disproportionally use tobacco products *(252)*, with studies showing that over a quarter of adults with disabilities currently use tobacco compared to 13% among adults without disabilities *(138)*. Prevalence of tobacco use among women with disabilities is even higher *(9, 10)*. Prevalence rates of alcohol consumption and substance use are also higher among persons with disabilities *(15, 18)*. It is important to note that very often these risk factors are a result of other determinants of health such as economic circumstances and level of education of an individual. For example, greater financial means can allow people to buy healthier food or have the means to exercise *(253, 254)*.

> **I have high blood pressure and have issues obtaining medication for it, as there is no treatment protocol for persons with disabilities [during the pandemic], but there never was one… Access to telemedicine is not an option for everyone [due to prohibitive costs of mobile phone plans]"** ***(255)***
>
> Juan Carlos, person with a disability and activist, Ecuador.

Persons with disabilities are also exposed, to greater extent, to environmental risk factors such as air pollution or road traffic injuries. Evidence from the United Kingdom of Great Britain and Northern Ireland shows that children with intellectual disabilities are on average 30% more likely to live in areas with outdoor air pollution from toxins such as diesel particulate matter, nitrogen dioxide, carbon monoxide or sulphur dioxide, compared to children without intellectual disabilities *(156)*. This exposure is to very large extent associated with the higher levels of poverty among these groups. Persons with disabilities are also at a higher risk of non-fatal unintentional injury from road traffic crashes *(256)*.

All these risk factors have direct effect on the health of persons with disabilities. The rise of NCDs, which are often the underlying conditions for persons with disabilities, has been driven primarily by four major risk factors: tobacco use, physical inactivity, the harmful use of alcohol, and unhealthy diets. NCDs including heart disease, stroke, cancer, diabetes and chronic lung disease, are collectively responsible for more than 70% of all deaths worldwide *(257)*. The greater exposure to risk factors for persons with disabilities increases their likelihood of developing secondary health conditions.

A major reason why persons with disabilities have increased exposure to risk factors is that public health interventions are often not inclusive. Health prevention and promotion campaigns that aim to address population health through reducing the impact of risk factors often do not reach persons with disabilities. There are several reasons for this. Firstly, public health information may be provided in a format that is not accessible *(258–260)*, or not tailored to the needs of persons with disabilities *(194, 261, 262)*, or distributed in locations and spaces not accessed by persons with disabilities *(258, 263)*. Secondly, public health interventions that take place in group sessions or at specific facilities may require travel to attend. A lack of appropriate and affordable transport can create barriers for persons with disabilities *(192, 194, 195, 258, 260, 264)*. Thirdly, the physical environment is a significant barrier. Inaccessible spaces such as fitness facilities, fitness equipment *(135, 195, 259, 265, 266)*, and limited or no water supply in their home *(119, 135, 267)* can hinder the participation of persons with disabilities in public health interventions.

Not identifying specific needs that persons with disabilities from the planning and design phase can exclude many from participating in public health interventions. For example, swim skills training is an important intervention for the prevention of drowning, and even though it is desirable that children with disabilities receive training wherever possible, they are often excluded from receiving the intervention. To accommodate any specific needs safely, such as appropriate additional support, smaller classes or buoyancy aids, determining these needs in advance is necessary. WHO has published a practical guidance that highlights the importance of identifying such needs for children with disabilities when providing swim skills training[13].

Factors related to the health system can also have a major influence. Health and care workers can reduce access to public health interventions by making assumptions about the appropriateness of referral or recommendations. Persons with psychosocial and intellectual disabilities are among the groups less likely to be offered interventions for smoking cessation *(268–271)* or weight management *(263, 272)* respectively, because of misunderstanding of the perceived benefits of such campaigns on persons with disabilities. Furthermore, a lack of data on the impact of public health interventions for persons with disabilities, and poor recording of disability in those accessing an intervention, reinforces the lack of disability inclusion in these settings *(85, 119, 120, 131, 136, 259, 267, 269, 273)*.

There are, however, documented efforts to include persons with disabilities in cross-sectoral public health interventions which address the risk factors for health. These efforts have highlighted the importance of tailoring and individualizing activities to the skills and preferences of persons with disabilities. Most of these examples relate to the promotion of healthy diet and physical activity in high-income countries. The different strategies for disability inclusion include instructors adapting their delivery style to the needs of the participants *(274–277)*, or allowing the participant to determine some aspect of the intervention (e.g. session duration, type of activity, activity pace and intensity) *(278–285)*.

Individualization of these types of public health interventions increases participation, enjoyment, or adherence over time among participants with disabilities *(276, 281–284)*. Such practices are aligned with an “abilities-based approach” commonly adopted when working with children with disabilities *(286)*. For example, abilities-based approaches built around group goals and common interests, cooperative activities, individualized instruction, adaptations, and challenging activities, can have beneficial effects for children with disabilities. This includes improved physical skills and positive psychosocial development *(275)*.

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[13] Preventing drowning: practical guidance for the provision of day-care, basic swimming and water safety skills, and safe rescue and resuscitation training. Geneva: World Health Organization; 2022.

2.2.4 Health system

Personal story

The challenge of oral health care for persons with disabilities

For Philippe Aubert, 42, seeking oral health care has been a challenge. Philippe, from France, has athetotic cerebral palsy (CP), which causes involuntary movements that prevent him from walking, talking or using his arms.

"Many simple details including the texture of the seats... the light, the noise of the dental drill, and even the typical smell of a dental clinic could easily trigger spasticity, anxiety or other symptoms for a patient with CP," Philippe explains.

Some visits have made him feel unsafe and reluctant to return. "Once I almost choked on a dental x-ray film put in my mouth and nearly destroyed the dental chair... because of the involuntary movements triggered by the procedure."

His teeth were a problem for a long time. "Due to pronounced bruxism (habitual teeth grinding), I had almost ground down all my teeth. I had serious difficulties chewing and eating."

Philippe strongly believes that the attitude and skills of dental staff – who usually know little of his needs – are crucial to successfully addressing the needs of persons with disabilities. He called for effective training and "respectful relationships" borne from "taking time to hear [patients] out and understand their needs."

Philippe finally found a non-profit organization, Handident, where he was warmly welcomed. "I had to go to the extreme of full mouth rehabilitation so that I could claim, and finally appreciate, my mouth and teeth," he says. These dentists "changed my life".

Philippe's book *Rage to exist* has led to him becoming a public figure highlighting the experience of persons with disabilities. His words are "spoken" via a speech synthesizer controlled by his gaze. "I have not spoken since birth! My mouth and teeth helped me to eat, not communicate. Today, my mouth plays an essential role in my communication and my aesthetic," he says with a bright smile.

Photo: © Philippe Aubert

Health and care workforce

The lack of knowledge, skills, and competencies by health and care professionals of the needs of persons with disabilities represents one of the most widespread and impactful barriers in the health sector. First, there is frequently a lack of knowledge, skills and competencies relating to the care of persons with specific conditions, including mental health conditions *(124)*, autism *(49, 287, 288)*, or new and rare diseases *(70, 289)* that are associated with significant levels of disability (e.g. congenital Zika syndrome) *(54, 59, 60, 115, 290–292)*, as well as the management of medication for some of these conditions *(49, 293)*. A recent survey in the United States found that only 41% of practicing physicians reported that they were "very confident" about their ability to provide the same quality of care to persons with disabilities as those without *(294)*. Second, health and care professionals may not be aware of policies, evidence or guidelines regarding disability inclusion or disability-related services *(51, 70, 109, 116, 190, 295, 296)*. Third, there is often a failure to recognize comorbidities, as well as the full range of barriers which may hinder the access and participation of persons with disabilities in interventions that promote health and prevent disease *(261, 269, 297–299)*. Lastly, in emergencies, health and care professionals may lack the capacity to adapt generic public health measures through individualized risk analysis. For example, generic regulations which restrict movement, physical contact, and visitors to hospitals and residential facilities can lead to persons with disabilities being isolated and without assistance for communication or psychosocial support *(300–302)*.

> **If we don't get a chance, it's completely hopeless; but when we get a chance, we can show what we can do, that we have the ability to do a job regardless of the disability that we have and do it just as well as a person without a disability."**
>
> Ayse, a social worker with hearing impairment from Denmark

A shortage of trained human resources also presents a challenge. In many countries of different income levels, the capacity to provide rehabilitation fails to meet existing needs, largely due to the lack of skilled rehabilitation workers or essential equipment for service provision. In southern Africa, for example, as few as 26% of persons with disabilities receive the rehabilitation they need *(303)*. A further significant issue is that persons with disabilities are not an active part of the health and care workforce. In the United States, only 2.7% of medical students disclose that they have a disability, which is far fewer than the proportion of persons with disabilities in the population *(304)*.

The lack of accommodations often leads to poor communication between health professionals and persons with disabilities, with some experiencing communication barriers making it difficult for them to express their needs without appropriate accommodations. These include people with cognitive impairments, speech difficulties, those who are deaf or hard-of-hearing; adults with autism who do not have verbal abilities or those with co-occurring intellectual disability, or psychosocial disabilities *(49, 56, 61, 79, 295, 305–307)*. Moreover, health and care workers may not be equipped with the appropriate practical skills to communicate effectively with persons with disabilities, or have the knowledge of certain communication methods and approaches *(51, 53, 54, 60, 62, 67, 70, 71, 73, 75, 109, 113, 114, 181, 289, 293, 295, 306–316)*. Although accommodations may require more time to adopt in standard appointment schedules *(73, 296, 315, 317)*, often those that are simple, such as moving closer to a person and looking at them, or using alternative means to communicate with people whose hearing aids have been removed for a procedure, can facilitate a smoother communication *(50, 60, 63, 123, 129, 306, 311, 313, 315, 317–320)*.

Health and care workers may also carry societal negative attitudes and beliefs about persons with disabilities which can manifest in discriminatory practices *(51–54, 58, 60–62, 65, 70, 75, 77, 109, 110, 114–116, 122, 123, 181, 193, 289, 291, 292, 295, 306, 310–313, 315, 319, 321–323)*. Such practices include providers refusing health services to persons with disabilities *(52, 75, 324)*, the use of derogatory or offensive language *(51, 54)*, or considering women with disabilities as "asexual" *(54, 319, 325, 326)*. Discriminatory practices can also involve forced sterilization *(129, 327–329)*, negative assumptions about the capacity of individuals with disabilities to engage in or make decisions about their own care *(58, 77, 181, 187, 199, 291, 292, 308, 315)*, undermining their autonomy and independence *(62, 110, 258, 263, 269–272, 315, 320, 330, 331)*, or demonstrating a lack of understanding and respect *(61, 63, 70, 232, 309, 310, 315, 320, 332)*. Negative and false beliefs concerning persons with psychosocial disabilities – for example that they are dangerous, a risk to themselves or others, or that they cannot make decisions for themselves – can lead to coercive practices including involuntary admission, treatment, seclusion and restraint *(161)*.

> “**I think the desexualizing and infantilizing thing is so huge, like, they… like, health-care providers kind of assume that you're not having sex." *(333)***
>
> Young person with a disability, Canada

All of the above factors can exacerbate health inequities in persons with disabilities. The lack of knowledge and skills or miscommunication of health and care workers is linked directly to several factors including hindered access to services or delayed treatment for persons with disabilities; less opportunity to disclose and seek support; an added risk of unhealthy behaviours; a negative impact on health-seeking behaviours; poor quality of care; and poor overall clinical outcomes *(52, 63, 73, 75, 79, 187, 191, 193, 309, 313, 317, 320) (47–49, 51, 53, 55, 56, 58, 60, 62, 63, 65, 67, 70, 73, 75, 80, 112, 114, 115, 122–124, 181, 187, 189, 190, 193, 199, 291–293, 295, 296, 305–310, 313, 314, 319–321, 334)*. The stigmatization of body weight and obesity in health-care settings can be pervasive; people with disabilities with obesity can be stigmatized, disrespected, and in some instances discriminated against through a lack of equitable access to care *(335)*. This often causes stress and an avoidance of seeking care, mistrust of doctors and poor adherence to care programmes among patients with obesity, all leading to poorer health outcomes and emphasizing the importance of appropriate training and education for health and care workers *(336)*. Persons with disabilities can also be denied organ transplantation on basis of false assumptions about the likelihood of failure of the transplantation due to the recipient's disability; the denial of potentially life-extending organ transplantation is linked directly to mortality *(241)*.

Although examples exist of interventions to increase awareness, knowledge and skills on disability-related issues among health and care workers, very little is known about their effectiveness. While a range of educational initiatives have been shown to increase knowledge and skills *(337–344)*, there are gaps in evidence of how these initiatives translate into changes in behaviours and practices. In addition, interventions are often developed and delivered by health practitioners without the involvement of persons with disabilities and may fail to reflect an approach that is based on human rights and in line with the CRPD *(344, 345)*. One mechanism to address health inequities is for students and trainees with disabilities to be included in medical education as they can empathize with patients and serve as an example for their peers *(346)*.

> **“He (a health worker) didn't just lecture me from what he had learned in books or courses. He listened and we worked on a plan. He asked me how I was feeling. That helped.”**
>
> Raja, a man with psychosocial disabilities from Lebanon

The WHO QualityRights Initiative is a good example of an intervention that engages persons with psychosocial disabilities and their representing organizations, and includes the design and delivery of training. The WHO QualityRights Initiative aims to promote the human rights of persons with psychosocial, intellectual and cognitive disabilities globally through changing the attitudes of policy-makers, mental health professionals and other stakeholders. The initiative works at the ground level to change attitudes and practices directly, as well as through policy to create sustainable change. Persons with disabilities and their organizations are central actors in all aspects of the QualityRights Initiative, from its design to its implementation.

As part of the initiative, WHO developed the QualityRights training based on the United Nations CRPD. The training provides health workers, policy-makers, carers, community members and people with lived experience of disability, with the skills necessary to advocate for a human rights-based approach to mental health and to support persons with disabilities to advocate for their rights. The first large-scale implementation and systematic evaluation was conducted in Gujarat, India and showed improvements in the attitudes of health professionals towards persons with mental health conditions; service users felt more empowered and satisfied with the services provided *(347)*. The initiative has more recently launched its QualityRights e-training programme which has enabled WHO to reach, engage and train tens of thousands of people around the world. Ongoing evaluation of the e-training shows a highly significant impact in terms of reducing stigmatization and discrimination and changing attitudes towards disability, including challenging issues such as legal capacity and the right to decide, ending coercive practices, choice and information about treatment and the right to community inclusion *(348)*. The initiative is currently implemented in several countries including Armenia, Bosnia and Herzegovina, Czechia, Estonia, Ghana (see Box 9), Italy, Kenya, Lebanon, Philippines, Poland, Türkiye, Ukraine, and Zimbabwe *(347, 349)*.

Box 9

QualityRights for persons with psychosocial disabilities in Ghana

In February 2019, WHO, in collaboration with the Ministry of Health of Ghana and 12 civil society organizations, launched QualityRights in Mental Health, Ghana with the aim of implementing the initiative throughout the country. The WHO initiative includes the dissemination of the QualityRights e-training programme on mental health, recovery and community inclusion among national stakeholders, including health and mental health practitioners, policy-makers, people with lived experience of disability and their families, organizations of persons with disabilities, faith-based organizations, teachers, the police, and journalists. The objectives of the project are: i) to build capacity and change attitudes among different national stakeholders in order to promote and respect the human rights of persons with psychosocial and intellectual disabilities; and ii) to transform mental health and social services to promote care and support that is acceptable, of good quality, meets people's needs and respects their dignity and rights.

To date, tens of thousands of national stakeholders have been trained; health profession bodies have accredited the QualityRights training as Continuous Profession Development course into their curriculum; and in May 2021, Ghana launched their new "Mental Health Policy 2019–2030: Ensuring A Mentally Healthy Population"– a policy that outlines key areas for action to promote the human rights of persons with psychosocial disabilities.

Health information systems

Across all levels of health care, it is evident that disability has been largely underprioritized in national health information systems (HIS). The method of operating HIS is very complex, due to health planners and decision-makers needing different kinds of information. Information is based on four main components: i) *inputs* to the health system; these range from policies and health infrastructure to costs and human resources; ii) *outputs*, in terms of the availability of interventions or service quality; iii) *outcomes*, such as the coverage of health interventions; and iv) *impact* in terms of improved health outcomes. As discussed earlier in the report, there is very limited information on health inequities for persons with disabilities, and data should be collected at the impact level of HIS. Of greater concern however is the lack of information on the drivers of these inequities – i.e. data that HIS would capture the levels of inputs, outputs and outcomes. Without evidence on whether policies exist, or if infrastructure is accessible, or coverage of interventions is unequal, it is difficult to determine why health outcomes for persons with disabilities are poorer than those for general populations.

While disaggregating data on disability is important at outcome and impact level – for example to understand whether persons with disabilities receive fewer services or die earlier compared to the general population – information at input and output levels can be gathered through other sources. Data at input and output levels relate to the way the health system is built and structured, and how the different building blocks operate. This information can and should be captured through administrative sources, facility assessments, or by other sectors.

To our knowledge, no country systematically collects information across inputs, outputs, outcomes and impact to obtain a comprehensive picture of health inequities experienced by persons with disabilities and its drivers. This lack of data on disability in HIS contributes to the persistence of health inequities for persons with disabilities. Without measurements, it is difficult to understand the magnitude of the health inequities, what drives them, and what can be done to address them. When not integrated into HIS, disability becomes "invisible" and underprioritized in the health sector.

Health systems financing

Health coverage programs primarily in low- and middle-income countries may not fully cover the health needs of persons with disabilities and their families. A good example is the coverage of rehabilitation services, which are fundamental for persons with disabilities. The erroneous belief that rehabilitation is an expensive and luxurious addition to essential health services has resulted in it being undervalued in the financing and development of health systems. Although rehabilitation plays a critical role in optimizing health outcomes for those who receive it, advances in the field have lagged behind those in other areas of health *(303).*

Furthermore, reasonable accommodations are often omitted from such schemes, and even persons with disabilities can be excluded based on pre-existing conditions *(193).* For example, in some high-income countries, health services rarely budget for the added time required to provide equitable health services to persons with disabilities *(115, 350)*, and even when they do, it is without remuneration from the relevant insurance companies *(59)*. Very often, persons with disabilities may find themselves uninsured or underinsured for their needs if public health interventions incur a cost *(194, 269)*.

In addition, funding for accessibility is of low priority in many countries, and few programmes include budget allocations for accessibility needs *(259)*. This may include ensuring signage, entrance area, parking and accessible toilets designated for persons with disabilities in health facilities, as well as accessible equipment like examination tables and beds.[14]

Systems for financing health that are not inclusive aggravate health inequities for persons with disabilities. Persons with disabilities need access to any mainstream health services as anyone else, not only to disability specific services. However, costs of health services that need to be covered by individuals can lead to catastrophic health expenditure *(47, 48, 51, 52, 54, 55, 57, 58, 64, 67-69, 75, 78, 80, 110, 112, 115, 124, 187, 190, 270, 289, 293, 295, 311, 312, 314, 351)*. Limited prepaid protection against these costs *(53, 61, 75, 77, 123, 143, 191, 295, 319)*, resulting in higher out-of-pocket payments *(53, 55, 57, 61, 112, 114, 123, 143)*, or difficulties obtaining disability benefits *(56, 57, 69, 111, 350)*, all lead to poorer access to essential health services.

Leadership

There is a gap in leadership on disability inclusion in the health sector. On the one hand, this gap relates to the unfulfillment of the responsibility of the health sector to advance health equity for persons with disabilities in many countries. This can be seen in the lack of prioritization of disability in national health strategies, or the unpreparedness of countries to protect persons with disabilities in health emergencies such as with COVID-19. On the other hand, there may be a lack of clear coordination between governmental sectors on who is responsible for disability. Very often disability spans multiple sectors, and despite all sectors having a role to play, no one takes the responsibility to act. Clear examples of this are cross-sectoral public health interventions, such as water sanitation and hygiene *(131, 135, 190, 352, 353)*. WASH, health and disability are often the responsibilities of different ministries and there may be minimal collaboration on disability-inclusive WASH within the government. As a consequence, WASH interventions are often not designed or implemented as being inclusive of persons with disability *(58, 112, 260)*.

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[14] Ndyamukama A, Dillip A, Chipwaza B. Access to Supportive Health Services for People with Physical Disabilities: A Case of Health Facilities in Singida Rural District, Tanzania.

The lack of leadership on disability inclusion is a major contributor to health inequities for persons with disabilities. Political leadership involves taking responsibility for advancing health equity for persons with disabilities and prioritizing their health, as well as committing to implementing actions to achieve this. Without strong leadership, it is impossible to strengthen the remaining components of the health system and address the structural and social determinants of health.

Service delivery

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There are multiple gaps in service delivery that disadvantage persons with disabilities. These gaps include unavailability of health services, as well as those specific to the underlying impairments and health conditions of persons with disabilities; gaps in the provision of telehealth services; poor coordination; inaccessibility of infrastructure and equipment; gaps in health information and interpreter services; lack of support services; and a range of discriminatory practices.

In many countries, there is limited availability of primary care services, including community care, and this is exacerbated in health emergencies. Evidence indicates that the lack of available primary care services disproportionately affects persons with disabilities, especially those living in rural areas *(48, 50, 52, 54, 56, 57, 60, 61, 64, 67, 69, 74, 75, 109, 111, 112, 116, 124, 143, 201, 289, 292, 295, 350, 354)*, In these situations, receiving health care may involve elevated costs of services, or travelling long distances *(47, 52, 54, 57, 67, 75, 109, 112, 123, 142, 355)* which may not always be feasible *(109, 112, 114)*. Health emergencies due to natural disasters can further reduce access to services and support for persons with disabilities *(356)*, and are mainly due to health and road infrastructure; overwhelming numbers of patients who may require health triage and prioritization of services; and displacement *(357–360)*. During health emergencies, the rate and severity of disabilities may suddenly and substantially increase, placing additional pressure on health systems *(361)*. The lack of long-term comprehensive planning for persons with newly acquired disabilities further complicates the provision of adequate health care in the emergency context *(72, 290, 362–366)*.

Access to services specific to the underlying impairments and health conditions of persons with disabilities frequently presents a challenge. In low- and middle-income countries, persons with disabilities tend to have low access to services, such as rehabilitation and assistive technologies *(367)*. There are often gaps in the delivery of services in basic health packages, such as vision rehabilitation, specific medicines and assistive products including orthotic and prosthetic equipment or wheelchairs. The proportion of people with an unmet need for assistive products, including spectacles, varies from 3–90%, depending on the socioeconomic development of the country *(368)*. A lack of systematic integration of assistive technology as a component of other health programmes, such as rehabilitation, NCDs, or care for older people, feeds the lack of awareness among health personnel and limits opportunities for action or referral. Furthermore, provision of eye care *(369–372)*, hearing screening, and audiology services is limited, including for infants and children who are deaf or hard-of-hearing children in most low- and middle-income countries *(373, 374)*. Major contributors to this gap are the lack of availability or access to services; concentration of services in urban centres; a lack of funding and transportation; and resource limitations including of skilled workers *(48, 60, 67, 112, 116, 126, 189, 295, 306, 375, 376) (47, 56, 60, 61, 112, 115, 189, 199, 295)*.

New modalities of delivering health services, such as digital health or telehealth, can present challenges for persons with disabilities. While, in principle, these services offer significant opportunities to reach priority populations living in marginalized conditions, the associated costs and lack of accessibility often create and exacerbate a digital divide that disadvantage persons with disabilities *(377)*. The digital delivery of services may be unavailable or inaccessible, especially for individuals living in rural, or displacement and resource-limited settings, as well as for those who have low levels of digital literacy, limited access to technology, reduced income, or experience gaps in internet infrastructure and connectivity *(103, 378–385)*. While global standards such as the Web Content Accessibility Guidelines exist, legislation in many countries does not yet require their adoption across all sectors. As such, the inaccessibility of many digital and telehealth platforms hinders persons with disabilities from engaging with, and benefiting from, these modalities *(379, 386–390)*.

Poor coordination of health services, including fragmentation, are major challenges for entire populations, and present additional barriers for persons with disabilities who often have heightened health risks or complex health conditions *(51, 307, 317)*; poor coordination may lead to the prioritization of some aspects of care while others are neglected *(47, 56, 59, 61, 65, 69, 75, 77, 109, 110, 114, 115, 124, 190, 308, 350)*. Fragmentation of services *(61, 308)* has been evidenced, including between services for mental and physical health, and as children transition to adulthood *(124, 293, 296) (112)*; fragmentation is also reported between sectors *(61, 62, 74, 115, 199, 293, 307, 308, 350)*, such as housing *(124, 296)*, social services *(49, 69, 181)*, and services for specific impairments and health conditions *(107, 232, 291, 332, 391, 392)*. Although persons with disabilities receive referrals to services that are specific to their underlying impairments and health conditions, they commonly encounter little consideration of care and support beyond the clinical issues *(393)*. This lack of coordination of care is often attributed to procedural, communication and administrative gaps, such as ineffective referral systems *(48, 49, 53, 61, 69, 70, 190, 293)*, non-aligned policies between services *(350)*, and ineffective communication between providers *(49, 59, 69, 70, 115, 307, 350)*.

> **“It was very siloed care. There were no strong linkages between the health, education and rehabilitation sectors… They were all not looking in the same direction. We were not powerful enough to pass by the professionals. We really hoped they would speak to each other but that didn’t occur. It felt strange trying to coordinate the communication”**
>
> Dr Masahiro Zakoji on the care that his daughter Haruka received in Japan, India, and the Philippines where he accompanied her for WHO assignments. Haruka is blind and has cerebral palsy.

Inaccessible environments present further significant barriers to accessing health services. Once persons with disabilities arrive at health facilities or locations where public health interventions are being conducted, they can encounter a range of environmental barriers relating to the physical environment. These barriers include inaccessible consultation rooms and changing rooms *(115, 123, 187)*, stairs with no ramps or lifts *(54, 58)*, inaccessible toilets or washing rooms *(54, 58, 60, 115, 291)*, inaccessible office doors *(187)*, and obstructed routes or parking areas around the facilities *(123)*. The sensory environment in *(61, 181)*, including the presence of strong smells, bright overhead lighting, unfamiliar and busy environments *(48, 61, 62, 199, 319)* or noisy clinical environments *(306)* can present further challenges. Within health-care facilities, a lack of accessible or specialized equipment, products, and devices can also hinder service delivery *(48, 52, 56, 57, 69, 122, 123, 189, 193, 199, 292, 295, 319, 321, 394)*. There are reports of gaps in adjustable examination tables *(58, 122, 123, 143, 187, 291, 292, 319)*, delivery beds *(54, 291)*, chairs *(115)* or benches *(189)*; lifting or transferring devices *(123, 143)*, wheelchair accessible weight scales *(122, 143)*, and accessible radiation therapy equipment *(123)*. Physical barriers are also reported in the delivery of public health interventions, which are often conducted in public spaces and business settings *(135, 195, 259, 266, 395)*.

The format, content and approaches to dissemination of health information that are not inclusive of disability contribute to lower health literacy among persons with disabilities. Public health information is often not provided in accessible formats such as Easy Read *(258–260)* and not tailored to the needs of people with disabilities *(63, 123, 187, 194, 261, 262)*, who may have literacy difficulties *(47, 50, 63, 103, 123, 313, 317, 385, 396–399)*. In addition, the unavailability of assistive technology can also hinder access to health information. Information about specific health conditions – for example for parents about cerebral palsy and how to support their children to improve functioning and independence – is often not provided *(116)*, may be unreliable or outdated *(299, 326, 387, 400–411)*, and may be disseminated in ways that do not reach persons with disabilities effectively *(258, 263, 412)*. In lower resource settings, health messages may be disseminated through community leaders and networks which do not include persons with disabilities *(413–415)*.

The lack of interpretation services for one-on-one consultations and wider public health information campaigns affect the deaf community uniquely *(378, 416, 417) (47, 50, 71, 73, 74, 296, 314)*. Health and care professionals may face a lack of, or difficulties in obtaining and working with, sign language interpreters *(50, 60, 123, 313, 317, 319)*. Even in contexts where interpreters are available, the interpretation provided may be of poor quality *(319)* leading to concerns of maintained confidentiality or an increased danger of misdiagnosis or adverse health outcomes *(50, 311, 317)*.

Gaps in health service delivery can often lead to an overreliance on caregivers and family members. Access to services, including for sexual and reproductive health, for persons with disabilities is often highly dependent on the support of family members to recognize health needs, reach services, and even in communication and decision-making with health and care professionals *(51, 54, 56, 63, 64, 69, 308, 311, 418)*. However, family members and caregivers may not have the necessary knowledge or skills, and take on these roles largely because there are few options for formal social support or trained support persons *(49, 260, 269, 299, 419–421)*. This situation is further exacerbated in health emergencies when support services that are already limited become disrupted, further increasing the demands on families and other informal networks *(103, 378, 422–426)*.

