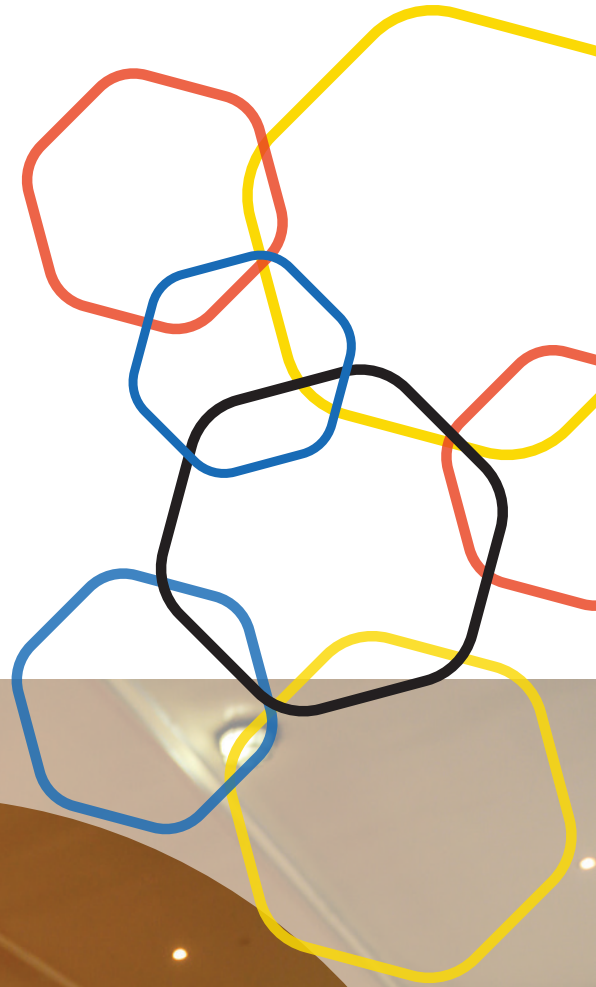


Policy brief on disability-inclusive health systems



Abstract

Disability-inclusive health is an important issue. There are 135 million people with disabilities in Europe. People with disabilities, on average, have higher health-care needs than others yet face many barriers in accessing health services. As a result, people with disabilities have worse health outcomes on average, including 2–3 times higher mortality rates across all ages. Policies and laws to support the right to health care for people with disabilities are in place, but often they are not put into practice. The aims of this policy brief are to provide a practical and actionable source of information and set out an approach that can be used to engage ministries of health on disability-inclusive health.

Document number: WHO/EURO:2021-4367-44130-62275

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Policy brief on disability-inclusive health systems



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Acknowledgments

This policy brief was written by: Satish Mishra, Health Workforce and Service Delivery Unit, WHO Regional Office for Europe; Hannah Kuper, Missing Billion Initiative; and Phyllis Heydt, Missing Billion Initiative.

The WHO Regional Office for Europe gratefully acknowledges technical inputs of the representatives of ministries of health, the European Disability Forum and lead academics in development of the brief. Technical support was also provided by experts in the Division of Country Health Policies and Systems, WHO Regional Office for Europe.

Abbreviations

EPW	(WHO) European Programme of Work 2020–2025, “United Action for Better Health in Europe”
EU	European Union
HLDF	high-level disability forum
NCPPD	National Clinical Programme for People with Disability (Ireland)
PHCPI	Primary Health Care Performance Initiative
SDGs	Sustainable Development Goals
UHC	universal health coverage
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities



Overview and objectives

This policy brief on disability-inclusive health systems was developed by the Health Workforce and Service Delivery Unit of the WHO Regional Office for Europe in collaboration with the Missing Billion Initiative (1) to support the engagement of ministries of health and other stakeholders in the WHO European Region. The brief was developed through: desk review of existing health system frameworks, literature on disability and health and disability-relevant health policies; consultation with key informants (representatives of ministries of health of three European countries, the European Disability Forum and lead academics); and internal review by health programmes of the WHO Regional Office for Europe.

Disability-inclusive health is an important issue. There are 135 million people with disabilities in Europe (2).

People with disabilities, on average, have higher health-care needs than others yet face many barriers in accessing health services (3,4). As a result, people with disabilities have worse health outcomes on average, including 2–3 times higher mortality rates across all ages. Policies and laws to support the right to health care for people with disabilities are in place, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (5), but often they are not put into practice. Consequently, people with disabilities in Europe and beyond continue to fail to realize their right to health. Meeting the health needs of people with disabilities is central to making progress towards universal health coverage (UHC), a key target of the United Nations Sustainable Development Goals (SDGs) (6).