Discriminatory practices within the health sector hinder access to health services for persons with disabilities, as noted previously. Persons with disabilities can be subjected to a range of coercive measures and involuntary practices within the health system which undermine their dignity and well-being and lead to unwillingness to seek help and engage with practitioners. Persons with psychosocial disabilities may not access services or disclose information for fear of coercive measures *(80)* and involuntary admission or treatment *(351, 427–429)*. Women and girls with disabilities, particularly those with intellectual or psychosocial disabilities, can be subjected to involuntary contraception, abortion, and sterilization. These procedures are undertaken without appropriate informed consent, under coercion, or even without their knowledge, thereby violating their rights *(207, 327–329, 430–432)*. Other forms of involuntary and potentially inappropriate medical treatment of children with disabilities who live in institutions include an over-reliance on psychotropic medication to control behaviours *(431) (433)*.

All the discussed gaps in health service delivery contribute to the health inequities experienced by persons with disabilities; there is a direct link between unmet health-care needs and increased mortality among this group *(375)*. Inaccessible environments that impede or delay the delivery of health services can increase morbidity or limitations in functioning *(58, 63, 122, 123, 291, 319)*. Limited health literacy among persons with disabilities or inaccessible health information can affect their access to timely and effective health care and worsen their health outcomes *(48, 50, 51, 55, 56, 58, 59, 61, 63–65, 69, 71, 75, 109, 110, 112, 114, 116, 181, 187, 190, 199, 292, 308–310, 313, 320, 434)*. In addition, the lack of support services is a contributing factor to deteriorated health among family members and caregivers of persons with disabilities who may often develop mental health conditions such as depression or anxiety *(232, 426, 435–444)*.

The different examples of interventions and practices applied in countries to address the gaps in health service provision include those aimed at integrating provision to better support persons with disabilities and improve care coordination. Integrated programmes for neurodivergent adults, which are available largely in high-income contexts only, commonly address financial and employment needs, along with social support, training in activities of daily living, and health and medical care. Collaborative care programmes, such as the Integrated Behavioural Health Primary Care programmes and Behavioural Health Homes, have been proposed as effective strategies to integrate physical and mental health care *(445–450)*. Some small-scale comprehensive family-centred early intervention programmes have demonstrated positive individualized outcomes for children with disabilities and their parents *(451)*. However, the scale-up of such interventions is challenged by more systemic issues in the health sector such as inadequate mentoring systems for health and care workers, and a lack of centralized funding for such programmes *(452)*. In addition, educational programmes (see Box 10), self-help and peer support groups are commonly adopted to secure inclusion of persons with disabilities within the health sector. These initiatives aim to foster coping, knowledge, individual learning, socializing, empowerment processes, and health service engagement *(276, 277, 383, 452–461)*.

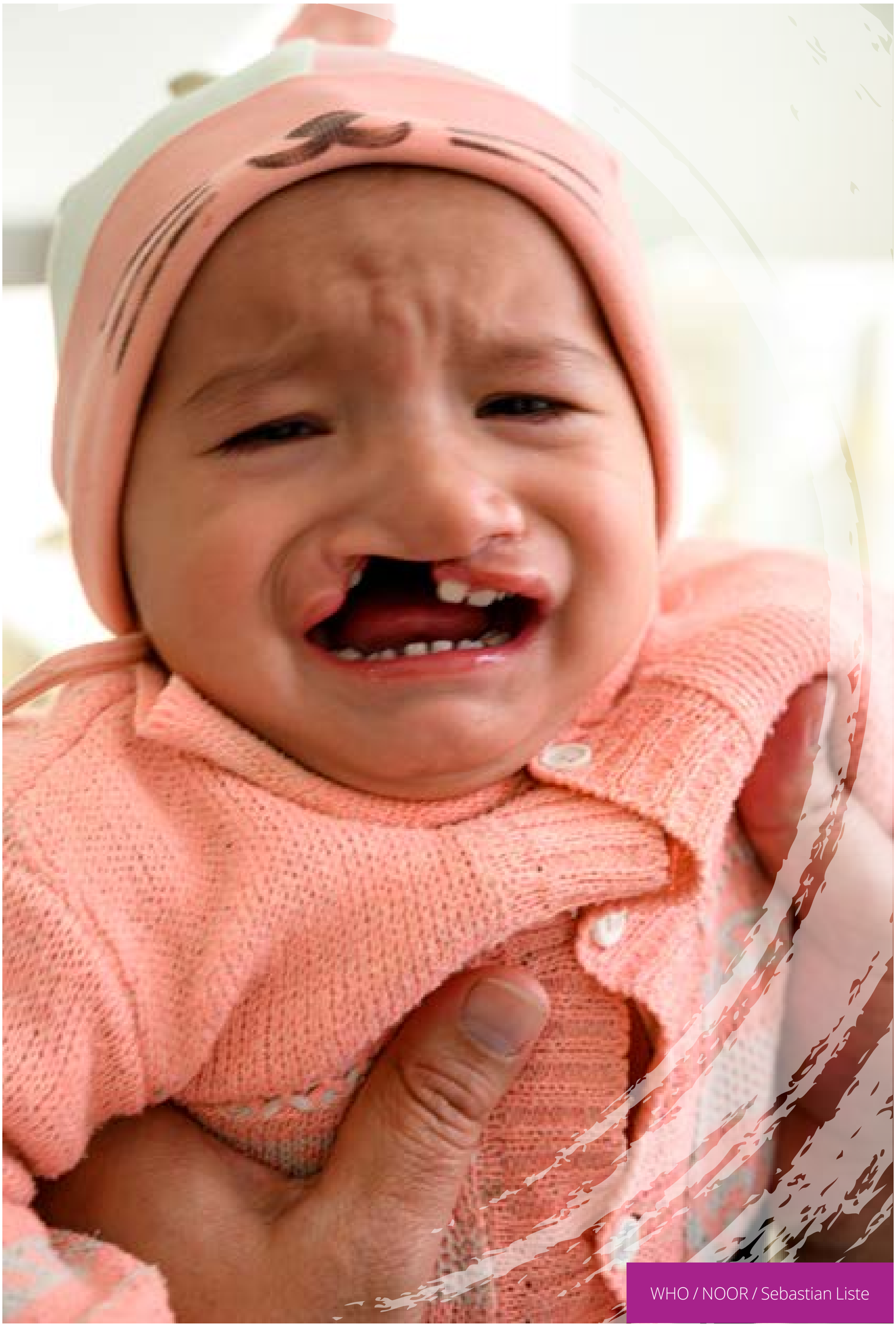
Box 10

Empowering women with disabilities in the Philippines

A good example of the impact of a sexual and reproductive health education programme for women with disabilities comes from the Philippines, where through the W-DARE project (Women with Disabilities taking Action on REproductive and sexual health), local communities of women with disabilities and health service providers were educated on sexual and reproductive health and rights. The programme was conducted in Quezon City in Metro Manila and in the City of Ligao in Albay province the aim being to raise awareness in participants of the rights of women with disability, and the challenges they face in accessing sexual and reproductive health services and information. The training sessions were co-facilitated by women with different types of impairments.

Evaluation of the effectiveness of the programme showed strengthened relationships between organizations of persons with disabilities and women's health service providers. The programme also increased knowledge among service providers and women with disabilities about sexual and reproductive health needs and rights, and practical changes in service provision, such as ensuring accessibility in health facilities or the provision of funds for adaptive equipment. Five years after the project took place, participants in the first participatory action groups are now advocates themselves for the sexual rights of women with disabilities and educate fellow women with disabilities *(462)*.

In conclusion, two major points can be drawn based on the presented evidence. Firstly, there are clear structural factors and social determinants, risk factors and health system barriers that drive health inequities for persons with disabilities. Although the evidence of the impact of these factors is very often indirect, and there is little information on how they intersect and reinforce each other, their contribution to the existence and persistence of health inequities can still be inferred unequivocally. Secondly, although many of the factors can be modified by the health sector, the wider range of structural factors or social determinants – such as societal values and beliefs which lead to stigmatization and discrimination, poverty, poor living conditions, or non-inclusive education and employment – exceed the scope of the health sector and require better understanding and a multisectoral response. For this reason, the setting and funding of a health policy and systems research agenda are urgently needed, so that countries can better understand how society should be organized to ensure that persons with disabilities achieve the highest attainable standard of health.



WHO / NOOR / Sebastian Liste

COVID-19 as a devastating wake-up call for the level of disability inclusion in the health sector

Personal story

Deafblindness: A disability not given the attention it deserves

Photo: © Frank Trigueros

For a community that relies on touch to function, COVID-19 restrictions impacted people with deafblindness severely. Forced isolation was a deathblow to their independence, given their need for interpreters to communicate and get around. As they communicate through hand-over-hand signing, physical distancing effectively cut off communication.

"I cannot get around myself. But we faced opposition to get interpreters. There was no understanding from health services or the public sector," said Frank Trigueros, president of European Deafblind and FASOCIDE, the Federation of Associations of Deafblind people in Spain.

"Interpreters were not even allowed in the emergency room, even though we tried to explain we need them. Again and again and again, we had to explain who they are and why we need them." Some doctors were empathetic, but the community cannot rely on "people's good will" he said.

In many countries, deafblind people were not properly informed about COVID-19 restrictions or the virus. "The government here neglected us. We had to do their work of informing [deafblind] people," he said, adding their capacity as a non-profit organization was limited.

While limited government funding for interpreters is problematic, other major issues include the lack of empathy and understanding, and their invisibility. Trigueros has had to ask many impatient public servants to "slow down" when conversing with interpreters. Once, when in hospital, a doctor did not take the time to explain what drugs he needed to take and when. "He just walked away backwards. I was mad. I had to find someone else to help me."

Another issue: his electronic health records do not state he is deafblind, although other disabilities get recorded on the system. He sometimes gets calls from health centres. "I've tried many, many times to tell them. They say the software is restricted. "It shouldn't be that difficult to put right. It is not an issue of money. The system just does not care enough."

The COVID-19 pandemic has served as a wake-up call for the health sector and highlighted the health inequities faced by persons with disabilities. During the pandemic, persons with disabilities had a significantly higher risk of mortality from COVID-19 than those without disabilities. In the United Kingdom of Great Britain and Northern Ireland and South Korea, more than half of the COVID-19 related deaths occurred among persons with disabilities *(463, 464)*. Those with intellectual disabilities are up to 8 times more likely to die than those without an intellectual disability, and mortality rates for persons with a learning disability are 6 times higher than the general population *(465, 466)*. This risk is even more marked among women than men with disabilities *(463)*. Persons with disabilities are also more likely to have underlying health conditions which are associated with poorer health outcomes if infected with COVID-19, such as diabetes *(467, 468)* and chronic kidney disease *(468)*. Persons with Down syndrome, cerebral palsy *(406, 468, 469)*, rheumatoid arthritis and spinal cord injury *(406)* are also at higher risk of COVID-19 complications. In addition, the pandemic has had wide-ranging psychosocial impacts which disproportionately affect persons with disabilities *(103, 422, 425, 470–476)*. Comparative studies demonstrate that adults with disabilities are significantly more likely to report current depressive symptoms *(477–480)* and suicidal ideation *(478)*.

COVID-19 has uncovered the deep-seated structural, social and health system factors that drive health inequities for persons with disabilities. While these factors are prominent in other health emergencies, COVID-19 has seen an unprecedented number of scientific publications, which have helped unpack and better understand the contributing factors to health inequities experienced by persons with disabilities. While this report focuses primarily on COVID-19 as a case example for a health emergency, it is important to note that all factors contributing to health inequities apply fully in other emergencies, such as humanitarian crises, or emergencies from hazards such as infectious diseases, chemical and radio nuclear incidents, food contamination, and threats associated with climate change, including extreme weather events and deforestation.

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In terms of structural factors, societal values during the pandemic have been manifested in negative stereotyping and prejudice of persons with disabilities in health messaging *(378, 481)*, physical violence, abuse, neglect and ostracizing *(104, 385, 482)*. In some countries, persons with intellectual disabilities with COVID-19 are twice less likely to be admitted to intensive care units, despite having similar rates of complications or having symptoms on admission that are more severe than those without disabilities *(483)*.

Unconscious bias *(406, 484–488)* and "ableist preconceptions of medical staff" *(406)* have been linked to discriminatory triage practices during the COVID-19 response, and the health policies and measures adopted largely do not consider the specific needs of persons with disabilities. Lockdowns, physical distancing requirements and prioritization of health services sometimes disproportionately affected the access to essential services for persons with disabilities including to specific medication, psychosocial support, rehabilitation and assistive products, all of which are critical to maintaining their health and functioning *(103, 378, 404, 422, 436, 471, 473, 489–491, 492, 493)*. There are also concerns that health emergency policies for COVID-19 may have led to measures which constitute human rights violations against some groups of persons with disabilities, particularly for those in residential institutions, older people and underrepresented groups *(494–497)*.

Organizations of persons with disabilities, and other organizations that include persons with disabilities such as associations of older persons, are often overlooked in decision-making processes during health emergencies *(498, 499)*.

Disparities in social determinants of health have also been exacerbated during the pandemic. In several countries, children with disabilities have been left even further behind in their education when countries have tried to ensure continuity of education. This is because distance education during the pandemic has not been accessible or well suited to those who require more individualized, in-person support *(378, 425, 497, 500, 501)*. It is important to note that for many children and young persons with disabilities, school is also an entry point to accessing other services, such as speech therapy, occupational therapy, counselling and behavioural support *(425, 502, 503)*. As regards employment, persons with disabilities have faced job losses and fewer hours of work, reduced household income, and in some countries, food insecurity at a greater extent during the COVID-19 pandemic *(103, 504–507)*.

Barriers to transportation have also affected access to appropriate testing and health care, with the impact being disproportionately on women and girls with disabilities *(404, 508, 509)*. Concerns have been raised regarding the safety of persons with disabilities during the pandemic *(510)*, especially women and girls *(511, 512)*, older persons and those in residential facilities or institutions *(496)*, due to an increased risk of violence. The United Nations Population Fund (UNFPA) reported increased risk factors for gender-based violence against women and girls with disabilities *(509)*, and non-binary and transgender persons with disabilities *(511)*, as well as compounded barriers to accessing relevant support services, the police, and mechanisms for justice.

Barriers in health systems have detrimentally impacted persons with disabilities during the pandemic. Movement, physical contact, and visitors to hospitals and residential facilities have been restricted, leaving persons with disabilities isolated and without people who could assist with communication and psychosocial support *(300–302)*. Essential health information has often been inaccessible, with a lack of captioning and sign language used in press conferences, public information sharing forums, testing locations and at health facilities *(103, 513, 514)*. The pandemic has hindered access to personal assistance, informal care and access to assistive technology for persons with disabilities *(496, 515, 516)* which in turn affects their access to health care. There are also reports of issues relating physical access to COVID-19 testing facilities *(404, 508)*. Finally, while there are examples of disability-disaggregation in COVID-19 data collection, there is little analysis of the full range of intersecting factors, such as those relating to sex, age, and socioeconomics, which may put some persons with disabilities more at risk than others *(117, 517–520)*.

More positively, the COVID-19 pandemic has mobilized the health sector and civil society in some countries to address health inequities for persons with disabilities. Standards, plans and guidelines have been developed at global, regional and country levels that relate specifically to persons with disabilities and disability inclusion in health emergency programmes *(521–526) (527–544)*. While these examples mark positive steps to build more inclusive policies and processes, few have been evaluated for effectiveness, and evidence that relates to implementation is limited. Given the wide-ranging impact of COVID-19, it is unsurprising that there has been a heavy focus on social protection interventions. As of 2021, 44% of countries that announced social protection measures in response to COVID-19 made a specific reference to persons with disabilities showing an increase from earlier analyses (98 countries in 2021 compared with 60 countries in 2020) *(545, 546)*. Cash benefits, including expansion of coverage for persons with disabilities, temporary top-ups to pre-existing benefits and administrative adjustments, were the most common COVID-19 social protection responses, followed by in-kind transfers and provision of services *(545, 547)*. In addition, there are isolated strategies to address physical barriers to COVID-19 vaccination for persons with disabilities, such as providing transportation to accessible community-level facilities *(548)*, and door-to-door/in-home vaccination services *(415, 548, 549)*. In New York State in the United States, drive-through COVID-19 vaccination for persons with developmental disabilities was established to achieve vaccination of patients who could not be served by the Federal Program of on-site vaccination *(550)*.

Civil society, including organizations of persons with disabilities, have played a fundamental role in the COVID-19 response for persons with disabilities. Examples from many countries show the driving force of civil society to develop tools for persons with disabilities to make their own individualized COVID-19 preparedness plans *(539)*. Organizations have developed and implemented adaptive learning methods for children with disabilities *(551)*, provided devices and covered internet costs for persons with disabilities to stay connected and to access information and services *(378)*, or given financial and other support *(104)*. Nongovernmental organizations have also played a critical role in identifying the injustices faced by persons with disabilities during the pandemic, influencing governments and health authorities to act accordingly. One such example, is that of the China Disabled Persons' Federation which issued a notice to local governments on the risks associated with gaps in care and medical services for persons with disabilities, especially when separated from carers. This led to a range of policy adjustments and the eventual development by the government of "Guidelines for the Protection of Disabled Persons with Major Infectious Diseases" *(537)*. All efforts and initiatives driven by civil society are fundamental; however, these should not substitute the responsibility of the health sector to guide the agenda of advancing health equity for persons with disabilities.

Case study

Integrating disability considerations during the COVID-19 response in Qatar

The national COVID-19 response plan of Qatar integrated considerations for persons with disabilities in several ways. Information about COVID-19 was provided in various accessible formats, such as infographics on preventive measures, social media videos, text messages and radio interviews. An admissions triage system in health-care facilities noted the needs of persons with disabilities; an allowance was given to support persons in quarantine.

Data on disability were collected by health-care workers among patients admitted to hospital with COVID-19. A checklist covered disability type and severity, assistive devices, communication mode, independence level in daily activities, information on family, medical history and medication. The data – disaggregated by gender, age and services provided – contributed to assessing the overall COVID-19 profile of persons with disabilities to inform planning and policy development.

A specific plan was developed for the continuity of essential health services; this included the provision of rehabilitation services and assistive technology at primary, secondary and tertiary levels. Telemedicine, telerehabilitation, phone consultations and home care programmes were introduced as mitigation strategies to minimize the spread of infection and to allow some continuation of rehabilitation services.

Importantly, the government consulted with persons with disabilities and their organizations in developing COVID-19 plans. For example, the Autism Society was consulted when developing online platforms for persons with disabilities as part of the essential health services continuity plan.

Qatar managed to integrate disability in its COVID-19 response partly because of its prior plan for an inclusive health system. The country now plans to establish a permanent, national patient and family advisory council, and to develop an online disability knowledge platform for disability support.

Several lessons have been learned from the COVID-19 pandemic that can shape the way forward for achieving health equity for persons with disabilities:

- The engagement and participation of persons with disabilities in the processes and decision-making of the health sector is a resource needed for advancing health equity. The participation of persons with disabilities provides strong support towards ensuring that policies, strategies, and programmes are more effective in addressing factors that drive health inequities, such as shifting attitudes, and dismantling stigmatization. Persons with disabilities have first-hand experience of the challenges they face and know best what can be done to enhance their rights, health, and well-being.
- Health services need to be provided close to where people live. The pandemic has shown that it is essential for persons with disabilities to have immediate and uninterrupted access to health care in their communities. The primary health care approach discussed in Chapter 3 presents an opportunity to advance service health delivery in communities.
- Support services and services that are specific to the underlying impairments and health conditions of persons with disabilities are essential. Such services can include vision rehabilitation, the provision of both assistive technology and disability support service staff (e.g. interpreters, care staff, support workers and personal assistants); they are fundamental to the health and safety of persons with disability, and for their participation and inclusion into communities, and should not be reduced in any capacity, including in emergency situations.
- It is crucial to deliver public health interventions and information in a format that is accessible to persons with disabilities. Organizations of persons with disabilities can be partners in public health information campaigns to ensure that messages are clear, inclusive, and accessible, and also for designing public health interventions and campaigns.
- Capacity-building and training of health professionals on disability-related issues are central considerations. If appropriately trained, health-care professionals will better understand the requirements of persons with disabilities and respond to the factors that influence their health outcomes.
- Deinstitutionalization is a major factor in moving forward. The COVID-19 pandemic has resulted in elevated rates of mortality among persons with disabilities in long-term care institutions, largely because of poor living conditions and the inability to ensure prevention measures. Person-centred, rights-based health services and support in the community are good alternatives to institutionalized care for persons with disabilities.

- Digital health interventions are alternative methods of providing health services and support. Telehealth, online and mobile phone peer support and counselling, counselling help lines, and tele-support have been widely used in countries as alternatives to physical health services and support. Importantly, when provided in an accessible manner, digital health can be an important platform to reach persons with disabilities.
- Monitoring which interventions work and where improvements are needed, by collecting and disaggregating data by disability, directs the actions of the health sector. Integrating disability in data collection allows countries to better understand the drivers of health inequities for persons with disabilities.
- A wider approach to strengthening health systems enables an inclusive health emergency response. Measures taken after the occurrence of an emergency are very often not inclusive and insufficient. A broader reshaping of the health sector is needed to ensure greater inclusion and equity, as well as to reduce risks and build resilience for future health emergencies.
- Strong leadership is needed to address the wider structural factors of society and health systems that drive health inequities for persons with disabilities; it involves a system-level approach that ensures inclusive policies, legislation, and financing, as well as multisectoral collaboration with major governmental and nongovernmental stakeholders.

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3. Advancing health equity for persons with disabilities in the health sector

Personal story

Turning around a life through accessible medicines

Photo: © Myanmar Epilepsy Initiative

For much of his life, Myint Aung, 46, has struggled to get proper care for epilepsy. After his first seizure at two years of age following a fever, his parents took him to people who claimed to be health providers, but soon afterwards he developed paraparesis and could no longer walk. Convulsive seizures then occurred a few times a week.

Visiting the rural health centre was difficult when he was young and involved riding on a bullock cart for seven miles. The township hospital was even further away at 11 miles. Later, there were roads and a limited bus service, but his condition made travel difficult.

There was also little money available for health care, which was not provided cost-free for his health condition. After his parents divorced when he was aged three, his mother had to support four children alone. Unable to walk, and without access to assistive products like a wheelchair, he could not attend school with his siblings. He seldom had contact with anyone beyond the people in his neighbourhood.

In 2018, following the launch of the Myanmar Epilepsy Initiative *(1)* a midwife told the family about available health services for epilepsy. The family travelled by taxi to the township hospital where Myint Aung was prescribed anti-epileptic drugs. Finally, his seizures were brought under control because of the medicine. He was later able to get his medication from the village midwife free of charge, meaning he no longer had to travel or pay for treatment. "I feel much better," he said. "Now I have a cartwheel which I operate with my hands. I can move about quite easily. It makes me happy." Because of the medication, he can now bathe and feed himself without assistance and even help his mother make snacks to sell.

Overview

- ✓ The primary health-care (PHC) approach is an approach to strengthen health systems.
- ✓ Although PHC can sometimes be confused with primary care, its scope extends beyond primary care; the important distinction is that PHC is built on three key pillars:
  - integrated health services with an emphasis on primary care and essential public health functions;
  - multisectoral policy and action; and
  - empowering people and communities.
- ✓ In principle, as an approach to strengthening health systems, PHC addresses the contributing factors to health inequities in the population. However, health equity for persons with disabilities will only be achieved if PHC is implemented through integrating targeted disability-inclusive strategies within the mainstream actions.
- ✓ Targeted actions for persons with disabilities also contribute to progressing global health priorities (UHC, promoting health, and addressing health emergencies), since the actions aim specifically to address factors that continue to exclude and leave behind persons with disabilities.
- ✓ Based on the PHC approach, this chapter outlines 40 key targeted actions for disability inclusion that can be integrated across 10 strategic entry points of the health system.

Chapter 2 highlighted two important issues for the health sector: i) that health inequities for persons with disabilities are driven by a variety of unjust factors that need to be addressed; and ii) that due to these factors, the global health priorities that countries are working to meet are failing to reach persons with disabilities, and in turn are unlikely to be met.

The evidence that relates to unjust factors, although fragmented, shows clearly that multiple structural factors and social determinants of health, risk factors and barriers in health systems, create health inequities for persons with disabilities. While many of these factors occur within the health sector, others relate to those outside; very often these factors are successive, interconnected, and mutually reinforcing. Furthermore, the contributing factors to health inequities compromise the realization of the global health priorities, namely UHC, the improvement of population health and protection in health emergencies. For persons with disabilities, access to quality and affordable health services is frequently challenging; public health interventions are rarely designed and delivered in ways that are accessible, and the management of health emergencies in countries is often not inclusive. Given the complexity and the linkages between these factors, a comprehensive and multifaceted system level response is required.

This chapter presents a vision of how governments can lead the health sector in addressing the contributing factors to health inequities for persons with disabilities. The only way forward includes a systems-level response, through strengthening health systems, that integrates targeted actions to advance health equity for persons with disabilities. **Addressing health inequities for persons with disabilities should not be a siloed activity conducted by the health sector in addition to other ongoing activities, but rather a strategy that is integrated into the overall efforts of a country to strengthen its health systems.** For example, when a country invests in developing its workforce of health professionals, building the competencies and skills for disability inclusion can contribute to addressing many of the health inequities encountered by persons with disabilities and other marginalized populations. This vision of strengthening health systems through the lens of PHC, advances health equity for everyone including persons with disabilities.

Achieving health equity for persons with disabilities through health system strengthening using a primary health care lens

In principle, PHC as an approach to strengthening health systems, addresses the contributing factors to health inequities in the population (Box 11). However, as outlined later in this chapter, health equity for persons with disabilities will only be achieved through the implementation of PHC that integrates targeted disability-inclusive strategies within mainstream country actions.

Box 11

Primary care versus primary health care approach

Primary care is the first level of care in the delivery of health services. Primary care provides promotive, preventive, curative, rehabilitative, and palliative services throughout the life course. The primary health care approach strengthens health systems; it extends beyond primary care and is built on three key pillars: i) integrated health services with an emphasis on primary care and essential public health functions; ii) multisectoral policy and action; and iii) empowering people and communities. In this report, the primary health care approach is presented as the foundation for achieving health equity for persons with disabilities. Only through implementing PHC that integrates targeted disability-inclusive strategies within the mainstream country actions, will health equity for persons with disabilities be achieved.

PHC is instrumental for health equity not only conceptually but also pragmatically since countries have already committed to the approach and are investing in its implementation *(2, 3)*.

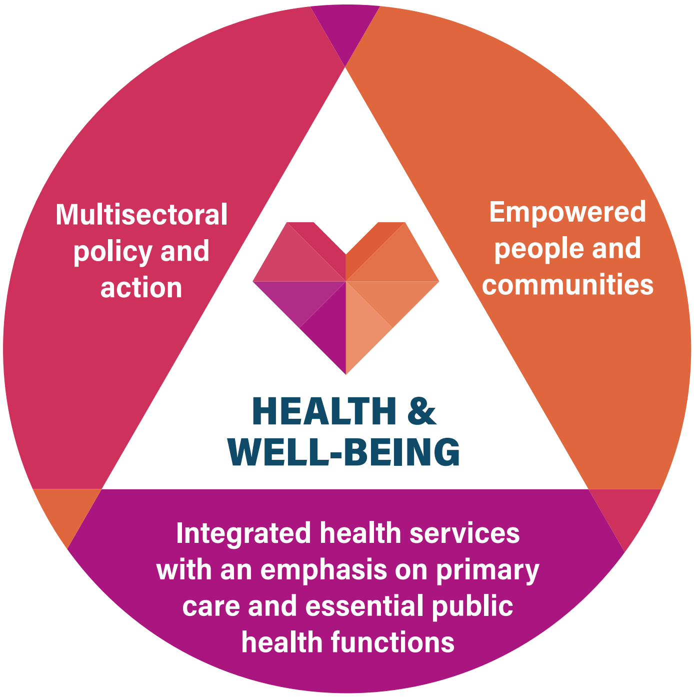
As illustrated in Figure 5, the three core conceptual pillars of PHC are:

i) integrated health services with an emphasis on primary care and essential public health functions;

ii) multisectoral policy and action; and

iii) empowering people and communities.

Figure 5. Conceptual pillars of the PHC approach



Integrated health services with an emphasis on primary care and public health functions are crucial for addressing many of the structural and health system factors for health inequities, including the accessibility, affordability, and availability of health services. Through integrated services, the health sector can provide people-centred care across the life course that is close to where people live and responsive to their unique requirements. Furthermore, people-centred care is essential to overcome stigmatization and discrimination within the health sector and improve the health outcomes of the population. The public health functions specifically relevant to PHC, and closely linked to primary care, are health protection and health promotion; the prevention, surveillance and response of disease; and emergency preparedness. Health promotion enables people to have more control over their own health through better health literacy and an improved ability to provide care for themselves and for others. Furthermore, through a wide range of multisectoral policies and interventions, health promotion aims to create physical and social environments that are health-enhancing.

Multisectoral policy and action are the mechanisms through which the broader determinants and risk factors for health are addressed. These factors generally lie outside the immediate influence of the health sector but are major contributors to health inequities, as discussed in Chapter 2. For example, inaccessible clean water and sanitation; air pollution; tobacco, alcohol, and other dependence-producing substances; physical inactivity; or poor nutrition can be addressed through collaborative multisectoral policy and action. Action can be in the form of regulatory or fiscal interventions, or population health promotion campaigns. The goal of the PHC approach is to recognize the roles that other sectors – from education, labour, finance and industry to agriculture and urban planning – play in addressing the determinants of health, and to ensure that these sectors design inclusive policies that reach everyone irrespective of who the people are and where they live.

The pillar *empowering people and communities* is fundamental in the context of health equity. It refers to how people can take an active role and have a say in any actions that are taken by the health sector; this includes the direct participation of individuals in decision-making, and the improvement of knowledge regarding them being active participants who contribute to their own health and well-being. Through PHC, empowered people and communities are inextricably linked to the second element of multisectoral policy and action; they are engaged in setting and implementing policy priorities that address the structural determinants that affect their lives.

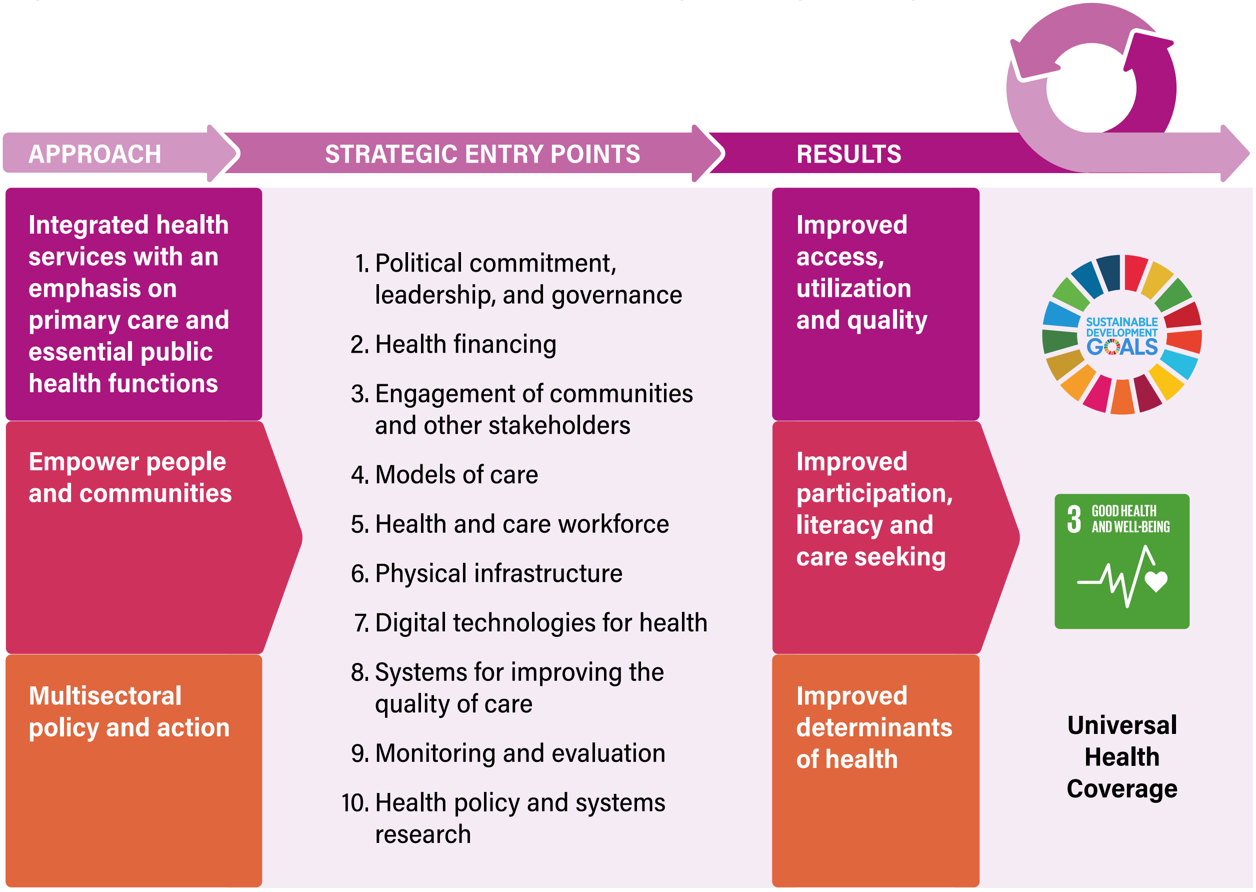
The three main pillars of the PHC are operationalized through a set of strategic entry points (Figure 6). These entry points are an extension of the building blocks of the health system introduced in Chapter 2 and represent all aspects of the health system that should be strengthened depending on the specific country situation.

The 10 strategic entry points for disability inclusion, adapted from the original PHC framework *(4)*, are:

1. political commitment, leadership, and governance
2. health financing
3. engagement of stakeholders and private sector providers
4. models of care
5. health and care workforce
6. physical infrastructure
7. digital technologies for health
8. systems for improving the quality of care
9. monitoring and evaluation, and
10. health policy and systems research.

The 40 targeted actions recommended in this chapter will contribute to progressing global health priorities without leaving behind persons with disabilities. The implementation of actions across the 10 strategic entry points needs to take into consideration the contexts, strengths and weaknesses of the health system, and the national and local priorities of countries. Countries can decide, depending on their circumstances, which entry points to prioritize in addressing the health inequities that exist for persons with disabilities. All strategies and actions must take a gender transformative and intersectional lens, so that everyone benefits and is included.

Figure 6. Framework for health sector strengthening through PHC*



*_Source_: Adapted from World Health Organization and United Nations Children's Fund. Operational framework for primary health care: transforming vision into action. Geneva: World Health Organization; 2020.

The 40 targeted actions for disability inclusion across the 10 strategic entry points are described in Table 4. Each strategic entry point starts with a brief description followed by a summary of the available evidence on disability inclusion within each area. The evidence provides the basis for promoting the targeted actions within each entry point; however, for some areas the evidence is limited. This is followed by a description of the disability inclusive strategies for each entry point, which are:

- practical and evidence-based;

- applicable to all countries but need to be contextualized depending on the country level of social or economic development, degrees of PHC orientation and health status;
- applicable at national or subnational level; and
- interdependent.

Each strategic entry point ends with examples of indicators for monitoring and evaluation. These indicators are only indicative of what governments can consider in tracking progress on disability inclusion; they are examples to increase the understanding of the strategic entry point and can be used and adapted by countries according to their context. WHO is in the process of developing and testing a comprehensive set of indicators for countries, as part of implementation guidance being created to accompany this report.

Table 4. The 40 targeted actions for disability inclusion across 10 strategic entry points

Political commitment, leadership, and governance:

1. Prioritize health equity for persons with disabilities.
2. Establish a human rights-based approach to health.
3. Assume a stewardship role for disability inclusion in the health sector.
4. Make international cooperation more effective by increasing funding to address health inequities for persons with disabilities.
5. Integrate disability inclusion in national health strategies, including preparedness and response plans for health emergencies.
6. Set actions that are specific to the health sector in national disability strategies or plans.
7. Establish a committee or a focal point in the Ministry of Health for disability inclusion.
8. Integrate disability inclusion in the accountability mechanisms of the health sector.
9. Create disability networks, partnerships and alliances.
10. Ensure the existing mechanisms for social protection support the diverse health needs of persons with disabilities.

Health financing

11. Adopt progressive universalism as a core principle, and as a driver of health financing, putting persons with disabilities at the centre.
12. Consider health services for specific impairments and health conditions in packages of care for UHC.
13. Include into health-care budgets the costs of making facilities and services accessible.

Engagement of stakeholders and private sector providers

14. Engage persons with disabilities and their representative organizations in health sector processes.
15. Include gender-sensitive actions that target persons with disabilities in the strategies to empower people in their communities.
16. Engage the providers of informal support for persons with disabilities.

17. Engage persons with disabilities in research and including them in the health research workforce.

18. Request that providers in the private sector support the delivery of disability-inclusive health services.

Models of care

19. Enable the provision of integrated people-centred care that is accessible and close to where people live.

20. Ensure universal access to assistive products.

21. Invest more finances in support persons, interpreters, and assistants to meet the health needs of persons with disabilities.

22. Consider the full spectrum of health services along a continuum of care for persons with disabilities.

23. Strengthen models of care for children with disabilities.

24. Promote deinstitutionalization.

Health and care workforce

25. Develop competencies for disability inclusion in the education of all health and care workers.

26. Provide training in disability inclusion for all health service providers.

27. Ensure the availability of a skilled health and care workforce.

28. Include persons with disabilities in the health and care workforce.

29. Train all non-medical staff working in the health sector on issues relating to accessibility and respectful communication.

30. Guarantee free and informed consent for persons with disabilities.

Physical infrastructure

31. Incorporate a universal design-based approach to the development or refurbishment of health facilities and services.

32. Provide appropriate, reasonable accommodation for persons with disabilities.

Digital technologies for health

33. Adopt a systems-approach to the digital delivery of health services with health equity as a key principle.

34. Adopt international standards for accessibility of digital health technologies.

Quality of care

35. Integrate the specific needs and priorities of persons with disabilities into existing health safety protocols.

36. Ensure disability-inclusive feedback mechanisms for quality of health services.

37. Consider the specific needs of persons with disabilities in systems to monitor care pathways.

Monitoring and evaluation

38. Create a monitoring and evaluation plan for disability inclusion.

39. Integrate indicators for disability inclusion into the monitoring and evaluation frameworks of country health systems.

Health policy and systems research

40. Develop a national health policy and systems research agenda on disability.

1

Political commitment, leadership, and governance

What does it mean?

Political commitment and leadership imply:

- prioritizing the health of the population and placing the strengthening of health systems at the heart of countries' efforts to achieve UHC and SDG3.
- providing strategic direction and priorities to the agenda of the health sector.
- creating commitment across the health sector and other sectors to address the priorities for improved health services.

Governance implies ensuring that:

- "strategic legal and policy frameworks exist and are combined with effective oversight, coalition building, regulation, attention to system design and accountability" *(5)*.
- the health sector is the steward for health and engages a full range of actors; this is critical for a comprehensive approach to strengthening health systems.

During the past decades, different actions have been taken to strengthen leadership, commitment, and governance for disability inclusion in the health sector. For example, there has been a marked shift in implementing the right to health for persons with disabilities in national constitutions. While only 6% of the 90 constitutions adopted prior to 1990 guaranteed some form of such right, today many constitutions include aspects of health rights. The greater recognition of their importance over the past 15 years is likely due to the wider adoption of CRPD *(6)*; nevertheless, overall guarantees of the right to health for persons with disabilities remain very low.

In addition, there have been calls in the literature for the development of multisectoral coordination mechanisms and collaborative plans which address the structural factors that add to the risk for persons with disabilities in health emergencies. Such mechanisms are required to support the acceleration of efforts for deinstitutionalization, to strengthen the wider social support sector, *(7, 8)*, and to "build universal and inclusive social protection systems" *(9)*.

A large body of evidence highlights the importance of social protection for persons with disabilities. While the participation of persons with disabilities in social protection programmes is very limited in low- and middle-income countries *(10),* evidence shows that with the provision of cash transfers, persons with disabilities are more likely to have regular visits to their general practitioner, have no out-of-pocket expenses, and are more likely to take advantage of other medical benefits schemes *(11).* It has been suggested that cash benefits entail lower administrative costs and can provide persons with disabilities with the choice and control to select services and providers *(12).* Also, social protection schemes can consider the wide range of added disability-related costs, and as such these should not be tied to work, minimum salaries, or number of hours worked.

In the context of COVID-19, the UN recommended the global expansion of both mainstream and disability-targeted social protection during the pandemic through several methods including advancing payments; extending coverage to those with disabilities previously deemed ineligible; providing "top-ups" to existing beneficiaries who may have to stop work to support persons with disabilities; and establishing electronic payment and home delivery for cash and essential food and non-food items *(13).* Organizations representing the rights of women, girls and gender non-confirming persons with disabilities have also raised the need to "urgently adopt social protection measures – including income supplementation, rent subsidies and eviction moratoriums, food subsidies, and free clean water and hygiene measures, including menstrual hygiene" to fill income gaps, meet basic needs, and in turn reduce risks faced by these and other groups *(14).*

Integrating disability into national health strategies or health programmes – for example strategies in response to HIV *(15)*, or management plans for health emergencies – has been suggested extensively. In relation to health emergencies, adopting indicators to monitor human rights in health can progress combating stigmatization and discrimination and can also serve as an "early warning tool". The United Nations has explicitly integrated disability into different thematic indicators that have been developed to monitor the response in human rights-based policy to the COVID-19 crisis, which in turn acts as an "early warning tool" for potential discrimination *(16)*.

Setting committees to oversee policies for disability has been discussed widely. In the context of COVID-19, for example, given the evidence of discriminatory practices adopted in health emergencies, decisions about prioritization, triage and rationing in times of crisis can be made by interdisciplinary committees, which include representation from communities advocating for the rights of persons with disabilities *(17–19)*. Such governance mechanisms can instil a wider change in culture across the sector, shifting wider perspectives and approaches taken by health professionals to ensure dignity, equality, and human rights in their work with persons with disabilities and their families *(20)*.

Regardless of the actions that have been put in place, the extent to which these actions are effective and how systematically they are implemented, remains open to question. A lack of monitoring of progress of the different governance mechanisms and policies has further contributed to the limited prioritization of disability in the health sector.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

1. Prioritize health equity for persons with disabilities

The prioritization of health equity for persons with disabilities can occur at different levels. It can involve raising awareness by regularly communicating the importance of health equity in national and international fora; in practice, it can mean formalizing governance mechanisms and commitments for disability inclusion through policies or legislation. It is important that these mechanisms and commitments prohibit discrimination and demand reasonable adjustments for persons with disabilities. Prioritizing health equity can include highlighting disability inclusion in key strategies such as the national health strategy, as well as establishing a plan for monitoring and evaluation to track progress on its implementation.

Box 12 provides an example of the commitment of Member States of the WHO European Region to advance disability inclusion in the health sector through the adoption of *The WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030.*

Case study

Striving to improve the lives of persons with disabilities in Tajikistan

For several years the care of persons with disabilities has been an important priority of the Government of Tajikistan, with significant progress made in policy, services and legislation, including the Social Protection of the Disabled law. The Government declared its commitment to improving rehabilitation and care for persons with disabilities in the 2019 Dushanbe Declaration on Disability Issues *(21)*.

A focus on disability emerged following a large outbreak of polio in 2010, which prompted a drive to provide rehabilitation services and assistive products for the children affected. With the support of WHO, a national priority Assistive Products List was developed in 2018. This list of 30 essential priority products – such as wheelchairs, hearing aids and prosthetics – offers a model for other countries.

After a situational analysis identified needs and challenges, a disability and rehabilitation programme was implemented; this included strengthening the provision of assistive products, services and personnel in primary care, with the "1-Stop" project offering an impactful model for nationwide scale-up. Today, over 7000 products of 23 different types, have been procured, with products distributed to the National Orthopaedic Centre and four ongoing pilots in primary health centres in Rudaki district, where 18 family nurses and doctors have received training on assistive products. A National Assistive Technology Centre is also being developed.

The 2020 National Plan of Actions serves as a roadmap to implement the United Nations Convention on the Rights of Persons with Disabilities and integrates the work of state authorities and civil society institutions. Meetings in 28 cities and districts raised awareness on disability issues and effective measures. In these meetings, health officials, partners and leaders of organizations of persons with disabilities met with officials from agencies dealing with social services, employment and construction. A new national disability and rehabilitation programme is being developed for 2023–2028, supported by WHO.

Box 12

WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030

In 2022, Member States of the WHO European Region committed to advance disability inclusion in the health sector through the adoption of *The WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030 (22).* The objectives of the framework focus on i) universal health coverage; ii) the promotion of the health and well-being of persons with disabilities; iii) the protection of persons with disabilities during public health emergencies; and iv) the creation of an evidence base on disability and health. The framework includes objectives, targets and specific actions for Member States of the WHO European Region, and national and international stakeholders, as well as a detailed monitoring and evaluation framework, to ensure that the right to health for persons with disabilities is fully realized. The framework will be implemented in the coming years.

2. Establish a human rights-based approach to health

Establishing a human rights-based approach to health means integrating and operationalizing the commitments for human rights across programmatic interventions taken by governments. Countries need to assume their obligations to respect, to protect, and fulfil the right to health for persons with disabilities. **Respecting** the right to health involves respecting the rights of persons with disabilities to have control over their own health and make decisions about their own treatment. **Protecting** the right to health involves ensuring that other people respect those rights, and that countries defend persons with disabilities against human rights violations.[15] Repealing laws and revising policies and programmes that discriminate and violate rights are steps that every country can take in this direction. In relation to **fulfilling** their obligations, countries need to take positive action to facilitate the enjoyment of the basic human right to health for persons with disabilities. Progress on this obligation can be achieved through strategies and solutions that address discriminatory practices and unjust conditions which are often at the heart of inequitable health outcomes for this group of people.

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[15] https://www.un.org/en/about-us/udhr/foundation-of-international-human-rights-law.

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For example, addressing the right to legal capacity (see Box 13), as well as having systems for safeguarding, can ensure that acts of coercion, violence and abuse in health-care settings are appropriately investigated and prosecuted. It is vital to recognize the right of all persons with disabilities, including those with psychosocial, cognitive or intellectual disabilities, to exercise their legal capacity on an equal basis with others in all areas of life. This implies that respect for legal capacity, without discrimination, is at the centre of all efforts to strengthen health care. Replacing all forms of substitute decision-making with supported decision-making so that persons with disabilities can be empowered to make decisions and take control over their lives and choices is a way to achieve this. When preparing changes to legislation, it is important that governments work closely with national and regional organizations of persons with disabilities and nongovernmental organizations (NGOs). In Germany, for example, as in some other countries, an arbitration service already exists[16] to support persons with disabilities in situations of discrimination by government agencies.

A human rights-based approach needs to be gender-responsive and cross-sectoral. Adopting a human rights-based approach can further address sexism and gender inequality, ageism, stigmatization and discrimination related to sexual orientation or gender identity, as well as discrimination based on race,

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[16] https://www.schlichtungsstelle-bgg.de/Webs/SchliBGG/EN/home/english-node.html.

ethnicity or religious background. In addition, such an approach should not only address health service delivery but also the broader structural factors, risk factors and social determinants of health, which, to a large extent, shape health outcomes for persons with disabilities. This can be facilitated through governance, and human rights-based frameworks and mechanisms beyond health service delivery, such as those led by other sectors (e.g. tobacco, WASH, nutrition).

When establishing a human rights-based approach to health, national and subnational laws and policies on disability must be aligned with international norms, standards and regulations, including the main concepts of the CRPD, and specifically in terms of availability, accessibility, affordability and quality of health-care goods, services and facilities. While the CRPD provides the framework for countries to develop or amend health laws, the non-ratification status of the CRPD should not be a barrier to advancing health equity for persons with disabilities.

Case study

Mainstreaming disability with a human rights approach in Uruguay

Since 2019, the Government of Uruguay has been driving a human rights approach to mainstreaming disability in the health sector under an innovative nationwide project involving several government bodies, United Nations organizations, civil society and organizations of persons with disabilities.

"The right to equality and non-discrimination of persons with disabilities" project aims to:

- **achieve better access to health**, particularly the sexual and reproductive health of young persons with disabilities through providing services that are more accessible and inclusive; training 400 health workers; providing accessible information; implementing initiatives for young people; and establishing new care protocols based on human rights.
- **prevent and highlight gender-based violence** and other forms of institutional violence by adapting protocols for accessible care, training 300 interinstitutional members of a response team, and providing information to relevant health, education and child protection agencies.

- **improve disability-related information** and design disability-inclusion policies by incorporating a disability component in administrative records and data sources, and by training state technicians, civil society organizations and academia on the methodologies to survey and assess disability.

Within the project framework, persons with disabilities provide technical input and take part in exchange spaces or dialogue tables. Consideration is given to the heterogeneity of disability and those most at risk of discrimination and violence.

To ensure the access to health for persons with disabilities, a set of "minimum requirements", with recommendations on how to incorporate these, has been developed for all health providers. Two delegates have been appointed from each provider for the ongoing training. The minimum requirements include:

- computer support for the registration of users in a disability situation;
- disability-awareness workshops with a human rights-based approach;
- a disability reference person to provide information on access, benefits and services;
- a list of accessible routes to care;
- diversity in communication and information, such as the use of Braille signage;
- modified waiting times if needed;
- a reduction in health costs; and
- universal design.

Box 13

The right to legal capacity

The right to legal capacity for persons with disabilities is enshrined in the Convention on the Rights of Persons with Disabilities. Persons with disabilities must have the same rights as any human being to make their own decisions in all areas of life. In particular, persons with psychosocial, cognitive or intellectual disabilities, and older persons with disabilities often experience challenges in exercising these rights. If the full exercise of legal capacity is not allowed, a health system cannot be inclusive or human rights-based.

In adopting an approach to health that is human rights-based, countries can support persons with disabilities in achieving their rights. This approach to health involves replacing substitute decision-making processes and frameworks with those based on supported decision-making. This may involve enabling persons with disabilities to have access to trusted support persons of their choosing who can assist them in understanding the options available to them; help them to consider the advantages and disadvantages of particular choices and decisions related to the health services they receive; and support them in communicating their will and preferences with health and care professionals. Within the frames of its QualityRights initiative, WHO has developed a core training on legal capacity and the right to decide, as well as on supportive decision-making for countries in strengthening their policies *(23, 24)*.

3. Assume a stewardship role for disability inclusion in the health sector

In taking a stewardship role, the health sector can ensure the strengthened provision of health services, and coordinate private sector services to make certain they are inclusive of persons with disabilities and linked with health priorities. In addition, in terms of multisectoral work, stewardship of the health sector can ensure any policies or public health interventions led by other sectors that directly or indirectly concern the health of the population are disability inclusive. Multisectoral coordination at both strategic and operational levels of social protection, education, food, housing, or WASH policies, among others, plays an important part in determining health equity and outcomes for persons with disabilities. For example, any physical activity campaign developed, or climate change policy established should be coordinated with the Ministry of Health. By assuming a stewardship role, the health sector can also leverage knowledge, expertise, reach, and resources from other sectors and partners, and thereby benefit from combined and varied strengths. Many countries have entities in place, such as national councils or committees for Disability Affairs, that coordinate cross-sectoral linkages and take a stewardship role across sectors. Strengthening the role of the Ministry of Health in these entities is important.

4. Make international cooperation more effective by increasing funding to address health inequities for persons with disabilities

Many low-income countries depend on international funding from donors to progress disability inclusion in their health sectors. It is important, therefore, for countries that can mobilize resources in terms of financial and technical assistance, to support others that lack these resources. Such assistance to implement strategies to address health equity for persons with disabilities can be a good approach in the short-term. Sharing information, cross-country knowledge, or training platforms on disability inclusion can strengthen international cooperation on disability. However, it is important that international cooperation does not segregate persons with disabilities, undermine their rights, or create or exacerbate barriers. Any efforts towards international cooperation must also recognize the fundamental requirement to include persons with disabilities in technical or other resource analysis or allocation processes as outlined in Article 32 of the CRPD.[17]

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[17] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-32-international-cooperation.html.

Case study

Mainstreaming disability in sexual and reproductive health in the Pacific

The Government of Australia has been a leader in advancing disability-inclusive development since 2009, by working with partners to build disability responsive policy and services in developing countries, with a focus on support for the Pacific region.

Across the Pacific, women and young people with disabilities face particular barriers to accessing sexual and reproductive health services, including physical access, health worker knowledge and attitudes, family and community attitudes and accessibility of information tailored to specific needs (for example information in Braille for people with vision impairment).

The Government of Australia is addressing these barriers through the $30 million 'Transformative Agenda for Women, Youth and Adolescents' programme, a major investment in the Pacific towards eliminating unmet need for family planning (FP) implemented by the United Nations Population Fund (UNFPA) and Governments in Fiji, Kiribati, Samoa, Solomon Islands, Tonga and Vanuatu.

The Transformative Agenda works with national and international organisations of people with disabilities, including Women Enabled International and the Pacific Disability Forum, to assess the sexual and reproductive health and rights as well as gender-based violence service needs of people with disabilities to inform guidance and recommendations that can improve service responsiveness *(25–27)*.

The Transformative Agenda has mainstreamed disability inclusion across its various activities. It surveyed health facilities on their accessibility and communication barriers, which led to increasing policy awareness and change. For example, in Tonga, a draft reproductive health policy calls for contraceptive information to be accessible for people with disabilities, and to strengthen disability-friendly skills of healthcare workers.

Other interventions include mainstreaming disability in family planning training packages, incorporating disability-inclusion guidance in adolescent guidelines, supporting disability-inclusive sexual and reproductive outreach programmes, and publishing, during the COVID pandemic, a “Know your rights” guide on sexual and reproductive health and rights and gender-based violence with a disability-inclusive approach *(28)*.

5. Integrate disability inclusion in national health strategies, including preparedness and response plans for health emergencies

To be prioritized within the health sector, disability needs to be integrated as a topic in national and subnational health strategies. The actions to be included to advance health equity for persons with disabilities would depend on the national context, priorities, and health needs of individuals. Such actions can include making mainstream health services and disability-specific services available and accessible for persons with disabilities; establishing multisectoral collaboration; ensuring the participation and engagement of organizations of persons with disabilities in health sector processes; and collecting and analysing sex-, age- and disability-disaggregated data.

6. Set actions that are specific to the health sector in national disability strategies or plans

Including actions specific to the health sector in national disability strategies can give visibility to health as a priority area; specific actions can be aligned with those relevant to disability. It is important to assign responsibilities within the health sector to relevant actors to implement the actions.

7. Establish a committee or a focal point in the Ministry of Health for disability inclusion

A committee or focal point within the Ministry of Health acts as a catalyst to raise the profile of disability inclusion within the health sector. It can have the responsibility of mainstreaming disability across the levels of governance, programmes and operations of the health system. It can also coordinate with other similar government structures, such as human rights focal points, focal points for the implementation of CRPD, or disability focal points in other ministries, as well as with international partners and human rights mechanisms. The committee should be multidisciplinary, be present at subnational structures, involve experts with different backgrounds, and include persons with disabilities. An example of establishing a focal point on disability is in Cambodia, where, in 2009, the Government created the Disability Action Council as the national coordination and advisory mechanism on disability. The council promotes, coordinates and strengthens actions to secure the rights and services necessary for persons with disabilities, thus facilitating their enjoyment of rights, obligations, opportunities, and quality of life equal to that of others in the community.

8. Integrate disability inclusion in the accountability mechanisms of the health sector

This includes integrating relevant indicators that measure performance, or how the health system delivers on its intentions to advance health equity for persons with disabilities, and public response, or whether it is responsive to their needs. The accountability mechanism to assess performance can show concrete results against set indicators and targets (further details of this mechanism can be found in the entry point, "Monitoring and evaluation"). For the accountability mechanisms to function, a clear designation of roles and responsibilities for different activities is needed, as well as standards that define what relevant actors should deliver, an established mechanism for accountability, and tools to do so. It is essential that persons with disabilities and their organizations participate in setting such mechanisms, and in building the capacities; these groups can then become implementers of policies.

9. Create disability networks, partnerships and alliances

Disability leadership is more powerful when united under a shared vision for a disability-inclusive health sector. Creating a united voice for disability advocacy and lobbying at the national level is fundamental *(29)*. To achieve this, a strong disability network, alliances or community of practice can be developed and include persons with disabilities, their representative organizations, families and caregivers, representatives from the Ministry of Health and other relevant governmental sectors, health professionals, development actors, NGOs and academia. Unity avoids the formation or persistence of silos and a fragmented voice. There may also be networks that represent different groups of persons with disabilities, including support networks, that drive the plan forward.
This can guarantee national or regional opportunities for cross-learning and knowledge-sharing among partners to drive timely and concrete actions for disability inclusion. An example of such an existing network is the Global Action on Disability (GLAD) Network[18] formed in 2015. This is a coordination body of bilateral and multilateral donors and agencies, public and private foundations, and major coalitions of the disability movement that share a common interest in achieving inclusive international development and humanitarian action. The GLAD Network share expertise, work together and coordinate joint actions, guided by the CRPD. Examples of country and national multistakeholder initiatives are presented in Box 14.