The 2021 World Health Assembly passed a resolution on health for people with disabilities in recognition of the importance of this issue. The resolution aims to make the health sector more inclusive by tackling the significant barriers many people with disabilities face when they try to access health services.

The aims of this policy brief are to provide a practical and actionable source of information and set out an approach that can be used to engage ministries of health on disability-inclusive health. The specific objectives are to:

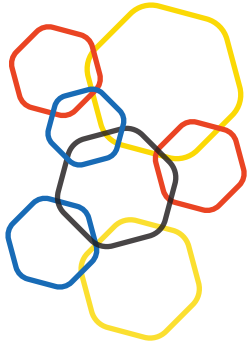
- promote a basic understanding of the importance of disability-inclusive health systems;
- highlight the policy context of disability-inclusive health in the European Region;
- provide a health systems framework that supports understanding of key challenges and possible actions/practical guidance, including good practices from European countries; and
- summarize key practical next steps to promote disability-inclusive health.



Framing disability-inclusive health systems

What is disability?

The UNCRPD (5) states that:¹



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

Globally, there are at least 1 billion people with disabilities, constituting 15% of the world's population (3). In Europe, 6–10 of every 100 people – an estimated 135 million – live with a disability (2). This number is set to increase as a result of population ageing and the rising prevalence of noncommunicable conditions, including injuries.

Ultimately, almost everyone is likely to experience some form of disability – temporary or permanent – at some point in their lives. People with disabilities are an extremely diverse group that includes individuals of different genders, ages, impairment types and levels of disability whose experience is influenced by their environment. People with disabilities face a wide range of exclusions (from, for example, education, employment and social participation) and consequently are poorer on average than others in the population (3).

Why do people with disabilities have greater health-care needs?

Of course, people with disabilities can be healthy, but for a number of reasons, on average they will experience worse health outcomes than people without disabilities (3, 4) (Table 1).

People with disabilities are at greater risk for poor health (Table 1). By definition, people with disabilities have an underlying health condition and/or an impairment, and this may result in further health conditions. For instance, a person may be blind as a result of diabetic retinopathy and the underlying diabetes may lead to stroke or cancer, and a person who is a wheelchair user will be at increased risk of pressure sores and respiratory diseases. People with disabilities are on average older and more likely to live in poverty (3), each of which is an important determinant of health (7). People with disabilities, including those in Europe, are also more likely to have risk factors for poor health, such as smoking, being overweight and having hypertension.

¹ There are different ways of measuring disability, depending on the purpose. In surveys and censuses, for instance, disability is often measured through the Washington Group Short Set, in which people self-report difficulties in functioning in six domains (mobility, hearing, vision, self-care, communication and understanding). Disability assessment for the purpose of receipt of disability allowances or other benefits are often more complex and medically based. There is a lack of consistency in how these are carried out across the WHO European Region.

Table 1. Examples of excess health risk factors and poor health service delivery and outcomes among people with disabilities in the WHO European Region

Greater risk factors for poor health	Limited service delivery	Poor health outcomes
Smoking (United Kingdom (8), Ireland (9), Belgium (10))	Greater needs/unmet health needs (United Kingdom (11), Ireland (9))	Higher total mortality rates (United Kingdom (12, 13), Sweden (14), Spain (15), Finland (16))
Low physical activity (Spain (17))	Less cancer screening (United Kingdom (18), Belgium (19), France (20))	Higher cause-specific mortality (such as influenza in the Netherlands (21), cancer in Sweden (22) and heart disease in the United Kingdom (23))
High blood pressure (Spain (24), Poland (25), Sweden (26))	Worse dental health provision (across Europe (27))	Higher prevalence of chronic disease (Ireland (9), Spain (28))
Obesity (across Europe (29))	Gaps in post-stroke rehabilitation (across European Union (EU) Member States (30))	Higher prevalence of diabetes (Ireland (9), Spain (28), Sweden (26))
Poor diet quality (Ireland (31))	Poor-quality maternal care (Austria (32), United Kingdom (England) (33))	Higher risk of cancer (Ireland (9), Spain (28), Sweden (22))
Alcohol/drug use (Belgium (10))	Lack of knowledge on intellectual disability among medical professionals (across Europe (34))	Higher risk of heart disease (Spain (28), United Kingdom (23))
Violence (Denmark (35), United Kingdom (36))	Lower-quality cancer care (Germany (37,38))	Worse sexual health outcomes (United Kingdom (36))
Poverty (EU countries (39)) and austerity (32 European countries (40))	Physically inaccessible services (31, mainly European, countries (41))	Higher prevalence of psychological distress (nine countries of the former Soviet Union (42))

People with disabilities also often experience challenges to accessing health care (through, for instance, discrimination, inaccessible transport or facilities, and lack of skills of health-care providers) and face greater out-of-pocket payments. As a result, they may not receive timely preventive or curative health care, which may increase their health-care needs in the future. Many people with disabilities may benefit from rehabilitation to maximize their physical, sensory, intellectual, psychological and social functioning. In the WHO European Region, it is estimated that 78% of years lived with disability result from health conditions that are amenable to rehabilitation (43).