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[18] https://gladnetwork.net.

Box 14

Country and international multistakeholder initiatives

The Foreign, Commonwealth and Development Office (FCDO) disability inclusion and rights strategy 2022–2030 of the United Kingdom of Great Britain and Northern Ireland *(30)*

In 2022, the FCDO published a disability inclusion and rights strategy 2022–2030 to reaffirm their commitment to act as a global leader on disability inclusion. The strategic vision of the document is that "people with disabilities in all their diversity – including marginalized and underrepresented groups – are meaningfully engaged, empowered and able to exercise and enjoy their full rights and freedoms on an equal basis with others, without discrimination and across the life-course. They are full and active members of society and decision-makers in all aspects of life, including diplomatic and development efforts."

One of the main priorities outlined in the FCDO strategy is the achievement of inclusive health for all. This involves removing barriers to equal, affordable, accessible and quality health services, and ensuring that persons with disabilities have access to gender-sensitive health services including sexual and reproductive health and rights, WASH, nutrition programmes, rehabilitation, assistive technology, and vaccines. The three key actions include:

- influencing disability inclusion through bilateral, multilateral and partner engagement and diplomacy;
- ensuring that data, data systems, research and evidence shape inclusive health systems; and
- supporting advocacy, and the inclusion and meaningful participation of persons with disabilities.

United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) Multi-Partner Trust Fund

The UNPRPD Multi-Partner Trust Fund was established in 2011 as a pooled funding mechanism that brings together the UN system, governments and organizations of persons with disabilities, to advance CRPD worldwide. The partnership provides funding to participating United Nations organizations to conduct joint programming on disability issues prioritized by local actors, including projects on health. In its programming efforts, the UNPRPD focuses on essential preconditions (or foundations) to accelerate implementation of CRPD. To achieve these preconditions, three cross-cutting approaches are also applied across the structures, processes, and programmes of the UNPRPD. These approaches include enabling meaningful participation of persons with disabilities, addressing gender inequality, and ensuring the inclusion of marginalized persons with disabilities. Since 2012, the UNPRPD has funded more than 80 joint programming initiatives across 57 countries, as well at a global level.

Global Disability Summit

The Global Disability Summit was held twice – once in 2018, organized jointly by the Department for International Development of the United Kingdom of Great Britain and Northern Ireland, the Government of Kenya, and the International Disability Alliance; and again in 2022, organized by the governments of Norway and Ghana, and the International Disability Alliance. This multistakeholder partnership is a good example of disability-inclusive international cooperation across different areas. In the 2022 Summit, health was a key theme, and more than 50 governments, international organizations and partners committed to including disability in the health sector. The event was a milestone in persuading governments and the international community to commit to equitable access to health services for all persons with disabilities.

10. Ensure that existing mechanisms for social protection support the diverse health needs of persons with disabilities

Social protection systems can play a critical role in laying the foundation for many persons with disabilities to access health services. Therefore, it is important that social protection mechanisms support the needs of persons with disabilities. Advancing work in this area requires multisectoral coordination and collaboration between various ministries, including health and social affairs for example. Many countries do not have the resources to establish a universal social protection scheme immediately and advance in a progressive manner. This allows countries to take continuous steps in improving their social protection system and cover as many persons with disabilities as possible. It is important to secure gender equality in social protection schemes; women with disabilities and women who are caregivers are especially at risk. Women who are caregivers often perform unpaid care work throughout their lives which challenges their ability to access formal employment, contributory social security, and decent wages. It is also essential that social protection mechanisms have the capacity to adapt and upscale during health emergencies. In the context of social protection, considerations regarding the processes of disability assessment, determination, and eligibility are provided in Box 15.

Box 15

The processes for disability assessment, determination, and eligibility in the context of social protection

The processes of disability assessment, determination and eligibility are fundamental to establishing how disability inclusive a social protection system is.

1. **Disability assessment** – this process involves estimating the extent of the impairment(s) of a claimant, and how such impairment(s) trigger barriers to participation in interaction with the specific context of the person concerned. In addition, an assessment of disability serves to identify the possible support needed to overcome such barriers, noting that assessments should serve to promote, protect and fulfil the equal participation and enjoyment of human rights by persons with disabilities, and not used to restrict or limit those rights. Considerable changes and discussions are taking place internationally around the optimal approach to disability assessment for social protection purposes. Although currently, in most countries, the impairment approach prevails, there is indisputable evidence that additional information on activities, participation and environment is important for assessing disability. Assessments that are purely impairment-based have been found to be invalid and ineffective in determining disability, forcing countries to re-evaluate their approach to assessment processes. This aligns with the standards set by the Convention on the Rights of Persons with Disabilities committee, which call for assessments to reflect, at a minimum, "the characteristics, circumstances and needs of persons with abilities".
2. **Disability determination** – this process uses the national legal definition of who is considered a person with disability, and the degree to which they are disabled, according to certain regulations, schemes and policies. For the process of implementation of social protection, the information gathered from the disability assessment(s) is considered in relation to certain pre-established thresholds or rules

set by governments. In some cases, this may result in an issuance of a disability certificate or card. It should be noted that, ideally, in the context of the health system, access to health services should not be dependent on the issuance of a disability card of certificate. Persons with disabilities have a right to essential health services, including the provision of assistive technology as part of UHC on an equal basis with others, and without being subject to disability determination. However, in reality, some countries may decide that, to prioritize certain groups, such as persons with disabilities, the criteria for eligibility for subsidies should be poverty-related or categorical. This would involve countries introducing disability cards or certificates to decide who would benefit; however, this should be a tritory step.

3. **Eligibility determination** – this process decides on a person's eligibility to receive a wide range of benefits, services and/or products, including disability pensions, and individual support services. As part of the eligibility process, additional information, such as age, place of residence and level of income, is collected from the claimant. This is then integrated with information gathered from the processes described in 1 and 2, to establish if a claimant meets certain criteria to receive a specific benefit, service or product. Particular attention is given to environmental support (such as assistive equipment, or financial support) and services available in-country, in order to determine what a claimant may be entitled to receive.

The ultimate objectives of the processes of disability assessment, determination and eligibility are to improve participation and inclusion of persons with disabilities. To achieve this, the processes are set out to:

- evaluate the level and type of the impairment, the support that the person requires, and the barriers to participation that they face in a specific context;
- make decisions around the personal entitlements of the individual in relation to specific national laws, policies and regulations; and
- assist system-level structures and programmes to be inclusive and enable the individual to participate in society on an equal basis with others.

Thus, the disability assessment, determination and eligibility processes not only identify those who require benefits, services, products or protection, they also identify and eliminate barriers and promote equal opportunity, accessibility and inclusion for persons with disabilities.

Most countries follow the three steps of the disability and eligibility determination process to varying degrees but will differ in terms of the disability assessment used, the complexity of the overall disability assessment, determination and eligibility processes and the eligibility criteria for services and benefits.

Disability and eligibility determination process from the perspective of the claimant

- ✓ What is the extent of disability?
- ✓ What barriers to participation are faced?
- ✓ What support is required?

- ✓ Is the person considered a person with disability, under the legal definition of the relevant regulations, schemes and policies?

- ✓ Which services, products or benefits is the person eligible for? Are there additional criteria (such as age, residence, or level of income) that need to be met?

Case study

An inclusive social protection programme in Brazil *(31)*

Brazil has taken steps to achieve universal social protection for persons with disabilities. The tax financed Benefício de Prestação Continuada de Assistência Social offers benefits equivalent to the minimum wage to more than 2.3 million persons with disabilities in the country. A recent study showed that these benefits buffered the economic impacts experienced by parents of children with microcephaly *(32).* In addition, Brazil has a comprehensive social insurance system, the Previdência Social, which includes the provision of a disability pension for persons with partial or full disability, as well as sickness benefits for those working in the formal sector. The system is a mix of tax financed and contributory disability benefits, and this has enabled the country to progress towards universal coverage for persons with disabilities. The country has also advanced their mechanism to assess eligibility for disability benefits and make the system more accessible.

An initial assessment is conducted by a social worker to determine the barriers in the labour market faced by the applicant. This is followed by an evaluation of the medical and functioning limitations of the individual. As assessment centres are located in less than 30% of the country municipalities, and many potential beneficiaries have to travel long distances to reach them, the transport costs of the applicant and those of an accompanying adult are reimbursed, regardless of the outcome of their applications.

Examples of how progress in political commitment, leadership and governance can be monitored

In this strategic entry point, example indicators to track progress towards disability inclusion include the formalization of governance mechanisms and commitments to disability inclusion through policies or legislation, and the establishment of a plan to monitor progress. In addition, indicators involve the integration of disability in national or subnational health strategies, the existence of a focal point or committee to oversee and monitor disability within the Ministry of Health and inclusive social protection.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Political commitment for disability inclusion	Has the Ministry of Health formalized governance mechanisms and commitments to disability inclusion through policies or legislation? Is there a plan to monitor progress?
Disability embedded in national or subnational health strategies	Are concrete priority areas for disability inclusion embedded in the national or subnational health strategy?
Focal point/committee to oversee disability inclusion within Ministry of Health	Is there a focal point/committee (which includes person(s) with disabilities) within the Ministry of Health to oversee and monitor disability inclusion in the health sector, and coordinate public health interventions with other sectors?
Inclusive social protection mechanisms exist	Is the social protection mechanism inclusive of persons with disabilities?

2

Health financing

What does it mean?

Health financing refers to: the function of a health system that is concerned with the mobilization, accumulation and allocation of money to cover the health needs of the people, individually and collectively *(33)*. More specifically, health financing is comprised of four interrelated functions and policies: revenue raising; pooling of funds (accumulation of prepaid funds on behalf of some or all of the population); purchasing of services (allocation of resources to providers); and policies on benefit design and rationing (who is entitled to what, and at what if any cost at the point of use)[19].

Given the overall goal of UHC, the specific objective of health financing is to ensure that all people have access to and use needed services without the risk of financial hardship. Based on accumulated evidence, WHO has defined a set of "desirable attributes" of each health financing function, i.e. the extent to which a country's financing arrangements exhibit those attributes is hypothesized to be associated with more progress towards UHC1[20]. Examples include the need to move to predominant reliance on public sources of funding, to reduce fragmentation in pooling, to drive provider payment by data on their performance and the health needs of their population while managing expenditure growth, and to establish a universal benefits framework with policies that place explicit limits on individual liability for out-of-pocket payments.

The available evidence shows that inclusive health financing is essential for advancing health equity for persons with disabilities. A recently published Lancet Global Health Commission on financing PHC made a global call for countries to invest more and invest better on PHC by putting people at the centre in any financing functions *(34)*. The Commission takes the position that progressive universalism should drive every aspect of financing, putting the rights and needs of the poorest and most marginalized segments of a population first.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

11. Adopt progressive universalism as a core principle, and as a driver of health financing, putting persons with disabilities at the centre

Adopting progressive universalism as a principle in health financing means putting the rights and needs of the most disadvantaged groups of the

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[19] Kutzin, J. A descriptive framework for country-level analysis of health care financing arrangements. Health Policy. 2001 56(3):171-204.

[20] Jowett, M, Kutzin J, Kwon S, Hsu J, Sallaku J, Salano JG. Assessing country health financing systems: the health financing progress matrix. World Health Organization. 2020.

population, such as persons with disabilities, first. Such an arrangement requires both political commitment and a long-term vision *(34)*. To be advanced, the health financing functions and policies need to be driven by equity, which is indeed inherent in the concept of UHC. In terms of revenue-raising mechanisms, these need to be based on public resources and defined by ability to pay. As persons with disabilities are often among the most disadvantaged and marginalized groups, this will allow them to avoid direct and catastrophic payments.

The pooling of public funds, which enables cross-subsidies to flow from those who are wealthier to those who are poorer, and from those who are healthier to those with greater health-care needs, such as persons with disabilities. Data systems used for purchasing should include identifiers for marginalized persons, such as persons with disabilities, to enable provider payment to be linked to lower copayments for persons in these categories.


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12. Consider health services for specific impairments and health conditions in packages of care for UHC

When benefit packages of care in the context of UHC are being developed, it is important that the overall approach considers population needs and the inclusion of services for specific impairments and health conditions that underly disability, such as spinal cord injury care. For many persons with disabilities, these services are vital. While inclusion or exclusion criteria depend on country's context, budget constraints and implementation, values, realities, it is important that a fair and transparent processes are followed, considering population needs. Engagement and participation of persons with disabilities and their representative organizations in package designing processes can not only help understand their specific needs and perspective, but also highlight the importance of considering criteria such as equity and severity in the design process giving more weight to disability services that may not be considered "cost-effective". However, opportunity costs, i.e., the fact that including some services can mean services in other areas cannot be included, need to be evaluated in a country's context.

Case study

Disability inclusion in health services benefits package to drive equitable care in the Philippines

In the Philippines, for persons with disabilities, PhilHeath's Z Benefits package funds services for specific impairments and health conditions that underly disability.

The benefits are determined by the Philippine Health Insurance Corporation (PhilHealth), to which all citizens have automatic membership and coverage for health services through the positive recommendation of the Department of Heath's health technology assessment process. This process is a priority setting mechanism for the development of policies and programs, regulation, and the determination of entitlements such as drugs, medicines, procedures and services. In the "Implementing rules and regulations of the Universal Health Care Act (Republic Act No. 11223)*, it is stated that among other principles, the health technology assessment should adhere to inclusiveness and preferential regard for the underserved and those most vulnerable. Through the health technology assessment, several services for persons with disabilities have been included in the benefit package. For example, PhilHealth has stated it aims to "mainstream and reintegrate persons with physical disabilities in the community" by providing assistive devices and prosthetic services for cases that fulfil the selection criteria. Benefits for children with motor, hearing, or vision impairments, and developmental disabilities are part of the "Z benefits,"** where "Z" is defined as a "life or limb-threatening" condition that requires "prolonged hospitalization, extremely expensive therapies or other care that would deplete financial resources", or in other words, "catastrophic" care.

* Department of Health (Philippines). Implementing Rules and Regulations of the Universal Health Care Act (Republic Act No. 11223).

** Z benefits for the Mobility, Orthosis, Rehabilitation, Prosthesis Help, (https://www.philhealth.gov.ph/circulars/2013/circ19_2013.pdf).

Z benefits for children with mobility impairment (https://www.philhealth.gov.ph/circulars/2017/circ2017-0031.pdf).

13. Include into health-care budgets the costs of making facilities and services accessible

Investing in making health facilities and services accessible for persons with disabilities is important for them and it benefits everyone. Accessible physical infrastructure and facility equipment are key facilitators for the access to health services for millions with disabilities. As discussed later in this chapter, the additional costs of implementing universal design in the construction of buildings can be minimal but highly beneficial. In addition, investing in provision of accessible services is also crucial. For example, the platforms for telehealth services are often not accessible for persons with disabilities; therefore, investment in accessible software for remote provision of services should be a consideration.

Examples of how progress in funding and allocation of resources can be monitored

Example indicators to track progress towards disability inclusion in this strategic entry point include health financing being based on progressive universalism, affordability of services, and inclusive social protection mechanisms for persons with disabilities.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Health financing is based on progressive universalism	Are resources allocated to reach the populations living in most marginalized conditions, such as persons with disabilities, first? Are perspectives of persons with disabilities incorporated into decision-making processes in health financing?
Health services are affordable	Can persons with disabilities afford health services, compared with persons without disabilities? What are the factors that contribute to unaffordability for persons with disabilities, e.g., price of services, income difference between persons with and without disabilities, etc.?

3

Engagement of communities and other stakeholders, including private sector providers

What does it mean?

The engagement of communities and other stakeholders:

- encompasses building collaborative relationships that enable the health sector and relevant stakeholders to jointly define health priorities, identify solutions and plan actions.

- brings to life the commitment of PHC to focus on the person and entire communities rather than diseases.
- should be part of a comprehensive strategy to reorient health systems to meet the requirements of people, while considering changing societal contexts.
- includes a diversity of actors, such as individual users of health services and their families, or private sector entities.

For the health sector to be inclusive of disability, it is vital to engage of persons with disabilities and their representative organizations. Evidence shows that strategies to engage and empower people and their extended support groups and communities, lead to improved patient experience; improved satisfaction and utilization of services; better compliance with services; improved health literacy and health outcomes; and the increased uptake of healthier behaviours *(35)*.

During the past decades, there have been calls from civil society to engage organizations of persons with disabilities in decision-making processes in the health sector. For example, during the COVID-19 pandemic, governments and international organizations have been requested to ensure that civil society can participate meaningfully in COVID-19 response planning. This includes representatives of priority populations, and those living in marginalized conditions, such as women, girls and gender non-conforming persons with disabilities, people with albinism, indigenous peoples with disabilities and persons with psychosocial disabilities.

Engagement with other health stakeholders and private sector providers is also important. The efforts of WASH in low-resource settings to be disability-inclusive showcase a good example for cross-sectoral collaboration. Such efforts, involving government departments for health and infrastructure, development partners, civil society and, notably, organizations of persons with disabilities, have supported consensus-building not only on the main principles and approaches for disability-inclusion, but also in establishing key standards for the WASH initiatives. For example, in Lao People's Democratic Republic, new designs for accessible water supply facilities and latrines were developed with the collaboration of civil society and the Ministry of Health, the Ministry of Education, AusAID and the World Bank. These new designs were then implemented in 1385 schools across the country *(36)*. Likewise, in Ethiopia, accessible water points, washing basins and latrines were designed by international NGOs, in partnership with national level organizations of persons with disabilities, in collaboration with, and approved by, the Ministry of Health *(36)*. While the role of the wider health sector is unclear in these examples, they illustrate a form of collaborative working that could be applied in other areas of public health.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

14. Engage persons with disabilities and their representative organizations in health sector processes

Engaging persons with disabilities, and organizations of persons with disabilities, in the processes of the health sector enables these groups to participate in strategic decision-making, as well as in the design, planning, development and delivery of health services *(37)*. It is essential to involve persons with disabilities when deciding the interventions to be included in benefit packages of care for UHC, and when designing plans for health emergencies. In bringing their diversity, experience, expertise, and knowledge, not only can persons with disabilities influence how policies and services are designed, commissioned, and delivered, they can also reveal inequities on the ground that would otherwise be unknown to health policy-makers.

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Consultation and active participation are rooted in the motto of the disability movement: “nothing about us without us”. Thus, representative organizations of persons with disabilities need to be involved in the formal mechanisms (e.g. round tables, participatory dialogues, public hearings, online consultations) that take place in countries when deciding packages of care or any other health-related matters (Box 16). Persons with disabilities who are at higher risk of exclusion or of marginalization from stakeholder engagement must be involved; these include adolescent girls, persons with intellectual, cognitive or psychosocial disabilities, deaf people, people in residential settings, indigenous peoples with disabilities, or older persons with multiple disabilities, amongst others.

Implementation of these consultations should also consider the necessary accommodations for the meaningful participation of persons with disabilities (e.g. provision of captioning services; sharing of materials in advance; giving time for information to be processed and responses provided).

Case study

Civil society contributing to progress for persons with disabilities in Nepal

During the past several years, the Government of Nepal has made significant progress in improving the lives of persons with disabilities, with a strong input from persons with disabilities themselves. The efforts of the health system to address their needs began after the earthquake in 2015, which left 20 000 people with injuries, some of these resulting in long-term impairment or disability. Within the Ministry of Health and Population, a focal unit oversees disability-inclusive health, which is guided by a technical committee comprising organizations of persons with disabilities and civil society, and external development partners.

In 2017, the Government's Rights of Persons with Disabilities Act, signified a move from a welfare-based to a rights-based approach to disability, ensuring equal access to education, health, employment, public physical infrastructure, transportation, and information services. The Act prohibited discrimination on the basis of disability, and furthermore, in preparedness plans for disasters and emergencies, recognized the specific needs of persons with disabilities, a step few countries have taken.

Various disability-specific initiatives have since been undertaken in the country, from an evaluation strategy to communications; another initiative is improving access to assistive technology. The expertise of civil society, professional associations and organizations of persons with disabilities has been critical to health trainings on disability-inclusion for provincial governments and health professionals. The engagement of organizations of persons with disabilities was also crucial to develop and implement a long-term plan – the Disability Management Policy, Strategy and Ten-Year Action Plan (2017–2026), which aims to ensure equal access to health services for persons with disabilities. In 2018, Nepal recognized the reproductive rights and access to services for persons with disabilities, including adolescents, in a law that mandates disability-inclusive sexual and reproductive health services. In addition, technical guidelines on disability-inclusive sexual and reproductive health services are being developed in partnership with organizations of persons with disabilities, civil society and external development partners.

Box 16

Organizations "of" and "for" persons with disabilities

There is a difference between organizations "of" persons with disabilities – which are led by persons with disabilities and usually focused on advocacy; and organizations "for" persons with disabilities – which are usually non-profit organizations that provide services to persons with disabilities but can also advocate on their behalf. Organizations of persons with disabilities ensure the representation of different groups. Funding and capacity development for these organizations is important, as is public support; not only do these organizations understand best how to serve the needs of the community, they can also further enhance the engagement of persons with disabilities in the health sector, including in health emergency programming *(38)*.

15. Include gender-sensitive actions that target persons with disabilities in the strategies to empower people in their communities

It is important to integrate strategies to facilitate persons with disabilities to be empowered users of health services as part of any universal actions taken by countries to empower people in the communities. This will support persons with disabilities to take control of their own health needs and make decisions about their health care. These strategies can be facilitated through gender-sensitive actions such as providing accessible health and legal information and tools concerning the rights of persons with disabilities (Box 17), with a specific focus on women, girls and non-cisgender persons with disabilities, or enhancing literacy and education in health and human rights. Other concrete actions include fostering shared responsibilities between health-care providers and persons with disabilities in the pathways of care, minimizing barriers within community settings, and enabling informed choice by supporting their control in decisions relating to behaviours, lifestyles, and advanced care planning, as well as in the selection of health providers.

Box 17

Providing mainstream health information in accessible format

What does it mean?

When publishing or disseminating health information, the use of appropriate modalities for communication ensures that the information reaches persons with disabilities who can then make informed choices about their health care. Moreover, when interacting with health and care workers and services, their dignity can be respected. For many persons with disabilities the widely-used communication modalities such as the spoken or written word, or the use of certain telecommunication devices, may not be appropriate for sharing information about health services or issues relating to personal health.

How can it be facilitated by governments and health sector actors?

Mainstream health information can be provided by governments and health sector actors in modalities such as Easy Read, sign-language interpreters, information in Braille or raised print, or captioning on video messages.

In addition, governments and health sector actors can ensure that information and devices used for communication between persons with disabilities and health professionals (e.g. smartphones or tablets) are accessible, and that information and communication are delivered in digitally-accessible formats. For example, interaction can be facilitated through alternative ways to understand non-text content; webpages can be accessed by using a keyboard only or navigated using text-to-speech recognition software or a screen reader; captioning can be provided; and sufficiently contrasted colour, font sizes and weights used.

How can the inclusiveness of health information materials be assessed? *(39)*

The following simple questions can be used to assess whether adaptation and/or targeted approaches may be necessary to reach persons with disabilities:

1. Who will be able to understand this information in its current form?
2. Who will not be able to understand this information in its current form?

3. How does the information reflect the needs of different people in the community? Will persons with disabilities and their caregivers see themselves and their experiences reflected in the images?
4. What do persons with disabilities think about the materials? Do they have any advice or feedback?

While it is helpful to have the advice and guidance of persons with disabilities before starting, it is also important that persons with disabilities and their caregivers are asked to review, critique and comment on the material when finished so that it can be adjusted accordingly.

Practice example from the United Kingdom of Great Britain and Northern Ireland

In 2016, National Health Service England (NHS) published the first Accessible Information Standard*, with the aim of making information on health and social care accessible. All organizations that provide NHS care or publicly-funded adult social care are legally required to follow this Standard. The Standard outlines a specific, consistent approach to identifying, recording, flagging, sharing, and meeting the information and communication support needs of patients, service users, carers, and parents with disabilities. The Standard includes guidance, a range of advice, and tools to support its effective implementation.

*https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/.

16. Engage the providers of informal support for persons with disabilities

The terms “informal care” or “informal support” cover all “non-professional care provided – by choice or by default – by family members, friends, neighbours or other persons caring for people with long-term care needs at all ages, usually in private households *(40)*”. When putting policies in place to engage with health-service users and their families, the engagement of informal support providers is crucial to raise awareness about their contribution and their needs, as well as to tailor recommendations for improvement of their services. The engagement of informal support providers should be accompanied by different strategies to improve their situation. Such strategies may include providing a clear definition of the role and status of informal support provider at national or subnational level to acknowledge their contribution; enabling them to reconcile employment and support responsibilities for persons with disabilities through policies providing entitlements such as flexible working arrangements; or protecting their health and well-being through different programmes. For example, WHO developed ‘iSupport’ as a knowledge and skills training programme for support providers of people living with dementia. This tool includes information on how to deal with behavioural changes such as memory loss and getting lost; how to provide support for a person’s everyday activities; or how to manage an individual’s own physical and mental health *(41)*.

Case study

Strengthening informal care in Slovakia and Slovenia*

In Slovakia, informal carers of persons with severe disabilities can receive care allowance. The amount paid is approximately the same as the net minimum wage in the country; for carers of pensionable age, a flat rate of approximately 50% of this amount is given in addition to their regular pension being paid. The allowance increases if the carer is caring for a child. The contribution is provided from the state budget. Informal carers do not have the status of employees, but the state covers their health and social insurance contributions.

In Slovenia, co-financed by the Ministry of Labour, Family, Social Affairs and Equal Opportunities, and by municipalities, the Anton Trstenjak Institute of Gerontology and Intergenerational Relations has developed and implemented a community-based training programme for informal carers. The training includes social and health aspects of caring, such as the understanding of, and communication with, the care receiver; skills for home care; care for the carers’ own health; knowledge on health conditions; palliative care; information about respite care possibilities and institutional care; and psychosocial management. Participants in the programme can learn directly from local and national experts and institutions related to caregiving, as well as from local community nurses, physiotherapists, doctors, and formal carers. The training consists of 10 weekly learning sessions; at the end participants are encouraged to continue with monthly meetings in “local relatives’ groups”, based on the principle of self-help groups.

**UNECE. 2019. The challenging role of informal carers. Policy Brief*

17. Engage persons with disabilities in research and include them in the health research workforce

Ensuring inclusive research can facilitate the full participation of persons with disabilities and other priority populations living in marginalized conditions in research opportunities. Ensuring inclusive research will also facilitate inclusive implementation of research outcomes. Testing new medicines and health products is a good example of this. While persons with disabilities use medicines and health products – possibly more frequently than many – they are systematically excluded from clinical research testing those medicines and products. Likewise in testing the effectiveness of public health interventions that aim to increase physical activity among the population; if persons with disabilities are not engaged, the outcomes will never be fully representative (see Box 18).

Persons with disabilities have valuable expertise and knowledge to share, and their engagement contributes to advances in health care. Engagement can be facilitated through integrating universal design in all phases of the research project or by providing reasonable accommodation throughout, depending on the requirements and needs of persons with disabilities. Moreover, ensuring persons with disabilities are included in the research workforce at all levels is necessary to strengthen and develop the wider workforce in the health sector. Inclusion is a prerequisite to enriching a country's public health efforts and achieving its health priorities *(42)*. Providing equal employment opportunities ensures access to an untapped pool of talent; increases innovation by including employees with diverse experiences who have different approaches to problem-solving; enhances the reputation of organizations as customers value companies that show true commitment to inclusion; and ultimately benefits everyone *(43)*. Inclusion can be facilitated through actions such as providing opportunities to students with disabilities in academic institutions, advancing the careers of researchers with disabilities, or ensuring that all institutional policies support disability inclusion *(44)*.

Box 18

Approaches to disability-inclusion in research *(45)*

1.Inclusive preliminary analysis and early engagement

Are health researchers with disability part of the research team? Has disability been considered in preliminary research and/or background analysis of the research context? Health researchers can review existing published and grey literature from different sectors, and consult with in-country disability stakeholders, including disability service providers and organizations of persons with disabilities.

2. Understanding the CRPD and its domestic legal frameworks

To develop and implement inclusive health research projects effectively, researchers and reviewers can receive training in the CRPD, its underlying principles, domestic legal frameworks, requirements, and language. Such training and its practical implications can be sought from local organizations of persons with disabilities.

3. Promoting partnerships with local researchers with disabilities

Where possible, research proposals can include collaboration with local researchers with disabilities as partners and consultants. Many donors support the building of partnerships and capacity-building between local researchers and institutions, and this can be integrated into the design of disability-inclusive health research projects.

4. Ensuring that the review and oversight processes for local ethics are inclusive

The CRPD sets out the right of persons with disabilities to participate actively in social, cultural, and political life, and to be involved in issues that affect them, including health research and innovation. It is helpful therefore, to establish whether local research institutions have in place processes for the representation of persons with disabilities on ethics committees or other forms, such as advisory boards or steering committees.

5. Engaging in critical reflection

Health research can be enriched by reflecting honestly, and acknowledging the limitations of the processes and outcomes, based on who is and is not included, avoiding generalizations, and highlighting where further investigation may be necessary. Researchers can also be encouraged to identify and reflect on their own biases, or the cultural value systems they bring to the research which may have contributed to exclusion or inclusion of certain groups.

18. Request that providers in the private sector support the delivery of disability-inclusive health services

A wide range of non-state actors play crucial roles in supporting the delivery of health services and goods. This includes formal and informal health-care providers, and for-profit and not-for-profit entities at local, national or international levels. The health sector can conduct stakeholder mapping *(46)* to determine who the private sector actors are in the country and set regulatory mechanisms to ensure that the delivery of health services and health products by non-state actors are inclusive for persons with disabilities. Services that are not inclusive should be coordinated by the health sector to ensure that they are connected to the health system and integrated to support public health objectives.

Examples of how progress in engagement of communities and other stakeholders can be monitored

Example indicators to track progress towards disability inclusion in this strategic entry point include accessibility of health information and communication, disability-inclusive research, engagement with organizations of persons with disabilities, and private sector.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Accessibility of health information and communication	Are health information and communication provided in accessible formats, e.g. Braille, Easy-Read, captioning, sign language?
Disability-inclusive research	Are persons with disabilities being actively involved in health research?
Engagement with organizations of persons with disabilities	Is there an established mechanism to engage organizations of persons with disabilities in decision-making in the health sector?
Engagement with private sector	Is there a coordination mechanism to ensure private sector entities provide inclusive health services?

4 Models of care

What does it mean?

Models of care:

- represent the concept of how services should be delivered. This includes the entire process of care, the organization and management of providers and services, and the defining of roles and responsibilities of platforms and providers along the pathways of care.
- significantly affect other components of the health system, such as governance, financing, the workforce, and information systems.
- change according to the health priorities of the population and can be tailored according to local contexts.

- are built on the principles of promoting integrated health services, prioritizing primary care and public health functions; facilitating equitable access to affordable services, providing essential medicines and assistive technologies closer to where people live; and ensuring continuous, comprehensive, coordinated, and people-centred care.

A large body of evidence suggests the importance of delivering inclusive models of care for advancing health equity for persons with disabilities. For example, strengthening referral systems and care coordination have been shown to be fundamental in meeting the breadth of the health needs of persons with disabilities. This is important, because while the health needs of some persons with disabilities are similar to those of the general population, others have greater needs that require more frequent, comprehensive and coordinated health care, including at primary care level. Studies have demonstrated the success and effectiveness of different types of care coordination programmes for children with disabilities, with reported reductions in unmet health-care needs, emergency department visits *(47)*, missed medical appointments *(48)*, and inappropriate use of services *(49)*. For many people, access to rehabilitation as early as possible – i.e. during the acute phase of injury, and provided on a continuum – is essential to maximize functioning outcomes and facilitate transition to community-living *(50)*. Early rehabilitation can also significantly reduce the prevalence of many chronic conditions and delay their onset *(51, 52)*.

The importance of models of care that promote early childhood development for persons with disabilities is also very well documented in the literature. Ensuring access to interventions in early childhood is vital for helping children with disabilities reach their full potential *(53)*. Research and country experiences present a strong rationale for investing in early childhood development for children with disabilities for at least four reasons: i) human rights – all children with disabilities have the right to develop "to the maximum extent possible" *(54)*; ii) societal – children with disabilities who receive good care and developmental opportunities during early childhood are more likely to participate meaningfully in society in the future *(55)*; iii) scientific – the first years of a child's life are critical for providing the essential building blocks for future growth, development and progress *(56)*; and iv) programmatic – early childhood development programmes can lead to improved rates of survival, growth and development, and ensure that later educational programmes are more effective *(57)*. Early childhood development programmes are shown to be effective for all children when they are an integral part of existing actions in health, education and the social system, and involve a range of sectors such as health and education, which share responsibility *(58, 59)*.

The importance of deinstitutionalization, particularly (but not exclusively) within the mental health field, is also very prominent in the literature. Currently, although community-based services are widely regarded as the best approach for providing mental health care, most low- and middle-income countries spend the majority of their scarce resources for mental health managing people with mental health conditions in institutions *(60)*. Deinstitutionalization and moving to community-based models of care is important for improving the quality of life for persons with psychosocial disabilities and protecting them from a wide range of human rights violations; it is also more cost–effective since it leads to better recovery outcomes *(61)*. Deinstitutionalization in the area of mental health is ongoing in several countries. For example, in Buenos Aires, Argentina, a mental health reform conducted between 2020 and 2021 resulted in the number of people in institutions falling from 1810 to 1391. This was achieved by stopping long-term admissions; giving the individuals a transfer subsidy to support discharge; and providing them with housing support and community-based mental health services *(62)*.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

19. Enable the provision of integrated people-centred care that is accessible and close to where persons with disabilities live

While countries make progress towards strengthened primary health-care services, it is important to plan how these services will reach the most marginalized populations, including persons with disabilities. For example, access to mainstream services through targeted actions such as making the infrastructure accessible, training the workforce, or removing financial barriers for persons with disabilities are required. A particular focus is needed on populations living in rural and remote areas that are difficult to reach; integrated health services should be well planned for persons with disabilities in these settings. The benefits of services in the community for persons with mental health conditions and psychosocial disabilities are shown in Box 19. Furthermore, any accessibility plan needs to ensure the provision of health care in an integrated people-centred manner across the life course. Integrated people-centred care is intrinsically inclusive as it adopts the perspectives of individuals, carers, families and communities as active participants in the health systems that respond to their needs and preferences in a holistic way. When implemented, such an approach has the potential to generate significant benefits to the health of persons with disabilities, including improved health and clinical outcomes, better health literacy and self-care, increased satisfaction with care, and reduced overall costs.

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In the context of health emergencies, maintenance of essential health services for persons with disabilities is fundamental. Therefore, the national plan for continuity of essential health services during health emergencies should also consider the needs of persons with disabilities. In addition, integrated people-centered health services are a vehicle to ensure that health emergency responses meet the needs of the diversity of people, including sub-populations who may face added marginalization, in the affected community. Given the complexity of analysis and the diversity of strategies required, it is critical that persons with disabilities and their representative organizations, family members, support services and health care providers play a central role in health emergency planning, working together to come to fully understand the consequences of the public health interventions planned for the response. Once implemented the consequences need to be analysed and corrective action taken if needed *(76)*.

Case study

Bringing services for persons with disabilities close to home in Ireland

Ireland is transforming health care and the delivery of social care through new models of care that aim to provide health and social care services to people within their own communities, or as close as feasible. The people-centred Sláintecare initiative ("*sláinte*" means "health" in the Irish language) is expanding and developing primary and community health services, with specific actions for persons with disabilities. The Sláintecare vision is to provide the right care, in the right place, at the right time.

An ongoing project is to reconfigure disability service staff working with a diverse range of children with disabilities, through the creation of 91 local Children's Disability Network Teams. These interdisciplinary teams of health and social care professionals provide services and support for children aged up to 18 years who have complex needs and who live within a specific geographical area, enabling them to have services delivered close to them. Team members offer expertise in such areas as physiotherapy, psychology or speech therapy, and work closely together in a family-centred model, focusing on the priorities of the child and family. There is no hierarchical structure within the teams.

Another project is the gradual phasing-out of institutional settings (care homes or long-term residential facilities), moving people from wards into homes – houses or apartments accommodating no more than four people – in the local community. Therapies, interventions, and other forms of support are mostly delivered at home. This has led to significantly increased community living, integration into mainstream health-care services, and an increased quality of life.

Box 19

Benefits of services in the community for persons with mental health conditions and psychosocial disabilities

The benefits of providing primary care for persons with mental health conditions or psychosocial disabilities are evident and include removing the risk of human rights violations particular to psychiatric hospitals. The process of deinstitutionalization simultaneously contributes to reinforcing a patient's dignity. Stigmatization and discrimination are significantly reduced because persons with psychosocial disabilities are treated in the same way as others *(63)* – for example, standing in the same queues, receiving appointments and seeing the same health workers. This is important not only for individuals, but also in terms of the perceptions of their families, communities and health professionals.

Primary health-care services for persons with psychosocial disabilities lead to significant improvement in health outcomes. Evidence, including from low-and middle-income countries, shows that primary care services are effective in improving the well-being of persons with mental health conditions such as depression or anxiety and that, with training and supervision, primary care workers can provide good quality care and support for persons with psychosocial disabilities *(64)*.

Primary care services for persons with psychosocial disabilities are the most cost–effective option of care *(65)*. People usually avoid indirect costs associated with seeking specialist care in distant locations, such as travel expenses, which are a major reason to drop out of health-care programmes *(66)*. Primary mental health care is also less costly for governments, as health workers, equipment and facilities cost far less than those needed at secondary and tertiary levels. Furthermore, community-based treatment models for mental health conditions involve fewer costs than hospital-based treatment *(67)*, as well as avoiding violations of rights through deprivation of liberty based on disability. Analyses show that scaling up a package of primary care services for mental health conditions such as schizophrenia, bipolar disorder, depression and use of alcohol over a 10-year period requires a total additional investment of US$ 0.20 per capita per year in low-income countries and US$ 0.30 per capita per year in lower-middle-income countries *(68)*.

20. Ensure universal access to assistive products

The provision of assistive technology is an intersectoral issue that needs an intersectoral mechanism. The Ministry of Health could lead this, while coordinating with other relevant departments, including the ministries of Social Protection, Education, and Labour, as well as ensuring integration with wider national systems. The WHO-UNICEF *Global report on assistive technology (69)* sets a clear strategy and guidance for improving the availability of assistive products as part of UHC. Four components need to be strengthened: policy, products, provision, and personnel. Policy includes the political will, legislation, and effective finance mechanisms for assistive products within the principles of UHC. Products involves the improvement of the range, quality, affordability, procurement and supply of assistive products through strategies such as repairing, refurbishing and reusing them, as well as production at local and regional level. Provision implies bringing service delivery of assistive products as close as possible to the communities of persons with disabilities, and integrated in other services, while ensuring equity of provision in terms of geographical areas and populations. Personnel involves the training and education of the workforce to increase effective identification, referral and provision of the products.

Case study

Training in priority assistive products in Papua New Guinea

The COVID-19 pandemic has emphasized the importance of having assistive technology services close to where people live, as well as the need for better strategies to support people who live in remote areas. With 2.5 billion people in need of assistive technology – a figure set to rise in the coming years – there is an urgent need to increase the integration of assistive technology at community and primary health levels.

In Papua New Guinea, access to assistive products has been limited, despite prior efforts to increase access. For example, studies have shown Papua New Guinea has the highest rate of blindness in the Pacific region while two-thirds of vision impairment was primarily due to untreated cataracts.

In response, during 2020 and 2021, the World Health Organization (WHO) worked with in-country partners in Papua New Guinea to implement a rapid, remotely-supported project to strengthen local capacity for community-level assistive technology services, thus addressing the issues highlighted by COVID-19 relating to access and distance to services.

Central to the remote support was the rollout of Training in Priority Assistive Products (TAP). This open access online learning platform, developed by WHO, helps build the skills and capacity needed in primary care, and in personnel at community level, to provide simple assistive products. The training supports task-shifting and task-sharing, thereby reducing pressure on secondary and tertiary level health services and increasing equal access to services.

A coalition of partners worked with WHO to supervise the TAP rollout. The training was provided to 11 personnel in six primary health-care centres, and 14 personnel from three tertiary care centres, all located in or near to the capital city, Port Moresby. The project also involved procuring more than 4000 products – reading glasses, walking aids, toilet and shower chairs, and washable absorbent products – which were provided at the primary health-care centres.

21. Invest more finances in support persons, interpreters, and assistants to meet the health needs of persons with disabilities

Persons with disabilities very often require support in the form of support persons, interpreters or assistants. For example, persons with deafblindness may require interpreter guides; persons with intellectual disabilities may need a support person during a health-care visit; and people who are deaf and hard of hearing may use professional sign language interpreters to facilitate communication with health-care professionals. It is important that the health sector considers these requirements, and plans and budgets for their provision to ensure that persons with disabilities receive the quality health care they need. In many countries, designing these services may require greater collaboration between the health and social support sectors so that they are available to persons with disabilities in all spheres of life.

22. Consider the full spectrum of health services along a continuum of care for persons with disabilities

While the health needs of some persons with disabilities are similar to the general population, others have greater needs that require more frequent, comprehensive and coordinated health care, including at the primary level. Examples include people with spinal cord or brain injury, schizophrenia, dementia, and children with congenital conditions (Box 20). People with these health conditions often require regular access to specialized medical services, as well as rehabilitation that may include the provision of assistive products. Additionally, they may require coordination of their care between health services, and across sectors such as health and social services, employment, housing, or education. Support for the development of models of care to advance this will vary according to context. In low-resource settings where services are underdeveloped, efforts may focus on establishing and expanding services and improving referral systems, whereas in high-income countries where services are available but users experience difficulties navigating complex service systems, efforts should focus on strengthening coordination mechanisms.

Box 20

Rehabilitation for people with spinal cord injury*

Spinal cord injury can result in limitations in many activities. Rehabilitation is an essential service that can prevent complications associated with spinal cord injury; it can assist the person towards living a fulfilling and productive life. Rehabilitation should commence in the acute phase; its availability should continue, to promote functioning; and it should be provided in a range of different settings from the hospital through to the home and community environments. Rehabilitation normally aims to assist people to overcome limitations by improving functions in the trunk and limbs, modifying the person's immediate environment, or providing assistive products and other reasonable accommodations to enable individuals to continue family and work roles.

* World Health Organization and International Spinal Cord Society. International perspectives on spinal cord injury. World Health Organization, 2013.

Case study

The age care system in Singapore

The intersection between the agendas of disability and ageing goes beyond the fact that many older people have disabilities. Both persons with disabilities and older people may experience the same barriers to accessing care, bear the same health inequities, and face similar issues such as discrimination, isolation and abuse. Addressing one agenda can support the other – thus policies for healthy ageing can benefit persons with disabilities.

Having recognized ageing as a growing issue, Singapore is one of several countries strengthening their policies to address healthy ageing. The care system for older people in Singapore begins with the individual and family, and emphasizes care that is home- and community-based. The aim is to deliver cost–efficient quality care and reduce unnecessary utilization of institutional care.

While recognizing that maintaining health is a multifaceted process, the Ministry of Health coordinates interministerial and multistakeholder collaboration, but has governance of the entirety of long-term care systems, including policy, financing and regulatory frameworks.

In the overarching Action Plan for Successful Ageing* there are 70 initiatives, including those that address wellness, income sufficiency, housing, transport and social inclusion. Currently being planned are the senior-friendly design of public buildings, legislation to protect older people, and research in ageing, with the aim of making Singapore an age-friendly city.

Some 3000 volunteers engage seniors at home or in the community; those found to be frail, isolated or experiencing disability are referred for assessment, socialization services or care management. Three insurance schemes provide disability cover. The "Elder Fund" provides financial support for low-income, severely disabled Singaporeans aged over 30 years. Regional health systems provide person-centred care using a multidisciplinary team, and bridge gaps between public, private, community and home-based care, making it easier to find providers.

* https://www.moh.gov.sg/docs/librariesprovider3/action-plan/action-plan.pdf.

23. Strengthen models of care for children with disabilities

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An important component of adopting a life-course approach includes investing in models of care that focus on early childhood development for persons with disabilities. Such models need to be family-centred and undertake developmental monitoring and screening; tracking of at-risk children; diagnosis; the provision of specialized, coordinated care; working with services for early childhood and in the education sector, as well as services that are home-based, and outreach to school. Such an approach would require the integration of disability in newborn, maternal, child and adolescent health, as well as cross-sectoral collaboration with relevant sectors such as education.

The WHO, UNICEF and World Bank framework, *Nurturing care for early childhood development (70)* proposes a progressive universal model, which requires addressing inequities from the outset to ensure that no child is left behind. Within this, the framework recognizes incremental levels of needs and support for families and children who have developmental disabilities or are exposed to deprivations. Home visits and parent groups facilitated by a skilled provider, are examples of approaches offering additional support to families and children. Community health workers can play an important role if they are well integrated into the health system; however, for home visiting and parenting sessions to make an impact, skilled workers and adequate intensity are highly desired. Countries need to progressively build expertise for identifying and addressing a range of developmental disabilities, through interdisciplinary services that address the mental, physical and social needs of children and their families. Planning and investing in building these services are essential, as are establishing the foundations of a universal approach through policies and services for nurturing care.

24. Promote deinstitutionalization

Deinstitutionalization refers to changing from long-term health and social care institutions to person-centred, rights-based health services and support in the community. Such a move allows countries to respect the rights and dignity of persons with disabilities, prevent their isolation or segregation from the community, and ensure better living conditions and inclusion. Deinstitutionalization can be a complex process technically and organizationally, and usually is undertaken gradually. It involves a process of i) simultaneously increasing the number of discharges by reducing new admissions to psychiatric or social care institutions, and enhancing the quality of care and rights of people in all short-term inpatient or residential care; and ii) reducing admissions by building a network of coordinated and linked community-based health and social care services, and scaling up care in the community *(71)*. WHO's *Guidance on community mental health services: promoting person-centred and rights-based approaches*, provides examples of community-based mental health care that is both respectful of human rights and focused on recovery *(72)*.

Example of how progress on models of care can be monitored

Example indicators to track progress towards disability inclusion in this strategic entry point include the presence of a plan to make primary care services inclusive for persons with disabilities, along with including early identification services and rehabilitation for children in service packages, and universal provision of assistive products.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Plan for inclusive primary care services	Is there an established plan or policy to make primary care services inclusive for persons with disabilities? Has access to health services improved for persons with disabilities compared to the general population?
Early identification services and rehabilitation	Are early identification services and rehabilitation for children with disabilities included in service packages?
Universal provision of assistive products	Is the provision of assistive products integrated into UHC packages of care? What is the percentage of the population with access to assistive technology? Has availability of assistive technology improved for persons with disabilities?
Maintenance of essential health services for persons with disabilities during health emergencies	Does the national plan for continuity of essential health services during health emergencies also consider the needs of persons with disabilities?

5 Health and care workforce

What does it mean?

The health and care workforce:

- can be defined as “all people engaged in actions whose primary intent is to enhance health” *(33)*.
- includes all occupations engaged in the continuum of promotion, prevention, treatment, rehabilitation and palliative care, including the public health workforce.
- includes clinical staff, such as physicians, nurses, midwives, rehabilitation workers, pharmacists, caregivers, and dentists; also included are management and support staff, or people who do not deliver services directly but are essential to the performance of health systems, such as managers, IT and administrative staff, ambulance drivers and accountants.

Strengthening the health and care workforce is fundamental to achieving SDG3 and the global health priorities. In terms of disability inclusion, integrating training on disability in the curricula of health professionals has long been a topic in the literature and requested by civil society. While there are many examples of disability trainings for health professionals, there is limited evidence of a systemic integration of training on disability at a national level within the curricula of health workers, and this has not changed in the past decade *(73, 74)*. There are calls for “transformative disability conscious medical education, training and practice” which, instead of focusing on “curing the abnormal”, would present disability as one of many diversity factors around which a range of structural barriers and systemic disadvantages influence health outcomes *(75)*. Training should sensitize the health and care workforce to the needs and rights of persons with disabilities. It is important that health professionals understand not only the health condition associated with the disability, but also the societal experience of living with disability. A basic tenet of the training is that the person with a disability is given the same respect for their autonomy and dignity as any person *(76)*. It has further been suggested that disability competencies *(75, 77–79)* and “unconscious bias training” *(12, 14, 80–82)* are important components to be established among the health and care workforce to address the knowledge, attitudes and practices which add to discrimination against persons with disabilities, and the health inequities they face.

Other topics that have been proposed for the training on disability inclusion are how to recognize the health-care needs of persons with disabilities – both those that are specific to health conditions (e.g. pressure sores among persons with mobility impairments, or preventing diabetes among persons with mental health conditions *(83)*) and those that arise when accessing mainstream health services, such as the maternity needs of women with disabilities *(84–87)*. Inclusive language (Box 21) and communication are essential for such training. During health emergencies such as the Zika epidemic, or the COVID-19 pandemic, health and care workers have been confronted with new conditions and syndromes, which are yet to be fully understood *(88, 89)*; they have to support people to understand and adjust to frequently changing public health rules, as well as to new information and ways of working *(90)*. The Health Equity Framework for People with Disabilities issued by the US National Council on Disability, for example, recommends the inclusion of effective communication as a key competency for the clinical care of disability, alongside others such as professionalism, patient-centred care, or teams- and systems-based practice *(91)*.

Box 21

Appropriate and pejorative language on disability*

When referring to persons with disabilities, there are certain terms that should be avoided, and be replaced with others that are recommended. For example, terms such as "atypical", "handicapped", "differently abled", "suffering from" or "troubled with" disabilities should not be used; nor, when referring to persons with an intellectual disability or impairment, should terms such as "retarded", "slow", "brain-damaged", "intellectually challenged", "subnormal" or "mentally handicapped". The same applies for persons with psychosocial disabilities, where words such as "insane", "crazy", "psycho", "lunatic", "demented", "mentally deranged" or "mentally agitated" indicate inappropriate language. For persons with physical impairments, words such as "crippled", "invalid", "deformed", or "bedridden" should be avoided, likewise with adjectives such as "mongoloid" for persons with Down syndrome.

It is important to flag that these terms may differ from country to country, and that language translation can lead to inappropriate terms being used inadvertently.

**Source*: United Nations (2021) Disability-inclusive communication guidelines (https://www.un.org/sites/un2.un.org/files/un_disability-inclusive_communication_guidelines.pdf).

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

25. Develop competencies for disability inclusion in the education of all health and care workers

Training on disability inclusion can be incorporated into the training curriculum of all health and care workers, from doctors to nurses, midwives and community health workers *(92)*. This strategy can be enhanced through making the accreditation of medical, nursing and midwifery programmes contingent on the completion of disability-specific curriculum components *(93)*. Such education will better equip health professionals to provide adequate and inclusive health services. It is essential that health-care providers have the adequate knowledge, skills, and behaviours on disability and the rights of persons with disabilities, to be able to communicate with them directly and understand their diverse needs. It will also help health and care workers understand the wide range of contributing factors that present challenges for persons with disabilities and their families when accessing health-care services and following advice *(94, 95)*. The responsibility for the curricula in health and medical training courses often lies outside the health sector – more specifically with academic and professional bodies; therefore, establishing training in disability inclusion in the curriculum would require good coordination between the health and education sectors and professional accreditation mechanisms *(96)*.

Case study

Rolling out training in disability inclusion for health and care workers in Mongolia

The training in disability inclusion of health-care workers is an essential step towards addressing barriers and biases that impact care. In Mongolia, a new training programme has been rolled out for a disability-inclusive health services toolkit. The toolkit aims not only to increase the knowledge and skills of health workers on disability inclusion, but also to support making health services accessible to all.

In May and September 2022, two trainings of trainers were organized. More than 300 health professionals participated from 14 of the country's 21 provinces, including from three reference hospitals, and six district health centres of Ulaanbaatar, the capital city where half the population lives. The comprehensive training, which was organized in seven modules, covered a range of issues including accessibility, attitudes of health personnel and communication barriers.

The training involved two stages. In the first stage, participants were trained for three days as trainers in Ulaanbaatar. In the second stage, the trained participants then returned to their provinces or districts, where trainings were organized for their colleagues, with the help of an online facilitator.

The training was designed using, as a foundation, existing WHO disability-inclusive health services guidance, and through a series of consultations with WHO personnel from all levels, as well as researchers from two health bodies linked with the University of Melbourne. Persons with disabilities, organizations of persons with disabilities and civil society organizations also played a role in the development of the toolkit, namely in the translation, the training, sharing experiences and monitoring the implementation of the module at a local level. The training is being coordinated by an international nongovernmental organization (AIFO) that has had considerable experience with disability in Mongolia.

Case study

Sign language training in Kenya

For persons with hearing loss, a visit to a health centre can be fraught with communication challenges, from hearing their name being called, to listening to a doctor's diagnosis. In Kenya, news reports confirm that this had led to some deaf people self-medicating or avoiding doctor's visits. Not all deaf people are literate and thus cannot communicate by writing; some take friends to interpret for them, but this raises issues of confidentiality.

Now, however, some of these communication barriers have been overcome by a programme to train health-care workers in the use of sign language. An initiative that began several years ago in maternity wards has since spread to other service points nationwide, and basic training in Kenyan sign language is provided to nurses and clinical officers in select hospitals by universities and non-profit organizations for deaf people.

Today, basic sign language is a required competency for all health-care workers in Kenya, with a training module embedded into health-care training at colleges and universities. To date, tens of thousands of health-care workers or students have been trained in sign language with professional health-care associations encouraging those already in the profession to be trained. Other sectors are also taking up training, as are civil servants who can learn with sponsorship from a disability organization. Disability activists have said that in the past, deaf people have been denied services in many public offices due to communication barriers.

In January 2020, the Kenyan Senate approved a new bill to make it compulsory for all government institutions – including state-owned businesses, the judiciary and schools – to provide for the use of sign language. Once the bill is passed by the National Assembly, sign language will become the third official language in Kenya after Kiswahili and English.

26. Provide training in disability inclusion to all health service providers

Training in disability inclusion can be integrated into the training activities of health and care workers already practising, or be conducted as a separate activity *(97)*. Wherever possible, persons with disabilities or their representative organizations should be directly involved in the conduct of the training, or even deliver it themselves *(98)*. Evidence demonstrates that health professionals are better equipped to communicate and work with persons with disabilities if they learn directly from them *(99)*.

27. Ensure the availability of a skilled health and care workforce

Besides the education of future and current health professionals, it is also critical to ensure that there are sufficient health and care professionals who can provide the services needed by persons with disabilities. This can be facilitated by increasing the number of appropriately skilled health professionals, including the rehabilitation workforce, whose numbers are insufficient in many low-income settings *(100)*. A strategy that some countries may use while investing in increasing the availability of skilled workforce is task-sharing. There are good examples of the importance of task-sharing as a valuable strategy, where certain tasks traditionally performed by specialists can be undertaken by non-specialists, such as community health workers, health aides, nurses and technicians, thereby expanding access to essential care needed by persons with disabilities. Task-sharing is a successful strategy used in the area of ear and hearing care *(101)*.

28. Include persons with disabilities in health and care workforce

Including persons with disabilities in the health and care workforce facilitates strengthening and development of the wider workforce in the health sector. Providing equal employment opportunities ensures a workforce with diverse experiences which not only enriches the health sector but ultimately benefits everyone *(43)*. Inclusion can be facilitated through actions such as providing opportunities to students with disabilities in academic institutions, career advancement for health professionals with disabilities, implementing universal design in health facilities, and ensuring that all institutional policies support disability inclusion *(44)*.

29. Train all non-medical staff working in the health sector on issues relating to accessibility and respectful communication

In addition to health and care workers, all staff working in the health-care sector, including administration, reception, cleaning and maintenance staff, IT staff and management, must be well trained and informed, especially on issues relating to accessibility, proper use of language, and attitudes to communicate with persons with disabilities, including those with psychosocial disabilities.

30. Guarantee free and informed consent for persons with disabilities

Guaranteeing free and informed consent enables persons with disabilities, including persons with psychosocial, intellectual and cognitive disabilities, to exercise the same rights as any person in making their own decisions. To facilitate this, health and care professionals can take several actions, such as providing health information and options in a clear and understandable manner, particularly consent forms that are in written format; or making sure that information and forms are accessible to blind persons and those who need interpretation or support with communication; or ensuring that mechanisms are in place to guarantee the right to supported decision-making is respected. It is also important to make clear the right of persons with disabilities to refuse treatment, and that any decisions made are voluntary and without coercion from others such as family members, support persons or even service providers *(102)*. This applies to all areas of health, including informed consent for women and girls with disabilities in the context of their own sexual reproductive health and rights and choices over their own bodies.

Examples of how progress in the health and care workforce can be monitored

An example indicator to track progress towards disability inclusion in this strategic entry point includes a mandatory module in the workforce curricula.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Disability inclusion module in workforce curricula	Does the workforce curricula include a mandatory module on disability inclusion?

6 Physical infrastructure

What does it mean?