On average, health outcomes are worse for people with disabilities as a result of greater risk factors for poor health and limited service delivery (Table 1). People with disabilities make up a large proportion of health-care users. In Denmark, for instance, half (51%) of older people (≥ 65 years) attending emergency departments had disabilities (44), and one in five women with breast cancer in Germany had pre-existing physical disability (37). Improving health-care access for people with disabilities ultimately will improve access for all.

What are the health care needs of people with disabilities?

People with disabilities experience three broad categories of health-care needs, to varying extents. These are the need for:



1. additional general health-care services because of their greater risk of poor health and poorer prevention and control of health conditions;
2. routine health-care services, including preventive (such as vaccination), promotive (health messaging) and curative care (emergency services and treatment for noncommunicable diseases); and
3. rehabilitation and specialist services for impairments (such as ophthalmology).

People with disabilities therefore require inclusive general health care and potentially rehabilitation to fulfil their fundamental rights. These are overlapping, but distinct, requirements, as illustrated in Fig. 1.

Fig. 1. Intersection of rehabilitation, inclusive health and disability



Rehabilitation is a health strategy to optimize functioning. Rehabilitation includes assistive technology. Many people with disabilities can benefit from rehabilitation.

Disability-inclusive health seeks to achieve equitable access to health care regardless of an individual's disability. Rehabilitation is a health strategy, so principles of inclusive health apply to rehabilitation.

The disability rights movement is a global concern that seeks to secure equal opportunities and equal rights for all persons with disabilities. The UNCRPD encompasses many rights, including to health (Article 25) and habilitation and rehabilitation (Article 26).

What challenges do people with disabilities face in accessing health-care services?

People with disabilities face a range of challenges in accessing health care (3,4), including:

- **financial** – people with disabilities may find medicines and services unaffordable or incur higher out-of-pocket payments than others (such as payment for accessible transport or for carer expenses);
- **attitudinal** – health-care workers may have negative preconceptions about disability because of lack of training on disability, or the health-care needs of people with disabilities may not be prioritized within families;
- **legal** – people with disabilities may be denied choice of treatment or the legal capacity to make decisions about their care;
- **physical accessibility** – health-care facilities, equipment or transport may not be accessible to people with physical impairments;
- **informational accessibility** – information and online services may not be accessible (for instance, lack of easy-to-read information, sign language interpretation or braille signposting, digital services, captioning or sign interpretation, and websites or booking systems being inaccessible); and
- **availability** – there are frequent gaps in provision of specialist services; where available, people with disabilities may face long waiting times for, and fragmented care within, these services.

These observable barriers may arise from health systems limitations (3,4), which include:

- **governance:** laws, policies and national plans are not always in place to protect the rights of people with disabilities, or are not monitored and enforced (45);
- **leadership:** lack of dedicated roles and responsibilities at national and local levels in the health sector (such as dedicated responsibility for disability, representation of disability/people with disabilities in national coordination bodies and meaningful consultation with people with disabilities);
- **health financing:** lack of funding or financing (such as insufficient funding available for adjustments and specific services such as assistive technology and lack of mechanisms to address affordability issues); and
- **data and evidence:** lack of disaggregated routine health data and operational evidence.

What are the implications for health outcomes of people with disabilities?

People with disabilities in the WHO European Region experience great challenges in accessing health care as a result of these health systems limitations, which have detrimental effects on their physical and psychological well-being (Table 1).

The higher vulnerability and worse outcomes experienced by people with disabilities have also been obvious during the COVID-19 pandemic in the Region (Box 1).

Box 1. COVID-19 and people with disabilities

The Office for National Statistics for England and Wales (United Kingdom) estimates that people with disabilities made up 16% of the population but 59% of deaths from COVID-19 between March and July 2020 (46). Clinical data have confirmed the higher risk of COVID-19 mortality among people with disabilities in the United Kingdom (47).

People with disabilities in the European Region experience other negative health consequences as a result of COVID-19. Globally, WHO has reported that rehabilitation services were disrupted in almost two thirds (63%) of countries (48). A survey in April 2020 across 35 European countries estimated that 1.3–2.2 million people with disabilities per day were being denied rehabilitation access as a result of COVID-19 (49). In the United Kingdom, people with intellectual disabilities are experiencing a rise in requests for psychotropic medication to control negative psychiatric consequences, including reduced access to rehabilitation, and higher levels of mental health concerns as a consequence of the pandemic (50).