Physical infrastructure:

- is a critical factor for many aspects of the environment and social determinants of health such as housing.
- has a fundamental impact on the access and provision of health services, and the ability of health-care providers to conduct their work in the context of health service delivery.
- involves key elements such as physical availability and physical quality of facilities, and includes facility design, amenities, safety, accessibility, sanitation and waste disposal, telecommunications connectivity, or power supply.

Universal design is commonly considered fundamental to disability inclusion in terms of making physical infrastructure accessible for persons with disabilities. Evidence shows that incorporating universal design into the initial planning and development of infrastructure can be more cost–effective than retrofitting facilities *(103)*. It is also less costly than generally considered, with studies giving a range of estimates. For example, if universal design is planned from the outset, an increase of as little as 0.5–1% of the total building costs could be expected *(103, 104)*. Given the long-standing assumptions around additional costs, it should be stressed that the costs involved in making facilities accessible are minimal. Moreover, the cost of not incorporating universal design is important since inaccessible environments limit education, health, social, economic and other opportunities. There are also good examples of the provision of reasonable accommodation for persons with disabilities in facilities *(105)*.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

31. Incorporate a universal design-based approach to the development or refurbishment of health facilities and services

Incorporating universal design into the development or refurbishment of health facilities and services can benefit the widest possible number of people. For example, installing a ramp at an entrance to a facility which has steps or a raised threshold facilitates entry for persons with disabilities who use wheelchairs, people who have difficulty managing stairs, women who are heavily pregnant, people who have a vision impairment, health users or health facility workers moving people, or goods in prams or on trolleys. The accessibility of transportation systems that support persons with disabilities to reach health facilities is also an important consideration (see Box 22). Universal design can also benefit other populations such as older people, persons with sensory impairments, people with temporary injury or illness, people with limited health literacy, and other groups in marginalized situations. In addition to universal design, implementing minimum standards for the accessibility of facilities and services that are open to the public is another strategy that countries may take *(106)*; training professionals to understand and apply such standards, and raising awareness among developers and funders to respect the accessibility regulations is a further important consideration.

Besides the changes of infrastructure in health facilities and services, poor infrastructure outside the health sector (e.g. safe water, electricity, road conditions, internet coverage), especially in rural settings, should also be addressed, as this reduces access to health care and other areas of life such as education, employment, social protection, or social participation.

Box 22

The principles of universal design*

Principle 1: Equitable use – the design is useful and marketable to people with diverse abilities.

Principle 2: Flexibility in use – the design accommodates a wide range of individual preferences and abilities.

Principle 3: Simple and intuitive use – the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current level of concentration.

Principle 4: Perceptible information – the design communicates the necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

Principle 5: Tolerance for error – the design minimizes hazards and the adverse consequences of accidental or unintended actions.

Principle 6: Low physical effort – the design can be used efficiently and comfortably and with minimum fatigue.

Principle 7: Size and space for approach and use – the appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility.

***Source*: https://universaldesign.ie/what-is-universal-design/the-7-principles/.

Case study

Universal design in Norway

Universal design was first introduced in 1997–1998 as a planning concept in Norway, when the Ministry of the Climate and Environment launched a development programme into the municipal planning process, to facilitate accessibility for persons with disabilities.

Since 2004, Norway has launched four action plans on universal design; the latest "Sustainability and equal opportunities – a universally designed Norway" for the period 2021–2025, was developed in a cooperation with eight ministries. The action plan states that the Government will make high demands for universal design when developing housing, infrastructure and business areas and ensure better compliance with regulations on the universal design of solutions for information and communications technologies in the public sector.

The Ministry of Culture and Equality is responsible for the Equality and Discrimination Act, which stipulates universal design and accessibility. Funds for financing measures for universal design follow the sectoral responsibility principle and lie mainly within the budgets of the various ministries *(107)*.

Case study

Laying the groundwork for accessibility in India

A decade ago in India, it was considered a luxury for a building to have accessibility features for persons with disabilities. Today, this way of thinking has changed and accessibility in buildings is increasingly seen as a human right.

In 2015, India embarked on a national campaign to offer universal access to persons with disabilities, recognizing that accessibility is essential for an inclusive society. The Accessible India Campaign (*Sugamya Bharat Abhiyan*) focuses on improving accessibility in three key areas: the physical environment; the transit system; and the information and communication ecosystem. The campaign drew inspiration from the United Nations Convention for the Rights of Persons with Disabilities (CRPD), which calls for governments to address accessibility issues.

Since then, change has been incremental but steady and significant. Meanwhile, the Government also passed the Rights of Persons with Disabilities Act 2016, enshrining accessibility into law.

Today, building codes for the Central Public Works Department (PWD), the authority in charge of public sector works and state PWD codes, require new buildings to be accessible. The Government's *Harmonized Guidelines* is a manual for the design of a barrier-free environment. The governments of many Indian states are adapting these guidelines for their own state PWD. Accessibility features in urban settings are also considered in the guidelines for "smart cities". In government hospitals, the effect of these changes is visible, for example in the installation of ramps and rails.

There is also a drive to ensure public transport vehicles are made accessible. New procurement guidelines for state-owned vehicles require that buses procured after 2018 are low-floor buses and/or with other accessibility features.

In the area of information and communication technologies, rapid changes were seen. Within the first year of the campaign, 25% of 1800 government websites had been made accessible. Sign language interpreters are now commonly seen on television news for national channels.

Much still needs to be done, but some of the groundwork for a more accessible India has been laid.

32. Provide appropriate reasonable accommodation for persons with disabilities

CRPD defines reasonable accommodation as "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". Not every person with a disability needs reasonable accommodation; however, for those who do, ensuring reasonable modifications where universal design has not been applied, is essential for the equal access to health services and goods. Reasonable accommodation may not necessarily apply to physical infrastructure only. Health-care providers can make reasonable modifications to existing policies, practices, or procedures when these are needed.

Examples of how progress in physical infrastructure can be monitored

An example indicator to track progress towards disability inclusion in this strategic entry point is the physical accessibility of health facilities in the country.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Health facilities are physically accessible	Is the physical infrastructure of health facilities accessible to all populations, including persons with disabilities?

7 Digital technologies for health

What does digital technologies for health mean?

Digital technologies for health:

- encompass a wide range of elements, such as information and communications technologies; or more recent developments in advanced computing such as big data, artificial intelligence and genomics.
- bring about fundamental shifts in how individuals and communities manage their own health, and access health information and health services.
- contribute to the empowerment of people and communities, and also improve the effectiveness and efficiency of integrated health services and delivery of care, particularly through the rapid expansion of interventions such as mHealth, eHealth or telehealth.

For persons with disabilities, digital technologies have provided long-awaited opportunities "to receive evidence-based health care comfortably in their own homes" *(81)*. However, often the "digital divide" faced by different groups, including persons with disabilities *(38, 108, 109)*, women and girls *(110, 111)*, and those living in displacement and resource-limited settings *(112)* remains a barrier when addressing equitable access to advancements in digital health. The involvement and inclusion of support persons and interpreters in the delivery of health care, including telehealth, have been strongly recommended, particularly for some persons with intellectual disabilities, who may need the support of carers, family members and support people in their interactions with health-care providers *(113)*.

There are calls for making digital health technologies accessible. One of the essential prerequisites proposed is that different groups of persons with disabilities are directly involved in the development process and research into adaptive technology, so that it is made more effective and accessible and to everyone *(114)*. In the digital transformation strategies of Sweden *(115)* and Australia *(116)*, for example, it is recommended that when drafting policies, vulnerable groups must be included and integral to the design process. Likewise in Canada, where funding agencies, when providing funding for a digital health project, require persons with disabilities to be included at every stage of the process *(117)*.

Recently, the Broadband Commission for Sustainable Development published *The future of virtual health and care: driving access and equity through inclusive policies (118)*. The report advocates for virtual health and care to be integral to health priorities, and highlights the importance of integrating disability-inclusive features into the digital mainstream.

There are many examples of emerging health technologies that are being made accessible. The use of mobile-based software applications for vision or hearing assessment, or artificial intelligence technologies, enhances the access of quality health care to the most neglected communities *(119)*. In addition, technological advances also allow the use of electronic medical records that can be accessed at any point in the health network, thereby facilitating the reorganization of health services around the patient's needs *(37)*. Electronic health records allow the compilation, sharing and monitoring of health and related information of each individual service user, including every contact the user has with the health system throughout their life course. The use of electronic health records helps health providers to make better decisions, and managers to audit service quality and cost, as well as to monitor system performance.


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Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

33. Adopt a systems approach to the digital delivery of health services with health equity as a key principle

Adopting a systems approach to the digital delivery of health services involves making the design of digital health solutions, including telehealth, disability inclusive, and a principle in national policies *(120)*; this allows a more proactive strategy towards the equitable use of digital innovations, rather than a reactive process of upskilling persons with disabilities after the digital health tools have been developed. At a systems level, key changes required are first, for countries to amend or create national digital health strategies that are appropriate for the local context (e.g. that consider the digital infrastructure available); and second for strategies to reflect the needs of the population, including the individual needs of persons with disabilities. This could involve the existing legislation, regulations, or policies that have been written for face-to-face health service delivery *(121)* being adapted to digital health provision in an inclusive manner. A wider multisectoral approach involving other relevant ministries and the private sector is required to advance this agenda.

Case study

Using digital technologies as respect for the rights of persons with disabilities in Ireland

Ireland is bringing together public and private partners to accelerate the development of digital health solutions for greater efficiency and to empower patients in their care, including persons with disabilities. An ecosystem of 50 “Digital Living Labs” across hospital and community health services are providing test beds for new digital technologies through high-impact projects, some of which will directly benefit persons with disabilities.

Some of the projects use technology to bring hospital services into homes. “Stay Left” recognizes that for people with chronic conditions or those in need of rehabilitation, services are best provided at home. Innovative technologies enable remote monitoring of heart failure and respiratory problems, and a mobile X-ray machine brought to a patient’s home after a fall is reducing transfers to hospital by 99%.

Also bringing health-care to the home is the Cooperative Real Engagement for Assistive Technology Enhancement (CREATE) initiative, where service users and providers work together to identify what will make a real difference to users of digital and assistive technology (DAT). Meeting the unmet needs for products and services among DAT users is a particular focus. The initiative also aims to create a stronger systemic approach within the disability sector; to stimulate organizations to work collaboratively and with service users; and to co-design systemic improvements for the future delivery of DAT services.

Other successful projects include the development of Ireland’s first Sit-to-Stand Wheelchair Service; a new assistive technology passport; enhanced experience in using respite services; a loan library; and a mentorship programme of expert DAT users.

34. Adopt international standards for accessibility of digital health technologies

Digital applications and software can be universally designed and accessible to everyone through the adoption of international standards, such as the Web Content Accessibility Guidelines (WCAG) *(122)*, or the *WHO-ITU global standard on accessibility of telehealth services* (See Box 23) *(113)*. The WCAG has been developed to make web content accessible to persons with disabilities in diverse contexts and using a range of user devices. The WCAG guidelines can also address the often inaccessible design of web pages and other digital interfaces which result in inadequate access to information and digital services for persons with disabilities. Inaccessibility affects not only health information, but also other key services that impact health equity, such as unemployment benefits and other forms of social protection, as well as educational, employment, and social opportunities, placing persons with disabilities in a disadvantaged position *(123, 124)*. The WHO-ITU standard includes a set of requirements that governments, health-care providers and manufacturers of telehealth platforms can incorporate to ensure the provision of accessible, equitable and safe health-care services to persons with disabilities.

Box 23

WHO-ITU Global standard on accessibility of telehealth services *(113)*

To address accessibility barriers to the uptake of telehealth services, in 2022, WHO, jointly with the International Telecommunication Union (ITU), published the *WHO-ITU global standard for accessibility of telehealth services*. This standard defines the accessibility requirements for technical features to be implemented by governments, health-care providers and manufacturers of telehealth platforms to facilitate the access and use of telehealth services by persons with disabilities. Following an inclusive approach, all technical requirements included in the standard are based on a comprehensive input collected from civil society including organizations of persons with disabilities, and the industry, ensuring their feasibility and relevance. Examples of these requirements include the presence of captioning during video conferencing for persons who are deaf or hard of hearing, or compatibility of telehealth platforms with screen readers or assistive products such as Braille keyboards, to remove barriers for people who are blind or visually impaired. If adopted by countries, the global standard can facilitate a universal access to telehealth for persons with disabilities.

Examples of how progress in digital technologies for health can be monitored

An example indicator to track progress towards disability inclusion in this strategic entry point is the formal adoption in countries of international standards for digital accessibility.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Standards for digital accessibility adopted	Have international digital accessibility standards been adopted at a national or subnational level?

8

Systems for improving quality of care

What does it mean?

Quality care means effective, safe, and people-centred care that is timely, inclusive, efficient, equitable and integrated. Good quality care is fundamental for:

- improving the performance of health service delivery.
- maintaining trust among service users.
- ensuring the sustainability of the health system.
- guaranteeing that all resources invested are translated into improving people's health.

Quality of care is fundamental for every person; care can only be of good quality if it is accessible and reaches everyone, including persons with disabilities. There have been different calls in the literature to improve the quality of care provided to persons with disabilities. Even though strategies to achieve this are complex and involve actions at different levels, specific activities have been proposed to facilitate the process.

One of the proposed solutions includes the electronic collection of feedback in more technologically-advanced settings. It has been demonstrated that collecting standardized information on disability-related accessibility from eye care patients through electronic health record-based questionnaire has been a feasible and effective approach *(125)*. At the community level, participatory approaches may be a more appropriate methodology to identify barriers and context-specific adaptations to health services, including group discussions, "stories of change" *(126)* and the use of "communication toolboxes" *(39)*. Examples of such approaches have been demonstrated in sexual and reproductive health research *(127)* and evaluations of programmes addressing gender-based violence in a refugee setting *(39)*. Participatory approaches can also support the development of user groups, such as those developed in the Philippines to provide ongoing feedback and education on the sexual and reproductive health needs of women with disabilities *(128)*.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

35. Integrate the specific needs and priorities of persons with disabilities into existing health safety protocols

Any existing safety protocols which include risks assessment of service users can be adapted to reflect the needs of persons with disabilities. A precondition is the establishment of reliable methods for identifying such needs through integration of a data collection method in hospital questionnaires. This process can identify persons with disabilities, as well as their specific needs, for example, a need for a support person of their choice. Ensuring safety may imply guaranteeing reasonable adjustments when needed, which can also facilitate the equal access to services or equipment of persons with disabilities. Reasonable adjustments in the protocols for health emergencies can include adapting generic public health measures, such as physical distancing during the COVID-19 pandemic (with appropriate risk mitigation strategies) to ensure that persons with disabilities receive appropriate care and support. Other actions for emergencies include the removal of physical barriers; providing suitable fire evacuation procedures; modifying equipment; providing sign language interpreters; adjusting the premises of facilities; and providing extra support. Health safety protocols that are disability inclusive will involve training health service providers on the specific protocols relating to persons with disabilities.

36. Ensure disability-inclusive feedback mechanisms for quality of health services

It is important to integrate, into existing feedback mechanisms, relevant questions and complaint processes so that the experiences and requirements of persons with disabilities can be better understood. Examples of questions that can be asked include experiences of perceived discrimination; barriers to accessing or receiving quality care; personal satisfaction with the quality of received services; or negative attitudes from health professionals. The channel for collecting feedback can vary depending on the operational procedures in the health facility; it is important that the format is accessible for everyone. In addition to feedback mechanisms, comprehensive safeguarding mechanisms that are accessible to persons with disabilities are essential, to report incidents of sexual exploitation or abuse perpetrated within the health sector. This includes raising awareness among communities and service users of these mechanisms and how to report incidences.

37. Consider the specific needs of persons with disabilities in systems to monitor care pathways

To achieve an inclusive referral system, several things need to be put in place. For example, ensuring person-centred care through consultation with users, including persons with disabilities, to determine which referral mechanisms and which forms of assistance they find most appropriate and accessible *(129)*. Guaranteeing the availability of a structured multidisciplinary plan of care that can provide and coordinate the care needed is essential, as is adapting existing clinical guidelines to patient specific needs and local structures and providing a good referral system within and across facilities and levels of care. When establishing referral systems, it is important to also develop, concurrently, informed consent and information sharing protocols, so that persons with disabilities have a choice over the type of interventions they receive and have confidence in the health service.

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Case study

Fostering inclusiveness in hospital disaster risk management in the Americas

Persons with disabilities are usually excluded from disaster risk management planning. Yet evidence indicates that they are disproportionately affected in health emergencies.

To foster inclusiveness in disaster risk management, a methodology was developed in 2018 by the Pan American Health Organization (PAHO), the Regional Office for the Americas of the World Health Organization: "Disability inclusion in hospital disaster risk management" (known by its Spanish acronym INGRID-H)*. The methodology supports countries to comply with the article on emergencies in the United Nations Convention on the Rights of Persons with Disabilities.

INGRID-H is an "evaluation-action" methodology designed to improve the level of training in hospitals to improve their response to emergencies and disasters caused by all hazards, focusing on persons with disabilities, which thus addresses the visibility and participation of persons with disabilities, universal accessibility, the improvement of capacities and the hospital response plan.

Chile, Ecuador, Colombia, Dominican Republic, Guatemala, Honduras, Nicaragua, Panama, and Peru have implemented the INGRID-H methodology in more than 60 hospitals. This has resulted in the improved participation of persons with disabilities in disaster and emergency risk management planning, as well as the inclusion of disability in response plans, procedures and protocols.

In Guatemala, INGRID-H was rolled out in six selected hospitals, where training workshops were organized with the participation of 126 civil society organizations, officials from the Ministry of Health, the Guatemalan Red Cross and National Coordination for Disaster Reduction, and representatives from Guatemala's National Council for the Care of People with Disabilities and Institute of Social Security. One of the most important achievements was the creation of a National Coalition on Inclusive Risk Management to enable coordination efforts and develop a route map for improving the inclusion of persons with disabilities.

* https://reliefweb.int/report/world/ingrid-h-disability-inclusion-hospital-disaster-risk-management.

Examples of how progress in systems for improving quality of care can be monitored

Example indicators to track progress of disability inclusion in this strategic entry point include integration of disability in health safety protocols, the establishment of inclusive care pathways, collecting information on the responsiveness, safety and timeliness of health services.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Disability integrated in health safety protocols	Has disability been integrated into existing national or subnational health safety protocols?
System to monitor care pathways	Are established care pathways inclusive for persons with disabilities?
Health services are responsive to persons with disabilities	Are persons with disabilities satisfied with the way their health needs are being addressed on an equal basis with others?
Service provision is safe and timely	Are health services safe and delivered in a timely manner for persons with disabilities on an equal basis with others?

9 Monitoring and evaluation

What does it mean?

Monitoring and evaluation of health progress and performance of the health system:

- are critical to ensure that any policies, actions, or decisions are implemented as planned.
- involve the inclusion of a set of indicators.
- allow countries to assess gaps, determine priorities, set baselines and targets, and track progress across their health system strengthening areas of action.

For disability inclusion, this strategic entry point is fundamental for several reasons. For example, disability-related data are essential to enable countries to develop evidenced-based policies to monitor the implementation of the CRPD. These data can also support countries in measuring progress towards national targets, as well as to take stock of the challenges that remain unresolved.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

38. Create a monitoring and evaluation plan for disability inclusion

To integrate disability inclusion into the monitoring and evaluation framework of the health system, countries first need to create a plan that outlines the process. The establishment of such plan normally includes several steps. First, governments need to identify actors to be engaged in the development of the monitoring framework. The Ministry of Health can create an informal group of people with expertise in disability, health information systems and evaluation; the focal person for disability within the ministry would generally lead the process. The participation of persons with disabilities in these discussions is important. Second, based on the established priorities of countries and the actions taken, or planned, to advance disability inclusion, indicators that are aligned with these priorities need to be selected. For example, if a country has taken steps to provide training for their health and care workforce or to adopt universal design in facilities, indicators that track progress on these two areas need to be selected. Third, governments should identify and develop data sources within the national health information system to collect data on, and monitor, the selected indicators. These data can be collected through all levels of the monitoring and evaluation framework – input, output, outcome or impact. Furthermore, it is fundamental that the monitoring and evaluation plan also considers the collection of baseline information for each indicator and sets the frequency of data collection.

39. Integrate indicators for disability inclusion into the monitoring and evaluation frameworks of country health systems

Throughout the strategic entry points presented in Chapter 3, different indicators have been proposed as examples to track disability inclusion in the health sector. The indicators are largely drawn and adapted from the WHO PHC measurement framework and indicators *(130)*; they are examples only, and countries can choose to adapt them according to their needs. WHO will conduct an extensive consultative process in due course, to recommend a full set of indicators for countries.

The indicators presented so far cover the health system determinants (structures and inputs of the health system), as well as service delivery (processes and outputs) that form part of the monitoring and evaluation framework. The different types of indicators are essential to understand how disability inclusion has been integrated within the health sector and what contributes to health inequities for persons with disabilities. However, to measure the impact of actions for disability inclusion on the health of persons with disabilities and whether the objectives of the health system are being met, additional indicators are needed under the levels of outcomes and impact in the monitoring and evaluation framework. These indicators are presented in Table 5 and integrated into the full framework (Figure 7). But until efforts are made to disaggregate the information by disability status it won't be possible to track many of them.

Data on indicators for "service delivery" and "health system objectives" can be collected largely within the national health information systems of countries.

For “health system determinants” as well as other determinants and risk factors for health, data may be collected by other sectors.

There are various sources of information that can be used to collect data across these different levels. For example, at input level, administrative sources such as financial tracking systems, databases and records on human resources, infrastructure or policies can be used to understand how financing for disability works, or whether health facilities are accessible. At output level, facility assessments or facility reporting systems can measure availability of services, service readiness or quality. All information collected at input and output levels will only be relevant if persons with disabilities are identified and data is disaggregated by disability.

Identifying persons with disabilities can be facilitated through the routine data collection in facilities. An effective and sensitive way for doing this is collecting data on functioning; for example, the systematic collection of coded and reported data on functioning as part of routine facility data collection, facilitates the disaggregation of data at output level to identify health inequities in health service provision.

In recognizing the value of capturing functioning information through routine facility assessments, WHO introduced a supplementary section for functioning assessment in the 11th revision of the International Classification of Diseases (ICD-11) *(131)*. This facilitates the joint use of the ICF and the ICD, specifically for practical purposes such as reimbursement *(132, 133)*. The section on functioning incorporates the WHO Disability Assessment Scale 2.0 (WHODAS 2.0), and the functioning module of the Model Disability Survey. This is a major step forward in collecting data on disability within the health information system, since most countries use the ICD for mortality and morbidity data, and many also for reimbursement purposes. Even if the functioning assessment section remains an optional module, countries now have a way to collect and code information on functioning that can also be used for reimbursement purposes and for disaggregation purposes at output, outcome and impact level.

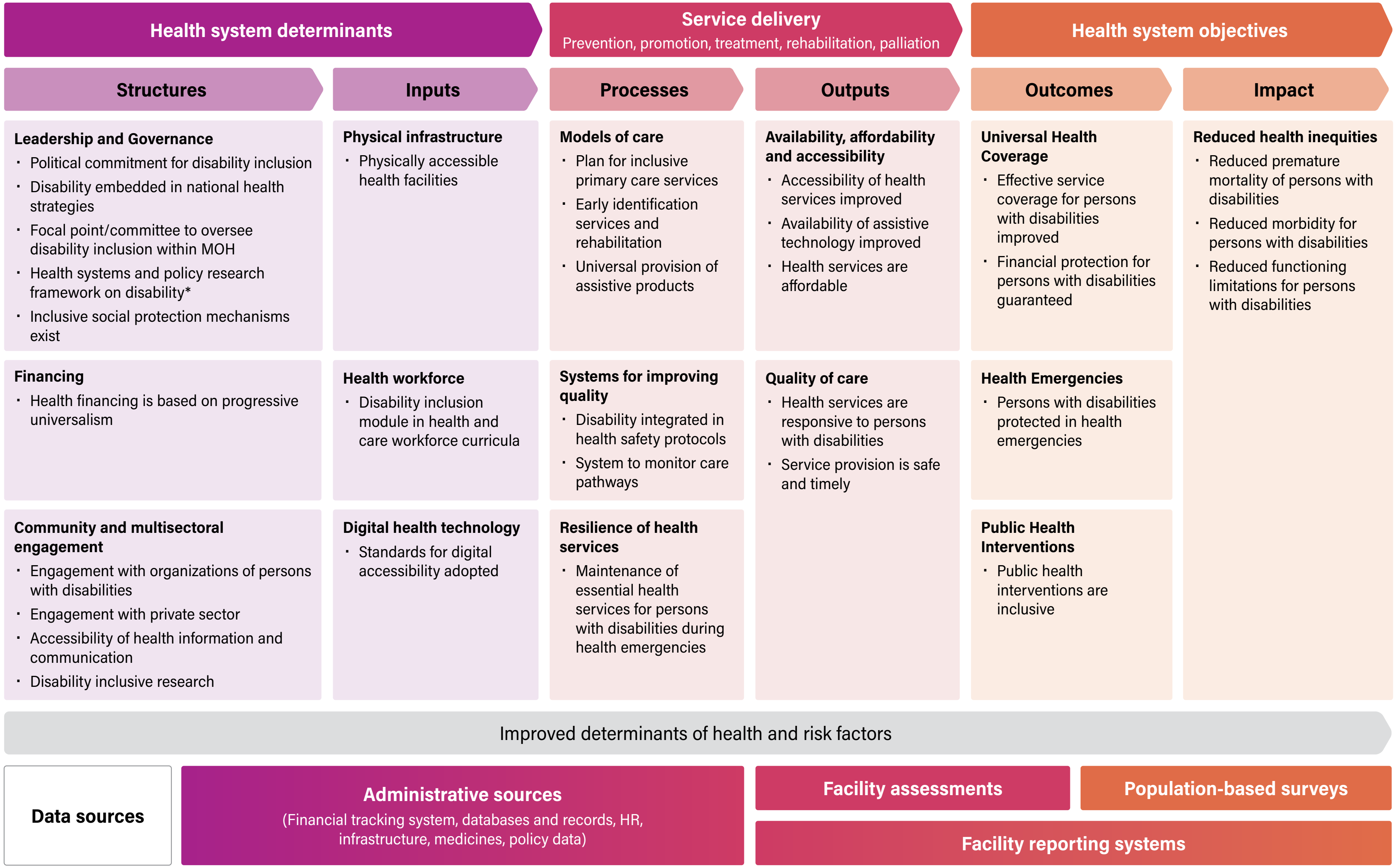
At the outcome and impact levels, both facility and population-based data are fundamental sources to capture information on health outcomes for persons with disabilities when disability status is identified. Annex 5 provides further information on the different population-based tools used to collect and disaggregate data on disability that are used mainly for outcome and impact indicators.

Table 5. Example indicators under the levels of outcomes and impact in the monitoring and evaluation framework

Entry points	Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Outcomes		
UHC	Effective service coverage for persons with disabilities improved	Is the average effective coverage of essential health services, as observed through tracer interventions or indices of health services, the same for persons with disabilities as those without?
	Financial protection for persons with disabilities guaranteed	Are persons with disabilities more likely to live in households who experience catastrophic health expenditure and/or impoverishing health spending compared to those without disabilities?
Health emergencies	Persons with disabilities protected in health emergencies	What is the percentage of persons with disabilities who receive emergency-related interventions compared to those without?
Public health interventions	Public health interventions are inclusive	Is the coverage of public health interventions such as WASH or vaccination the same for persons with disabilities and those without?
Impact		
Reduced health inequities	Reduced premature mortality of persons with disabilities	Is there a difference in the percentages of persons with disabilities and the general population who die prematurely because of avoidable causes?

Entry points	Example indicator	Questions that provide insight into the status of disability inclusion in country actions
	Reduced morbidity for persons with disabilities	Is there a difference in the percentages of persons with disabilities and the general population who develop health conditions due to avoidable causes, such as smoking, physical inactivity, alcohol consumption, etc.
	Reduced functioning limitations for persons with disabilities	Is there a difference in the functioning status of persons with disabilities and the general population due to avoidable causes, such as inaccessible environment?

Figure 7. Examples of disability inclusion indicators categorized according to health system determinants, service delivery and health system objectives



Health system determinants

Service delivery
Prevention, promotion, treatment, rehabilitation, palliation

Health system objectives

Structures

Leadership and Governance
- Political commitment for disability inclusion
- Disability embedded in national health strategies
- Focal point/committee to oversee disability inclusion within MOH
- Health systems and policy research framework on disability*
- Inclusive social protection mechanisms exist

Financing
- Health financing is based on progressive universalism

Community and multisectoral engagement
- Engagement with organizations of persons with disabilities
- Engagement with private sector
- Accessibility of health information and communication
- Disability inclusive research

Inputs

Physical infrastructure
- Physically accessible health facilities

Health workforce
- Disability inclusion module in health and care workforce curricula

Digital health technology
- Standards for digital accessibility adopted

Processes

Models of care
- Plan for inclusive primary care services
- Early identification services and rehabilitation
- Universal provision of assistive products

Systems for improving quality
- Disability integrated in health safety protocols
- System to monitor care pathways

Resilience of health services
- Maintenance of essential health services for persons with disabilities during health emergencies

Outputs

Availability, affordability and accessibility
- Accessibility of health services improved
- Availability of assistive technology improved
- Health services are affordable

Quality of care
- Health services are responsive to persons with disabilities
- Service provision is safe and timely

Outcomes

Universal Health Coverage
- Effective service coverage for persons with disabilities improved
- Financial protection for persons with disabilities guaranteed

Health Emergencies
- Persons with disabilities protected in health emergencies

Public Health Interventions
- Public health interventions are inclusive

Impact

Reduced health inequities
- Reduced premature mortality of persons with disabilities
- Reduced morbidity for persons with disabilities
- Reduced functioning limitations for persons with disabilities

Improved determinants of health and risk factors

Data sources

Administrative sources
(Financial tracking system, databases and records, HR, infrastructure, medicines, policy data)

Facility assessments

Population-based surveys

Facility reporting systems

* This indicator is presented in the next entry point on health policy and systems research

Case study

Strong monitoring and evaluation in a new disability inclusion plan in Fiji

Fiji has taken a significant step forward in disability inclusion by laying out a carefully developed plan: the National Disability Inclusive Rehabilitation and Health Action Plan 2022–2026. The Plan is grounded in human rights, focused on equity, and developed through multisectoral collaboration; it further sets out a path towards an inclusive, barrier-free and rights-based society for Fijians with disabilities.

The Plan has two components – disability and rehabilitation, which reflect the twin goals to ensure access to inclusive health services for all persons with disabilities, and to build rehabilitation and assistive product services for those in need, including strengthening the rehabilitation workforce. Each component has a separate coordinator to facilitate implementation, effective coordination and mobilizing of resources.

Monitoring, evaluation and learning have been recognized as essential elements to the success of the Plan. Effective and regular monitoring of clearly-defined, meaningful indicators will serve to ensure that progress is being made and to inform reviews and evaluation of the Plan.

For example, for the goal of improving inclusion and equity of access to health services, the indicators are setting a relevant budget and monitoring access at a certain review date for policies with disability inclusion. To monitor the strengthening of rehabilitation services, there will be assessments of role delineation and staffing levels, including a staff audit. Auditing existing services will help ascertain the number of wheelchairs and prosthetics fitted by a facility.

Development of the Plan, which began nine years ago, has involved several discussions with a wide range of stakeholders, from town councillors (to ensure accessibility at local levels) to organizations of persons with disabilities. These consultations have helped establish unmet needs and gaps in services. The Plan has concluded its internal final review and will be submitted to the Head of Ministry of Health for approval and endorsement shortly.

10 Health policy and systems research

What does it mean?

Health policy and systems research (HPSR):

- focuses primarily upon the organizations and policies of health, rather than clinical services or basic scientific research.
- explores a wide range of system-level questions – from financing to governance, through issues surrounding the implementation of services and delivery of care, to the roles and responsibilities of different stakeholders in the health sector.
- is crucial for decision-makers in the health sector to make informed decisions about which actions will contribute to the realization of UHC, and to the smooth coordination between sectors.
- is fundamental to help reduce global health inequities.

The importance of health policy and systems research on disability was emphasized through the World Health Assembly resolution WHA74.8: "Resolution on the highest attainable standard of health for persons with disabilities" where Member States requested WHO to "support the creation of a global research agenda that aligns with UHC, health emergencies and health and well-being, including health systems and policy research" *(134)*. This request underlines the timeliness and importance of bringing a systems perspective into research actions towards health equity for persons with disabilities.

Disability targeted actions to strengthen PHC and advance health equity for persons with disabilities

40. Develop a national health policy and systems research agenda on disability

Following the request of the World Health Assembly resolution WHA74.8, WHO will move forward with developing an HPSR agenda for health equity for persons with disabilities. The agenda will seek to produce evidence to determine how to organize society and health systems to ensure health equity for persons with disabilities. This report presents an optimal starting point for this. In this chapter, the proposed questions introduced in line with each of the indicators for monitoring and evaluation represent key questions to be addressed. Development of a national HPSR agenda should not be seen as an additional siloed action, but rather as an integrated strategy that builds on the information obtained through the health system indicators.

Case study

Moving the disability agenda forward through research in Australia

The Australian National Health and Medical Research Centre of Research Excellence in Disability and Health (credh.org.au) hosted by the University of Melbourne, has explored diverse research areas related to disability and health, particularly on the social and economic drivers of health inequalities. Research projects include the monitoring of inequities, policy analysis, health economics, disability services, COVID-19, violence and discrimination, and employment. Research themes may consider various related issues. For example, the theme of violence and discrimination among persons with disabilities was explored through various projects, such as:

- a report for the Royal Commission* into the nature and extent of violence, abuse, neglect and exploitation of persons with disability in Australia;
- a study to build the evidence base on violence against women with disability and what works to prevent it;
- a survey on community attitudes towards disability, with the Victoria state Government;
- a framework for young persons with disability who use violence at home to guide prevention and response.

The Royal Commission found that two in every three persons with disability have experienced at least one incident of violence since the age of 15 years (this excludes people in group care settings where the risk of violence is higher). The report also found rates of violence are higher among persons with psychosocial disabilities; and women with disability are twice as likely to report sexual violence during the past year than women without disability. The project, which included producing a disability and violence data compendium with over 25 unique datasets, was widely reported in the media.

*https://disability.royalcommission.gov.au/about-royal-commission

Example of how progress in health policy and systems research can be monitored

An example indicator to track progress in this strategic entry point is the integration of disability in health systems and policy research in countries.

Example indicator	Questions that provide insight into the status of disability inclusion in country actions
Health systems and policy research framework on disability	Are the results of policy and programme actions towards disability inclusion in the health sector (as the actions proposed in this chapter) investigated? Is there research capacity for health policy and systems research in disability inclusion?

Box 24

What would a disability-inclusive health sector mean for persons with disabilities*

What would a disability inclusive health sector mean for Alberto?

Alberto is an adolescent living in a high-income country, who was involved in a car crash; he subsequently acquired a disability due to a spinal cord injury and related impairment. He is a wheelchair user and resides in a small town with his mother, who is a support provider. Alberto is an active and vocal member of the community and a member of an organization representing persons with disabilities that meets regularly with decision-makers in the health sector to discuss improvements in the implementation of health services in the community. His primary health practitioner is close to his home in an accessible community centre. He also exercises regularly in the outdoor gym built in the community.

What actions led to this?

Inclusive governance and leadership:

The government, after an inclusive dialogue with civil society, integrated disability into the national health strategy and adopted a national policy for the accessible provision of essential health services such as rehabilitation, as part of their UHC package of care. The policy outlines several strategies to advance health equity for persons with disabilities. These include removing barriers to the physical access of health facilities and services; capacity-building for the health and care workforce on disability inclusion to address stigmatization; integrating disability inclusion in national finance arrangements to address the extra costs of disability, such as the provision of assistive products; enhancing community care to provide services close to people's homes; strengthening actions to support providers; and the provision of specialized disability services for those who need them. In addition, the Ministry of Health, in collaboration with the Ministry of Sports, worked together to make sure that existing playgrounds and outdoor gyms built in the community were accessible.

Community and multisectoral engagement:

The Ministry of Health established a mechanism of regular dialogue with organizations of persons with disabilities and other community stakeholders, as well as with the private sector, with the aim of improving the delivery of health services at the community level for persons with disabilities. This helped policy-makers better understand the grassroot challenges encountered by persons with disabilities.

Accessible physical infrastructure:

The accessibility of health facilities was one of the key changes prioritized in the national policy. A plan to construct new health-care centres, or to refurbish old facilities, following universal design for the next 10 years was mandated at national level. The government estimated that an additional 3% of the costs associated with construction or refurbishment of facilities would be sufficient to fulfil the basics of universal design.

Available medicines and health products, including assistive technology:

Due to good collaboration between the Ministry of Health and the private sector, the most essential assistive products, such as wheelchairs, are now made universal for those who need them. The Government has clear policies relating to the procurement of priority assistive products, with provision systems and trained personnel in place, with the aim of having sufficient and affordable access and ongoing support close to where people live.

What would a disability inclusive health sector mean for Amara?

Amara is a woman living in a middle-income country with her husband. Amara has an intellectual disability and works in a factory. She benefits from a social insurance scheme at her work which gives her the opportunity to receive free health services. Amara and her husband are planning to have children and so Amara receives family planning and has access to sexual and reproductive health services. In her communication with her doctor, Amara is always given health information materials in Easy-Read format. Initially, she received a short information manual on how to access her electronic medical record and how to hold a telehealth meeting with her doctor.

What actions led to this?

Inclusive financing:

Due to good coordination between the ministries of health, social affairs and finance, the Government invested in improving UHC for its population. This included not only expanding the packages of care, but also introducing strategies to reduce catastrophic health expenditure. Moving to health financing arrangements based on population needs, the health sector increased investments in the health system to make service delivery accessible.

Inclusive digital health technology:

The Government invested in increasing digital health literacy among people, especially the most marginalized groups who have been underusing services such as telehealth. In addition, a directive was adopted to provide essential health information materials in a format accessible to the needs of persons with disabilities.

Inclusive governance and leadership

The Government aligned their national laws and policy on disability with the CRPD, ensuring that the country adopted a human rights-based approach towards disability inclusion in the health sector. It promoted campaigns to address stigmatization and discrimination on the basis of disability, with a focus on raising community awareness and increasing knowledge. Furthermore, the health sector adopted policies to ensure that free and informed consent was promoted and protected across health facilities.

What would a disability inclusive health sector mean for Sayo?

Sayo is a woman in her sixties, living in a low-income country, who has had a psychosocial disability for the past 12 years. COVID-19 has made things more difficult for her, and she has struggled to deal with the pressure of the pandemic. Sayo now receives psychosocial support. She feels included in any decisions that are made, does not feel any threat of coercive treatment, and is provided comprehensive information about her condition and treatment options. Sayo also feels supported by her community which knows about her mental health condition. She no longer feels that her disability is "invisible" to others.

What actions led to this?

Inclusive governance and leadership:

As part of country efforts to strengthen the health system, the Government incorporated different disability considerations in the health emergency response before the COVID-19 pandemic hit. This included a well-prepared plan that aimed to ensure as few disruptions as possible of essential health services for persons with disabilities; a response that included the accessible provision of remote health services; equity in triage procedures and vaccination; special considerations for persons with disabilities in pandemic measures, such as physical distancing; and the provision of accessible health information.

Community and multisectoral engagement:

The Ministry of Health initiated a mental health campaign for awareness-raising, which focuses on community dialogues with the aim to raise awareness of disability, include discussions on hidden psychosocial disabilities, and address stigmatization towards persons with disabilities. Community champions have been cultivated and supported to increase knowledge and change attitudes among other members of the community.

Skilled workforce:

A mandatory training on disability inclusion was provided to health workers with a learning focus to target unconscious biases and correct false beliefs that may be negatively impacting care. The training also focused on the importance of recognizing and meeting the needs of persons with psychosocial disabilities.

Improved quality of health services:

As part of the efforts of the health sector to improve the quality of services for persons with disabilities, a routine feedback mechanism was established, which asks all health-care users to evaluate the quality of health services they receive at community level. The evaluation form measures quality in different components, such as responsiveness, timeliness, safety, or accessibility of care.

*Hypothetical examples

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4. Recommended principles for implementation

Chapter 3 of the report recommends 40 disability-targeted actions in 10 strategic areas of health system strengthening. As each country has a unique context, each will choose specific actions and areas on which to focus their efforts to achieve an optimal outcome for disability inclusion. To support the process of identifying the areas where actions are needed, and to implement those actions, WHO is developing a guide for action on disability inclusion in the health sector. The guide for action will:

1. facilitate leadership and planning processes for the inclusion of disability in the health sector;
2. provide practical guidance on how to implement the 40 actions on mainstreaming disability in the health sector as presented in Chapter 3; and
3. support the strengthening of accountability for disability inclusion in the health sector.

Regardless of the actions taken by countries, certain principles need to be applied (Figure 8). Chapter 4 presents the recommended principles for implementation to achieve health equity for persons with disability. These should be followed by all health sector partners irrespective of which of the specific actions outlined in Chapter 3 they are implementing.

Recommended Principle 1: Include health equity for persons with disabilities at the centre of any health sector action

This principle implies prioritizing first, in any health sector action, those most left behind, such as persons with disabilities. When planning health financing, for example, the rights and needs of the most disadvantaged groups of the population must be put first. Adopting a human rights-based approach to health is at the core of this principle and involves a change in the mindset of the health sector and the way it operates. The principle ensures that policies, programmes and their implementation are all guided by respect, protection and the fulfillment of human rights. In particular, a human rights-based approach to health provides strategies and solutions to address wider contributing factors to health inequities such as discriminatory practices, unjust power relations, or wider determinants of health.

To implement the recommended principles, strong commitment and targeted actions are required. While governments have the most significant role, other stakeholders play important roles as well. Key actions to be taken by stakeholders are set out in the points below.

Governments are encouraged to:

- make health equity for persons with disabilities a political priority in health by creating the necessary policies and legislation.
- enforce disability policies and legislations in a transparent and accountable manner.

Service providers and private sector are encouraged to:

- prioritize persons with disabilities in policies, strategic plans, investments and health sector actions.
- ensure accessibility in health services; and for public health interventions to reach people of all ages, including persons with disabilities, without discrimination.

Health researchers are encouraged to:

- always investigate the extent to which persons with disabilities and other populations in marginalized situations are reached by health services and public health interventions.
- ensure that remedial actions to address disadvantage, discrimination, or exclusion are included in publications and other research products.
- ensure inclusive and non-discriminatory health research that integrates universal design in all its phases and considers the priorities of persons with disabilities.

Persons with disabilities and their representative organizations are encouraged to:

- advocate for prioritization of disability inclusion in the health sector.
- request audits and raise awareness on discriminatory practices and contributing factors to health inequities within the health sector.

United Nations agencies and development organizations are encouraged to:

- prioritize persons with disabilities and other populations in marginalized situations in health sector investments, in the development and implementation of aid programmes, and in all health-related country activities.

- support countries in identifying and removing discriminatory practices in the health sector and advance health equity for persons with disabilities.

Recommended Principle 2: Ensure empowerment and meaningful participation of persons with disabilities and their representative organizations when implementing any health sector action

The principle of empowering and engaging persons with disabilities is rooted in the motto of the disability movement: "nothing about us without us". The principle involves enabling persons with disabilities and their representative organizations to participate in strategic decision-making, including involvement in the design, planning, development and delivery of health services and public health interventions, as well as in the planning and implementation of health emergency responses. Families and carers can be important allies and should be engaged meaningfully in enabling persons with disabilities to participate in all decisions concerning their lives.

Governments are encouraged to:

- establish a mechanism between the health sector and civil society to systematically consult with, and include, representative organizations of persons with disabilities to inform policy and programme development.
- ensure equal opportunities for persons with disabilities to be active members of the health and care workforce.

Service providers and private sector are encouraged to:

- design and implement health services in consultation with persons with disabilities and their representative organizations.
- create opportunities for persons with disabilities to participate as actively and as equally as others in service delivery.

Health researchers are encouraged to:

- involve persons with disabilities in the design, decision-making and implementation of research projects.
- create systems and processes that ensure the participation of persons with disabilities is as equal as others in the research workforce.

Persons with disabilities and their representative organizations are encouraged to:

- participate actively in health sector processes and decision-making.
- raise awareness and be involved in the training of health professionals on disability-inclusive practices.

United Nations agencies and development organizations are encouraged to:

- ensure the participation of persons with disabilities and their representative organization in all operational and programmatic work of the organizations.
- guarantee inclusive international cooperation and development.

Recommended Principle 3: Monitor and evaluate the extent to which health sector actions are leading to health equity for persons with disabilities

Whatever actions are taken to advance health equity for persons with disabilities, a well-planned monitoring and evaluation process is fundamental to track progress and adjust actions as the context evolves. This implies collecting information on different actions through specified "indicators" that measure the extent of progress towards the achievement of objectives. Monitoring and evaluation also allow for the entire health system to learn what works and what does not work, to inform constant improvement.

Governments are encouraged to:

- monitor the realization of the right to health for persons with disabilities.
- establish health policy and systems research informed by the monitoring indicators to advance health equity for persons with disabilities.

Service providers and private sector are encouraged to:

- monitor whether health service delivery advances health equity for persons with disabilities.
- contribute actively with data to gain a better understanding of the drivers of health inequities for persons with disabilities.

Health researchers are encouraged to:

- advocate for health research that is not discriminatory and that monitors the extent to which persons with disabilities and other populations in marginalized situations are reached.
- provide recommendations to governments on steps to address inequities and advance health equity for persons with disabilities.

Persons with disabilities and their representative organizations are encouraged to:

- collaborate and advise those involved in the monitoring and evaluation of services and processes in the health sector.
- collaborate with researchers to support health policy and systems research that can contribute to addressing inequities and advancing health equity for persons with disabilities.

United Nations agencies and development organizations are encouraged to:

- monitor whether persons with disabilities and other populations in marginalized situations are prioritized in health sector investments, in the development and implementation of aid programmes, and in all health-related country activities.
- support countries in the monitoring of inclusive practices.

Figure 8. Framework to advance health equity for persons with disabilities through PHC

Approach

40 targeted actions for disability inclusion across the 10 strategic entry points

Results

Integrated health services with an emphasis on primary care and essential public health functions

Empower people and communities

Multisectoral policy and action

Political commitment, leadership, and governance

1. Prioritize health equity for persons with disabilities.
2. Establish a human rights-based approach to health.
3. Assume a stewardship role for disability inclusion in the health sector.
4. Make international cooperation more effective by increasing funding to address health inequities for persons with disabilities.
5. Integrate disability inclusion in national health strategies, including preparedness and response plans for health emergencies.
6. Set actions that are specific to the health sector in national disability strategies or plans.
7. Establish a committee or a focal point in the Ministry of Health for disability inclusion.
8. Integrate disability inclusion in the accountability mechanisms of the health sector.
9. Create disability networks, partnerships and alliances.
10. Ensure the existing mechanisms for social protection support the diverse health needs of persons with disabilities

Health financing

11. Adopt progressive universalism as a core principle, and as a driver of health financing, putting persons with disabilities at the centre.
12. Consider health services for specific impairments and health conditions in packages of care for UHC.
13. Include into health-care budgets the costs of making facilities and services accessible

Engagement of stakeholders and private sector providers

14. Engage persons with disabilities and their representative organizations in health sector processes.
15. Include gender-sensitive actions that target persons with disabilities in the strategies to empower people in their communities.
16. Engage the providers of informal support for persons with disabilities.
17. Engage persons with disabilities in research and including them in the health research workforce.
18. Request that providers in the private sector support the delivery of disability-inclusive health services.

Models of care

19. Enable the provision of integrated people-centred care that is accessible and close to where people live.
20. Ensure universal access to assistive products
21. Invest more finances in support persons, interpreters, and assistants to meet the health needs of persons with disabilities.
22. Consider the full spectrum of health services along a continuum of care for persons with disabilities.
23. Strengthen models of care for children with disabilities.
24. Promote deinstitutionalization.

Health and care workforce

25. Develop competencies for disability inclusion in the education of all health and care workers.
26. Provide training in disability inclusion for all health service providers.
27. Ensure the availability of a skilled health and care workforce.
28. Include persons with disabilities in the health workforce.

29. Train all non-medical staff working in the health sector on issues relating to accessibility and respectful communication.
30. Guarantee free and informed consent for persons with disabilities.

Physical infrastructure

31. Incorporate a universal design-based approach to the development or refurbishment of health facilities and services.
32. Provide appropriate, reasonable accommodation for persons with disabilities.

Digital technologies for health

33. Adopt a systems-approach to the digital delivery of health services with health equity as a key principle.
34. Adopt international standards for accessibility of digital health technologies.

Quality of care

35. Integrate the specific needs and priorities of persons with disabilities into existing health safety protocols.
36. Ensure disability-inclusive feedback mechanisms for quality of health services
37. Consider the specific needs of persons with disabilities in systems to monitor care pathways

Monitoring and evaluation

38. Create a monitoring and evaluation plan for disability inclusion.
39. Integrate indicators for disability inclusion into the monitoring and evaluation frameworks of country health systems.

Health policy and systems research

40. Develop a national health policy and systems research agenda on disability.

Improved access, utilization and quality

Improved participation, literacy and care seeking

Improved determinants of health

Universal Health Coverage

Principles of implementation

Include health equity for persons with disabilities at the centre of any health sector action

Ensure empowerment and meaningful participation of persons with disabilities and their representative organizations

Monitor and evaluate the extent to which health sectors actions are leading to health equity for persons with disabilities

Annex 1. Methodology of scoping reviews of literature

Three scoping reviews were carried out to inform the evidence presented in Chapters 2 and 3 of the report. The methodological framework used for them is the one by Arksey & O'Malley[21] with five steps: i) identifying the research questions; ii) identifying relevant studies; iii) study selection; iv) charting the data; and v) collating, summarizing, and reporting the results. Additionally, WHO conducted the optional sixth step, "consultation" to identify literature from persons with disabilities, representatives of organizations for persons with disabilities, UN agencies, and academics. All reviews conformed to international reporting guidance for evidence synthesis as appropriate (PRISMA-ScR)[22].

Scoping review on access to health services for persons with disabilities

The scoping review aimed to address two research questions (RQ): RQ1: What are the barriers in accessing health-care services experienced by persons with disabilities; and RQ2: Which interventions have been implemented in health services to address health equity for persons with disabilities?

Searches were conducted using two databases: MEDLINE (Ovid) and Web of Science. The search strategy was framed around the combination of three main concepts: i) accessibility; ii) persons with disabilities; and iii) health-care services. The list of key words for each concept was developed using MeSH (Medical Subject Headings; National Library of Medicine) and informed by other reviews on similar topics. Boolean, truncation, proximity operators were used to construct and combine searches, and adjustments were implemented as required to account for the specific functionalities of each database. Both databases were searched on 13 October 2021, for entries from 1 January 2011 to 12 October 2021. The applied search strategy for PubMed can be found in Box A1.1.

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[21] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Social Res Methodol. 2005;8:19-32.

[22] https://prisma-statement.org/Extensions/ScopingReviews

Box A1.1

Search strategy for scoping review on access to health services for persons with disabilities

1 exp Health Services Accessibility

2 exp Healthcare Disparities/

3 (Health Services Accessibility or Healthcare Disparities or Access or Barrier* or Challenge* or Equal* or Equit* or Exclusi* or Imped* or Inaccess* or Inclusi* or Inequal* or Inequit* or Inhibit* or Unequit* or Uptak* or Utilis* or Utiliz* or Obstacle*).ti,ab*

4 exp Disabled Persons/

5 Intellectual Disability/

6 Developmental Disabilities/

7 Amputees/

8 Disabled Children/

9 Persons with Mental Disabilities/

10 Mentally Ill Persons/

11 Persons With Hearing Impairments/

12 Visually Impaired Persons/

13 Learning Disabilities/

14 Hearing Loss/

15 Deafness/

16 Blindness/

17 (Disabled Persons or Intellectual Disability or Developmental Disabilities or Amputees or Disabled Children or Persons with Mental Disabilities or Mentally Ill Persons or Persons with Hearing Impairments or Visually Impaired Persons or Learning Disabilities or Hearing Loss or Deafness or Blindness).ti,ab.

18 ((Acoustic or Cognitive or Communication or Developmental* or Ear* or Eye* or Hearing or Intellectual* or Invisible or Language or Learning or Mental* or Mental Health or Mobil* or Motor or Neurodevelopmental* or Neuro-developmental or Neurological* or Physical* or Psychiatric or Psychological* or Psychosocial* or Sensory or Speech or Vision or Visual*) adj1 (Deficienc* or Delay* or Difficult* or Disabilit* or Disabled or Handicap* or Ill* or Impair* or Loss or Retard*)).ti,ab.*

19 ((Adolescent or Adult* or Child* or Men or People or Person* or Teen* or Women) adj3 (Disabilit* or Disabled or Handicap* or Impair* or Deaf or Blind)).ti,ab.*

20 Health Services for Persons with Disabilities/

21 Health Services/

22 Primary Health Care/

23 Community Health Services/

24 Reproductive Health Services/

25 Family Planning Services/

26 Maternal Health Services/

27 Child Health Services/

28 Adolescent Health Services/

29 Mental Health Services/

30 Psychiatric Rehabilitation/

31 Rehabilitation/

32 Occupational Health Services/

33 Speech Therapy/

34 Language Therapy/

35 Cancer Care Facilities/

36 Cardiac Rehabilitation/

37 Neurological Rehabilitation/

38 Stroke Rehabilitation/

39 ((Community or Primary or General or Sexual or Reproductive or (Sexual and reproductive) or SRH or Contracept or Antenatal or Prenatal or Postnatal or Maternity or Family planning or Gynaecolo* or Gynecolo* or Obstetric or Pregnancy or Midwifery or Maternal or New-born or Infant* or Bab* or Child* or Adolescent or Paediatric or Paediatric or Women or Mother* or Family or Mental or Psychiatric or Psychiatry or Psychological or Psychopathology or Psychotherapy or Rehabilitation or Physiotherapy or Physical Therapy or Occupational Therapy or Speech Therapy or Language Therapy or Noncommunicable Disease* or Non Communicable Disease* or Non-Communicable Disease* or Diabetes or Cancer or Oncolog* or Chemotherapy or Radiotherapy or Cardiac or Cardiovascular or Cardiolog* or Neurological or Stroke* or Respiratory) adj1 (Health service* or Health care or Healthcare or Care or Care service* or Service*)).ti,ab.*

40 1 or 2 or 3

41 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19

42 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39

43 40 and 41 and 42

44 limit 43 to yr="2011 -Current"

For identifying grey literature, the following steps were followed:

- The creation of an online survey which was circulated to academic and civil society advisory groups with request for grey literature sources.
- A review of reference lists of recommended grey literature sources and those found in the publication database.
- A search of websites of key organizations of persons with disabilities.
- Searches using a web search engine for relevant civil society websites and reports/policy documents.

The criteria for inclusion were set to represent a range of perspectives over a 10-year period. Various publication types were included (peer-reviewed journal articles; qualitative, quantitative, and mixed-method studies; systematic reviews; and reports produced by organizations and governments) to capture the voices of different stakeholders and identify key themes and trends in the field. Publications from 2011 to current date were included, with the threshold of 2011 being chosen specifically due to the publication of the *World Report on Disability*, which reported on the literature published before 2011. Publications were eligible if they documented the perceived or measured barriers of access to health services and interventions that target health inequities for persons with disabilities in health-care service delivery.

The search yielded a total of 11 858 results; 9440 results remained after deduplication. Following the title and abstract screening, the reviewers identified 736 and 754 publications eligible for full-text review, respectively addressing RQ1 (barriers) and RQ2 (interventions).

Scoping review on disability inclusion in health emergencies

This scoping review aims to address three research questions: RQ1: How do health emergencies affect person with disabilities, what are the barriers that they face in different types and phases of health emergencies, and what are the outcomes of these barriers at personal, household and community levels? RQ2: How do health emergencies consider disability and include persons with disabilities, and what are the most common strategies or approaches to disability inclusion in different types and phases of health emergencies; and RQ3: What are the gaps and opportunities to strengthen disability inclusion in health emergencies?

Two databases were searched: MEDLINE (Ovid), and Web of Science, for articles published during the past 10 years. Search terms included "disability", “access”, “inclusion”, “health emergency”, “pandemic or epidemic”, “outbreak”, “COVID-19” or “coronavirus”, “Zika” and “Ebola”, with appropriate Boolean operators and truncation to construct and combine searches for these terms (see Box A1.2). Articles were included if they discussed the key concepts relating to the impact of health emergencies on persons with disabilities, barriers to access, and inclusion in emergency responses, as well as strategies to promote disability inclusion in these responses. Articles, conference abstracts and editorials which did not present substantial evidence relating to the experiences of persons with disabilities were excluded, as well as those focused on specific clinical interventions for persons with disabilities. The academic literature search was supplemented with a search of grey literature, including COVID-19 and other health emergency response plans, organizational research reports, and recommendations from organizations of persons with disabilities. A small number of articles were also located through review of reference lists of key academic papers.

Box A1.2

Search strategy for scoping review on disability inclusion in health emergencies

1 (disab and "health emergenc*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]*

2 (disab and health and emergenc*).m_titl.*

3 (disab and (pandemic* or epidemic*)).m_titl.*

4 (disab and (zika or ebola)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]*

5 (disab and outbreak*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]*

*6 *Disabled Persons/*

7 (access or inclusion).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]*

8 "health emergencies".mp.

9 6 and 7 and 8

10 (COVID or coronavirus).m_titl.*

11 disab.m_titl.*

12 10 and 11

13 1 or 2 or 3 or 4 or 5 or 9 or 12

14 limit 13 to (yr="2011-current")

A total of 569 papers were identified through academic searches, of which 242 were included in the scoping review. Of these 242 papers, the vast majority – 86% – focused on the COVID-19 pandemic, followed by the Zika outbreak (9%), and then a range of health emergencies relating to other infectious disease outbreaks or disasters (4%). Most of the COVID-19 papers included (92 out of 209) focused on how the pandemic has affected the health of persons with disabilities and/or how persons with disabilities were more broadly affected by the crisis (82 out of 209). A smaller number of papers focused on education, employment and social protection, and support in the context of COVID-19. It is important to note that most of the empirical evidence presented in these papers is from high-income countries. Only 17 papers had a specific focus on low- to middle income countries.

From the grey literature search, a total of 130 publications were identified through searches of organizational websites and databases, specifically: International Disability Alliance; AskSource; Disability Inclusion Helpdesk; Disability Inclusive Development Resources; International Centre for Evidence in Disability; Health Cluster; Institute of Development Studies, and WHO's Health Emergency website. Of these 130 publications, most were focused on health emergencies caused by the COVID-19 pandemic (65%), followed by humanitarian and conflict crises (28%), disasters (5%), and lastly the Zika outbreak (2%). These publications included research reports (50 publications), operational guidance (44 publications), health emergency response plans or reports (8 publications) and a small number of commentaries/ expert meeting reports (5 publications). Statements from a diversity of civil society organizations, particularly relating to disability inclusion in the COVID-19 response (20 publications) were also purposively sampled. Three additional statements were included from UN agencies, treaty bodies and donor governments.

Scoping review on access to public health interventions for persons with disabilities

This scoping review aims to address two research questions: RQ1: to identify the barriers experienced by persons with disabilities when accessing public health initiatives; and RQ2: to identify interventions for disability inclusion in public health interventions.

A systematic search was conducted on the following two databases: MEDLINE (Ovid) and Web of Science. In addition, a process to explore grey literature was established and included the following steps:

- The creation of an online survey circulated to academic and civil society advisory groups with the request for grey literature sources.
- A review of reference lists of recommended grey literature sources and sources found in the publication database.
- A search of websites of key organizations of persons with disabilities.
- Searches using a web search engine for relevant civil society websites and reports/policy documents.

The search strategy was framed around the following three main concepts: i) barriers and interventions for accessibility; ii) persons with disabilities; and iii) public health initiatives. The key words used in the searches were developed using MeSH (Medical Subject Headings used by the National Library of Medicine to index articles) or equivalent headings, as well as from other reviews on similar topics. Boolean, truncation, proximity operators were used to construct and combine searches for the main concepts, and adjustments were implemented as required for individual databases. The search strategy applied in Web of Science can be found in Box A1.3.

Literature published since 2011 was included. Studies or documents that include the perspectives of persons with disabilities and other stakeholders (e.g. caregivers, service-providers, policy-makers) were used, and all methodologies (qualitative and quantitative outcomes) were considered. Studies that do not evaluate a defined public health intervention or the impact of public health interventions on persons with disabilities were excluded.

A total of 4584 articles without duplicates were identified and screened, and 53 references were included and referenced in the report. Most of these articles were conducted in high-income countries, primarily in Australia, the United Kingdom of Great Britain and Northern Ireland and the United States of America. In addition, 12 sources were identified via a grey literature search.

Box A1.3

Search strategy for scoping review on access to public health interventions for persons with disabilities

1 Blindness or Deafness (Topic)

2 “people with disabilit*” or “disabled people” (Topic)

3 (TS=(“person* with disabilit*” or “disabled person*”)) OR TS=(“physical impairment*” or “psychosocial disabilit*” or “physical disabilit*” or “mental disabilit*” or “sensory disabilit*”)

4 TS=(“disabled person*”)

5 TS=(“Intellectual Disabilit*”)

6 TS=(“developmental disabilit*”)

7 TS=(Amputee*)

8 TS=(“Disabled Child*”)

9 TS=(“Person* with Mental Disabilit*”)

10 TS=(“Mentally Ill Person*”)

11 ((((TS=(“Person* With Hearing Impairment*”)) OR TS=(“Visually Impaired Person*”)) OR TS=(“Learning Disabilit*”)) OR TS=(“Hearing Loss”)) OR TS=(Deafness)

12 TS=(Dementia or “Intellectual Disabilit*” or “Hearing Loss” or schizophreni*)

13 TS=((Adolescent* or adult* or child* or men or people or person* or teen* or women) near/3 (disabilit* or disabled or handicap* or impair* or deaf or blind))

_14 ((((((((((((#1) OR #2) OR #3) OR #4) OR #5) OR #6) OR #7) OR #8) OR #9) OR #10) OR #11) OR #12) OR #13_

15 (TS=(“public health” near/3 intervention*)) OR TS=(“public health intervention*”)

16 TS=((obesity or obese) near/3 (intervention* or program* or strateg* or policy or policies or campaign*))

17 (TS=(“Health promotion”)) OR TS=(Health behavio?r)

18 TS=((“accident* prevent*” or “road safety”) near/3 (intervention* or program* or strateg* or policy or policies or campaign*))

19 TS=((“traffic accident” or drown* or injur*) NEAR/3 (intervention* or program* or strateg* or policy or policies or campaign*))*

20 (TS=(“public health” near/3 strateg)) OR TS=(“public health” near/3 campaign*)*

21 TS=((alcohol or smoking or tobacco or cessation or substance or drug or self-examination or “breast examination” or screening) NEAR/3 (intervention or program* or strateg* or policy or policies or campaign*))*

22 TS=((fluoride or oral or dental) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

23 TS=((vaccine? or immuni?ation) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

24 TS=((violence or “domestic violence”) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

25 TS=(hypertension near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

26 TS=((diet or nutrition or exercise or “physical activity” or sedentary or fitness) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

27 TS=((“air pollution”) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

28 TS=((“drinking water” or sanitation or WaSH or “water insecurity” or “water, sanitation and hygiene”) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

29 TS=((housing or “sustainable housing”) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

30 TS=((“food supply” or “food security”) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

31 TS=((life-style) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

32 TS=((“health literacy” or “health communication”) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

33 TS=((sugar) near/3 (intervention or program* or strateg* or policy or policies or campaign*))*

34 TS=(“behavio?r modification” or “community mobilization” or “determinant of health” or” health determinant*”)*

35 TS=(“population health management”)

36 TS=(((“environment change” or “healthy environment*”) near/3 (intervention* or program* or strateg* or policy or policies or campaign*)))*

37 TS=(((“Health program” or “Health education” or “Health communication” or “Health advocacy” or “health intervention” or “social intervention” or “Social campaign*”) near/3 (intervention* or program* or strateg* or policy or policies or campaign*)))*

38 TS=((gender or ethnic or race or poverty) near/3 (intervention* or program* or strateg* or policy or policies or campaign*))*

39 (((((((((((((((((((((((#15) OR #16) OR #17) OR #18) OR #19) OR #20) OR #21) OR #22) OR #23) OR #24) OR #25) OR #26) OR #27) OR #28) OR #29) OR #30) OR #31) OR #32) OR #33) OR #34) OR #35) OR #36) OR #37) OR #38

40 TS=(Inequalit or “health for all” or “health-related exclusion*” or exclusi* or inclus* or “health disparit*” or “healthcare disparit*” or “health equit*” or equit* or inequit* or vulnerable or disparit* or gap* or access or barrier or challenge* or equal* or obstacle* or imped* or inaccess* or inhibit*)*

41 ((#14) AND #39) AND #40

Annex 2. Consultation process

The WHO Global Report on Health Equity for Persons with Disabilities was developed in close consultation with Member States; civil society, including persons with disabilities and their representative organizations; UN entities and all WHO regional offices; and a range of health sector stakeholders, including academia, health practitioners and development specialists. A total of 24 consultation activities were conducted engaging over 1,250 stakeholders.

This section provides a detailed description of the consultation activities undertaken while developing the report. Table A2.1 provides a summary of the stakeholder groups targeted with different consultation activities. More information in the methodologies adopted for prevalence studies, economic analysis, and scoping reviews can be found in annexes 1, 3 and 4.

Table A2.1: Summary of consultation activities

Consultation Activity	Meetings / Timeline
Forum on Disability Inclusion in the Health Sector	Four webinars from September – December 2021.
Technical group	Three meetings from October 2021 – September 2022.
Civil society group	Three meetings from October 2021 – September 2022.
Regional consultations	Six consultations from March – June 2022.
Global consultations	Three dialogues in June 2022.
WHO internal consultations	Two meetings from May – September 2022.
UN focal point consultation	One meeting in July 2022.
Member States Information Session	Two meetings – one in October 2021 and one in September 2022.
Total	**24 meetings conducted**

Consultation methods

WHO consulted with stakeholders at global, regional, and country levels through both online and in-person meetings and by sharing drafts for review and feedback. Accessibility features provided included sign language interpretation, captioning, and producing documents in UN languages and easy-read formats.

Consultation activities

Consultation activities spanned the entire development process of the report, informing early conceptual frameworks, through to validation of research findings, and then detailed draft review and feedback.

Global forum on disability inclusion in the health sector

Following the World Health Assembly Resolution (WHA 74.8) call for a global report and collaboration between relevant stakeholders, WHO and disability partners hosted a series of fora to establish a common narrative among disability actors on disability inclusion in the health sector. Four fora were conducted in the series focusing on universal health coverage, health system strengthening, public health interventions and health emergencies. In total, 597 participants located in 68 countries joined these. Included were presentations from international experts, facilitated discussions for participants to share lessons learned and experiences from their countries, and working groups to develop advocacy messages for the health sector. This series of fora facilitated critical networking with the wider disability community and among health sector partners, mobilizing their support to engage in later phases of the report development.

Technical and civil society groups

WHO established two expert groups that were consulted at different stages of report development, including in the design of the conceptual framework and structure, validating scoping review methodology and findings, and later feedback on content and key messages. The technical group (17 participants) included prominent academics and policy experts working in the field of health and disability and having a track record of their work, e.g., through publications. The civil society group (12 participants) represented key international civil society organizations working in the field, including those representing persons with disabilities. For both groups, members were selected based on their expertise, geography (e.g., representation from all WHO regions), gender and age. Three meetings were conducted with the technical group and three meetings with the civil society group. Some meetings were repeated twice to facilitate participation from those members in a range of time zones. Report drafts were also shared with these groups for their contributions and feedback.

Member States information session

Member States, through the UN missions in Geneva, were invited to two information sessions where the structure, and later the key findings and recommendations from the report were shared for their feedback. At least 26 Member States attended these information sessions, with many providing added written feedback on review of the full draft.

Regional consultations

Another critical step in the consultation process was to engage Member States and development partners from the regions, giving voice to the range of countries and contexts where persons with disabilities live and receive health services. A series of regional consultations were conducted, led by the WHO regional offices, to seek feedback on the analyses and recommendations of the report; build momentum for implementation of the report recommendations; and promote disability inclusion in the health sector as a priority for Member States and development partners. Six consultations were conducted – one in each WHO region (African Region; Region of the Americas; South-East Asia Region; European Region; Eastern Mediterranean Region; and Western Pacific Region) – engaging at least 283 stakeholders. These consultations also served as an entry point to identify examples and case studies to include in the report.

WHO internal consultations

WHO colleagues at all three levels of the organization were engaged at different points in the consultation process. Two internal meetings were conducted to share the overall structure of the report, the evolving findings from scoping, and the detailed content, key messages, and recommendations. WHO colleagues played an important role in positioning disability inclusion in wider health equity and the frameworks and initiatives for health systems strengthening.

UN focal point consultation meeting

A consultation meeting was also conducted with disability and health focal points in other UN agencies. A total of 13 UN entities participated in the meeting which provided an overview of the report and evolving findings for their feedback and future collaboration. This meeting provided appropriate briefings and answered questions to support the review and submission of written feedback from UN partners on the draft report.

Global civil society dialogues

In addition to regional consultations, a series of civil society dialogues gave voice and strengthened the relevance of the report to a wider range of stakeholders. With the support of Sightsavers, a total of three civil society dialogues were conducted to cover as many time zones as possible, ultimately engaging over 280 people. These open forums drew participants from all regions, including policy or programme representatives from civil society organizations, across health and disability; persons with disabilities and representatives from organizations of persons with disabilities; academics; regional networks and coalitions; and private sector associations and foundations.

Written feedback

In addition to the consultation processes described above, WHO also made drafts of the report available for review and feedback from all the groups consulted. A draft was also made available to the public through the WHO website, so that interested stakeholders could easily review and provide comments and suggestions. The summaries of the report and feedback survey were available in English, French, Spanish, Arabic, Russian and Chinese, and Easy Read format. A total of 150 submissions were received through the online call and feedback survey, providing a range of diverse perspectives to be considered in the final draft.

Sightsavers, an organization in official relationship with WHO, also coordinated the collection of feedback from country level stakeholders, using the draft report shared online. This was done through a series of consultations, many of which were conducted in-person providing opportunity for those with less digital access to engage with and contribute to the process. These consultations targeted a range of civil society stakeholders, including NGOs, persons with disabilities and their representative organizations, in Bangladesh, Ghana, Guinea, India, Kenya, Malawi, Mali, Nigeria, Pakistan, Senegal, Tanzania, and Uganda.

WHO also shared and encouraged the dissemination of the draft report through partners and networks including the International Disability Alliance, the International Disability and Development Consortium and the CBR Global Network, as well as WHO Collaborating Centres and various professional associations and health sector networks.

Annex 3. Prevalence of disability – Methodology

Overview of the approach

To estimate the current prevalence of disability, WHO used the estimates generated through the Global Burden of Disease (GBD) study.

The GBD has been the source of the most comprehensive global, regional and national epidemiological evidence for all health conditions and injuries in the past two decades. For the 2021 round of data used in this report, it collects and analyses data through a consortium of more than 8,500 researchers in more than 156 countries and territories, capturing data on more than 350 health conditions and injuries in 204 countries and territories, by age and sex. The design of the GBD allows for regular updates as new data and epidemiological studies are made available.

The foundational principles of the analyses presented in this report are identical to the 2011 World report on disability. Age and sex-specific prevalence estimates of health conditions and impairments that typically last longer than 6 months and are associated with moderate or severe levels of disability were selected. To include only those conditions associated with moderate or severe levels of disability, a cut-off in the severity weights of health conditions was set. Severity weights range between 0 and 1 and represent the severity level of each disease and injury. To avoid double counting of people who have more than one underlying health condition or impairment, an adjustment for comorbidity is made that considers the probability of having multiple conditions.

Why can the 2011 World report on disability and the current report estimates not be compared?

Despite the identical approach used in both reports, the estimates of the 2011 World report on disability and the current report cannot be compared because first, the evidence included in the GBD study has increased over the years and secondly, the methodology in relation to the disability weights assigned to each health condition and sequelae[23] has been refined and the approach to take into consideration comorbidities has advanced. All those changes have led to more accurate estimates.

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[23] Sequela refers to the consequences of diseases and injuries. For example, blindness due to diabetes mellitus type 2 retinopathy is a sequela of diabetes mellitus type 2.

Regarding the increase in evidence, the 2021 cycle of GBD study used for this report includes health conditions and sequelae for which data were not available in 2004. New and comprehensive prevalence estimates were made available in the last 15 years from health surveys, administrative data or insurance data from a number of countries.

Regarding the methodological refinements, the most substantial is the one on disability weights. The 2004 weights were derived from an expert consensus whereas for the 2021 estimates, a much more robust methodology was used. Weights are now derived from population surveys using general public rating of lay descriptions of functioning of an individual with a particular health condition. This means that the general public rates the severity levels of each health condition. Such surveys have been conducted with over 60,000 people in nine countries and an open-access internet survey. The update in the severity weights has led to changes in severity level, meaning that one condition associated with severe disability in the past may now be moderate or vice versa.

The change in the severity weights also led to a decision for the current report to adjust the cut-offs for moderate and severe disability. In the GBD data used for the 2011 World report on disability, all health conditions and sequelae were grouped into seven classes per consensus, where classes I and II represented health conditions associated with mild disability with weights below 0.12, classes III, IV and V, moderate disability with weights between 0.12 and 0.5, and classes VI and VII, severe disability with weights above 0.5. Those above the cut-off of 0.12 were included to calculate the overall prevalence of disability, and those above the cut-off of 0.5 used to calculate the prevalence of severe disability. Since there are no classes any more in the GBD study to select cut-off for the current report, the highest weight of the health conditions from classes I and II used in the 2011 report but using their 2021 weights was applied as threshold, i.e., 0.149. All health conditions above this threshold are considered for the prevalence estimates of disability in the current report. Similarly, to determine the cut-off for severe disability, the lowest weight of the health conditions from classes VI and VII was used as threshold, i.e., 0.54; all health conditions above this value were included.

A substantial advantage of the new 2021 GBD data is that now each severity level of a health condition has an associated severity weight. For example, mild, moderate and severe depression have severity weights, which allows us to count only those persons with depression that have moderate or severe levels of disability. This differs from the 2011 report where severity weights existed primarily for the health condition as a whole, meaning that all persons with depression including those with mild levels, for example, would be counted, if the severity weight for the condition was above the selected cut-off for moderate and severe disability.

Regarding the methodology used to avoid double counting of those people who have more than one health condition, a comorbidity simulation to quantify the number of people with multiple conditions based on independent probabilities is now used in the GBD study. Full details on the methodology to estimate comorbidities can be found elsewhere (1, 2).

As mentioned in the report, to explore time trends in estimates, we did not compare the estimates presented in the 2011 WHO and World Bank World report on disability, but the estimates of the GBD study produced by IHME in 2021 for the years 2010 and 2021. This comparison reveals a significant increase in the number of people with musculoskeletal, mental health and neurological conditions, as well as sense organ conditions such as hearing and vision loss (Table A3.1). A 4-fold increase in respiratory infections associated with moderate or severe levels of disability is also observed. Age distribution reveals that more people live and age with chronic health conditions with the number of people aged >60 years with noncommunicable disease being significantly higher compared to 2010.

Table A3.1. Change in prevalence of health conditions associated with moderate and severe levels of disability, globally, 2010 and 2021

Health condition	2010* (In millions)	2021 (In millions)
Musculoskeletal conditions	298.5	370
Mental health conditions	180	252
Neurological conditions	159.7	191.4
Sense organ conditions	81.2	100
Cardiovascular diseases	62.5	84.3
Respiratory infections and tuberculosis	14	60
Injuries	47.9	56
Other non-communicable diseases	46.5	52
Chronic respiratory diseases	41	51
Maternal and neonatal conditions	38.2	44
Skin and subcutaneous diseases	38	43
Substance use disorders	27	31.5
Diabetes and kidney diseases	14.6	20.5
Neglected tropical diseases and malaria	14	16.5
Neoplasms	9	11.5
Digestive diseases	9	10.2
HIV/AIDS and sexually transmitted infections	9.7	5.5
Nutritional deficiencies	2.8	2.4
Other infectious diseases	0.3	2.3
Enteric infections	0.01	0.02

**Estimates are based on the 2021 Global burden of disease data*

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Annex 4. Methodology of economic analyses

The economic analyses presented in Chapter 1 followed a stepwise methodology.

Step 1. Identify published WHO economic analyses that estimate return on investment for population-wide interventions.

The scarcity of data on costs and coverage of interventions to advance disability inclusion in the health sector (e.g., making health facilities physically accessible, or providing health information in an accessible format), limited the possibility to develop a detailed investment case analysis. Therefore, a decision was made to review and adjust existing WHO-led studies on population-wide interventions. We only considered studies that use standardized WHO methods, which had been peer reviewed and where we could access data and models used.

A list of published studies on population interventions using WHO standard economic evaluation methods was identified through a search in the WHO IRIS publications database supplemented by the writing team's knowledge of WHO-led studies published in academic journals. The list included interventions such as malaria control interventions; interventions to address NCD risk factors; cervical and breast cancer screening, and cancer treatment; interventions for the health of women and children, including maternal and newborn health; immunization; family planning; and HIV/AIDS, among others *(1-6).*

Step 2. Rapid scoping review to identify gaps in coverage for the selected interventions between persons with disabilities and the general population

A second step involved analysing existing evidence on the lower levels of access of interventions identified in Step 1 for persons with disabilities compared to persons without disabilities. A rapid scoping review was carried out in PubMed and in grey literature to identify studies that report quantitative data. Articles were limited to studies that: (a) were published between 2011 to 2022 in English language (b) published as a peer reviewed and scholarly manuscript or report, and (c) quantitatively compared differential coverage of population-wide interventions for persons with and without disabilities. Additional manual search of the reference lists of identified articles assisted in identifying other primary sources of data. Table A4.1 below shows an example of a search strategy applied for the evidence gathering of one intervention of interest.

Table A4.1. Search strategy applied in PubMed for HIV prevention and treatment

Topic	Search Term
HIV/AIDS	disability[Title] OR disabled[Title] OR disabilities[Title] AND (HIV[Title/Abstract] OR AIDS[Title/Abstract] OR HIV PREVENTION[Title/Abstract] OR HIV TESTING[Title/Abstract] OR HIV TREATMENT[Title/Abstract])

The analysis identified data for the following interventions: vaccination, family planning, cancer screening and treatment, and prevention of NCDs. The studies revealed substantial gaps for certain interventions. For example, data showed that women with disabilities have 0.63 lower odds to receive or undergo cervical cancer screening compared to women without disabilities; the odds are even lower (0.77) for breast cancer screening *(7).* A similar situation can be seen in cancer treatment *(8,9).* There is a 14% gap in basic immunization for children aged 24 to 35 months between those with and without disabilities *(10).* Interventions for preventing NCDs such as supplement and nutrition programmes reach 20% less young adults with disabilities compared to the general population *(11),* and in some countries the gap in surgical interventions for cardiovascular disease can reach 45% *(12).* Gaps in family planning also exist as well *(13-15).* Based on the available data showing lower levels of access to interventions between persons with and without disabilities, three of the already identified WHO-led studies in Step 1 were selected:

- Stenberg et al. (2021) which reports cost-effectiveness estimates for vaccination ((DPT, H. influenzae b, Pneumococcal, Rotavirus, Pentavalent DPT + Hep B + Hib, and Measles) and family planning *(2)*
- WHO (2020) which reports estimated return on investment on cancer prevention and care *(3)*
- Bertram et al. (2018) which reports estimated return on investment on NCD prevention with a focus on prevention and care of cardiovascular diseases *(4)*

Step 3. Adjust the previous economic analyses by incorporating disability considerations

The last step of the process is the adjustments of the 3 original studies. For the analysis, we used a simple approach of increasing the average costs of the interventions studied by 10% to account for any additional costs associated with making services accessible.

The 10% increase in costs is to ensure interventions are accessible for persons with disabilities, addressing the existing barriers experienced by persons with disabilities. While the range of barriers to be addressed is very wide as presented in Chapter 2 of the report, for the current analyses we considered conservatively only 4 groups of barriers that are very common among persons with disabilities – physical, informational, attitudinal, and those related to reasonable adjustments in the actual delivery of the intervention. Addressing each of these barriers implies additional costs. For example, health centers or vaccination centers need to be physically accessible for persons with disabilities, e.g. having ramps, accessible toilets, or equipment. Universal design should ideally be applied from the outset, and some studies show an increase of as little as 0.5–1% of the total building costs that could be expected *(16,17)*, however, the costs may be higher when retrofitting facilities. Additional costs are also needed to provide all health information materials or appointment letters related to the interventions in accessible format, e.g. Easy Read versions for persons with intellectual disabilities. Training of health and care professionals on disability inclusion can facilitate reducing negative attitudes towards persons with disabilities. Finally, some persons with disabilities may require reasonable adjustments to receive an intervention. For example, this can mean giving a person with a psychosocial disability a priority appointment if they find it difficult waiting in the hospital, or longer appointments if someone with an intellectual disability needs more time with a doctor to make sure they understand the information they are given *(18)*.

As information is limited on the costs associated with removing these barriers for persons with disabilities, a conservative assumption was made to add a 10% increase in the average cost of service provision for interventions, to make them disability inclusive. The 10% increase in average costs was applied to both cost-effectiveness analysis and return on investment analyses. This decision has its limitations. Firstly, the 10% increase in costs is arbitrary given the absence of comparable data. The additional costs in some settings may be higher than 10%. Secondly, addressing other barriers like inaccessible transportation, which are not considered in the added costs for this analysis, may be associated with much higher costs. Despite these limitations, adding

10% to the average costs of service provision for the interventions is already a very substantial increase which can ensure large improvements in the accessibility of the interventions for persons with disabilities and economic and societal benefits.

Cost effectiveness study

The Stenberg et al. (2021) cost-effectiveness analysis reports the estimated costs and health benefits of 37 interventions (separated into six investment packages) in 74 countries, all of which target the health of women and children. Firstly, data from the study were extracted. More specifically, the costs and healthy life years per million data were extracted for seven of the 37 interventions where evidence for lower access for persons with disabilities exists - family planning and six vaccination routines, in two regions, sub-Saharan Africa and South-East Asia. Only data for the 95% coverage scenario from the original study were used. After the data were extracted, we replicated the original analysis, but applying 10% increase in the average costs, thus recalculating the cost-effectiveness ratios. The adjusted ratios thus reflect what could be the cost-effectiveness of interventions if they were to be provided in a disability inclusive manner.

The adjusted analysis based on the original Stenberg et al. study, reports cost-effectiveness estimates, meaning that the cost per healthy life year gained is reported. In the original study, deaths averted due to the intervention are converted into healthy life years gained based on age at time of death, average life expectancy, and the average health state valuation for a life saved from age at death until life expectancy. For family planning as an intervention, as it does not directly impact on mortality, the effect was measured in terms of averted maternal mortality resulting from fewer births. The original study does not consider economic benefits of improved health status.

Return on investment studies

Two WHO-led cost-benefit studies were adapted for this report. The first study analyses cancer prevention and care *(3)*, and the second one – NCD prevention *(4)*. As with the cost-effectiveness analysis, after data were extracted, the analyses were replicated for 95% coverage scenario, including additional 10% costs to the average costs.

Limitations of the analyses

The results of this study are intended to be indicative and are not prescriptive. All of the limitations of the existing models are propagated and are discussed in the respective published papers. Future work could aim to adapt the structure of existing models to incorporate more accurately the changes to interventions to remove barriers for persons with disabilities. In addition, the estimation of costs to make public health interventions accessible is conservative and may not reflect the actual costs varying in countries, as discussed above.

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Annex 5. Standardizing data collection on disability

Collecting data through instruments that gather information on functioning limitations ensures a standardized method that can generate cross-country and cross-cultural comparable data on disability. The selection of a tool will largely depend on the purpose of the data collection, the resources of a country, and their objectives and specific contexts. Different tools have been widely applied in countries and are recommended for use in different settings; selection depends on purpose and need of the data collection or disaggregation efforts. Examples include:

- The WHO Model Disability Survey (MDS). This is a general population survey developed by the World Bank and WHO in 2012 *(1, 2)*. The MDS estimates the distribution of disability in the population of a country or region, and identifies unmet needs, barriers and inequalities faced by persons with mild, moderate and severe disability.
- The WHO Functioning and Disability Disaggregation Tool (FDD11). This is a short, standalone instrument, comprising 11 questions that assess the difficulties experienced by individuals due to a health problem, when undertaking various activities *(3)*. The questions in FDD11 are derived directly from the brief version of the MDS and can be used primarily when the focus is disaggregation by disability of indicators, or information collected by the survey in which it has been integrated.
- WHODAS 2.0 measures the individual's level of functioning in six major life domains: cognition, mobility, self-care, getting along, life activities, and participation *(4, 5)*. As with FDD11, WHODAS 2.0 can be used when the focus of the data collection is disaggregation by disability of indicators, or information collected in the survey in which it has been integrated.
- The Washington Group Questions are designed to identify people with functioning limitations *(6)*. The short set contains six questions on functioning which can be used to disaggregate survey results. The questions can be included in any existing data collection activity within a programme-level monitoring and evaluation framework, or can be incorporated into smaller-scale surveys that collect data at the individual level.
- The Washington Group/UNICEF Module on Child Functioning covers children aged 2–17 years, and assesses functioning difficulties in different domains including hearing, vision, communication/comprehension, learning, mobility and emotions *(7, 8)*. The set of questions is intended for use in national household surveys and censuses.

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