The COVID-19 pandemic itself may increase disability and demand for rehabilitation services. Emerging evidence shows that approximately one in 10 people who had the virus are still unwell after 12 weeks, experiencing symptoms such as pain, fatigue and cognitive dysfunction (51). Many will benefit from rehabilitation to alleviate symptoms and maximize functioning.

A large proportion of the early mortality among people with disabilities potentially is preventable through better access to health care. For instance, in the United Kingdom, a confidential inquiry into premature deaths of people with intellectual disabilities showed that men with intellectual disabilities died on average 13 years earlier, and women 20 years earlier, than their peers without disabilities (52). Thirty-seven per cent of these deaths would have been preventable with good-quality health care.

More broadly, studies in the United Kingdom (England) repeatedly have shown an increased mortality risk among people with disabilities that is not explained entirely by demographic, socioeconomic and behavioural risk factors (12,13). Improving health care for people with disabilities may not only improve outcomes, but also be cost-saving. A study in the United Kingdom showed that providing rehabilitation for people with complex neurological disability produced substantial savings in ongoing care costs, especially in high-dependency patients (53), and similar results were obtained in Ireland for people with brain injury (54).

These health gaps experienced by people with disabilities matter, as they result in:

- reduced ability to achieve global health goals, including SDG 3;
- failure to comply with international law and violations of the UNCRPD;
- additional costs incurred by health systems (53);
- difficulty in achieving other SDGs, as good health contributes to engagement in areas such as education and employment; and
- poor health and reduced quality of life of individuals.

Health-care systems therefore need to adapt to better meet the needs and fulfil the rights of people with disabilities.



International policy context for inclusion in health

Health disparities will be reduced by making health systems more inclusive at all levels. Seven important documents outline the legal and international policy context for disability-inclusive health (Table 2).

Table 2. Legal and international policy context for disability-inclusive health

Document	Summary
UNCRPD (5)	Article 25 sets out parameters for disability-inclusive health. It requires that people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Article 26 confirms the right to rehabilitation and assistive technologies. Other relevant articles include Article 5 (Equality and non-discrimination), Article 9 (Accessibility), Article 12 (Equal recognition before the law) and Article 14 (Liberty and security of person).
SDGs (6)	SDG 3 aims to “Ensure healthy lives and promote well-being for all at all ages” (emphasis added) and therefore clearly is relevant to people with disabilities. Moreover, it includes the target to achieve UHC, meaning that the full range of necessary quality health services (including rehabilitation) are available for the whole population, without incurring financial risk.
WHO Disability Action Plan 2014–2021 (55)	The draft action plan has three key objectives: remove barriers and improve access to health services and programmes; strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation; and strengthen data collection.
World Health Assembly resolution EB148.R6	This resolution on achieving “the highest attainable standard of health for persons with disabilities” was adopted by the Seventy-fourth World Health Assembly in 2021 and prioritizes: ensured access to health services; protection during health emergencies; access to public health interventions; and disability data.
European Commission European Disability Strategy 2021–2030 (56)	The strategy identifies equal access to health care as an area for action and recognizes that people with disabilities face challenges in accessing health services, despite their right to equal access. The Commission makes commitments to share good practice and address disability-related inequalities in cancer care. It calls on Member States to “improve access for persons with disabilities to the entire healthcare portfolio” and raise awareness of the health-care needs of patients with disabilities related to rare diseases.
United Nations Declaration on Universal Health Care (57)	Adopted by the United Nations General Assembly in September 2019, the declaration includes the requirement to “increase access to health services for all persons with disabilities, 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, who represent 15 per cent of the global population, continue to experience unmet health needs”.
WHO’s European Programme or Work – “United Action for Better Health in Europe” (2020–2025) (58)	Leaving no one behind and including vulnerable groups are strong foundational principles of this programme. Protecting the rights of persons with disabilities to access the health-care services they need on an equal basis is strongly reflected in the three core priorities of the programme, on UHC (ensuring everyone can use the quality health services they need without financial hardship), protecting against health emergencies, and promoting health and well-being.

Common to all of these directives is the will to improve access to health care for people with disabilities through a twin-track approach that includes:

- **mainstreaming of disability** – ensuring that people with disabilities have access to services and programmes (such as sexual health services, child health screening and vaccination) on an equal basis with others by, for instance, ensuring that sign-language interpretation is available and medication has accessible packaging; and
- **targeted programmes** – addressing the specific needs of people with disabilities (such as provision of wheelchairs) by implementing additional services.

These policies and guidance provide a benchmark against which a framework for a disability-inclusive health system can be built.



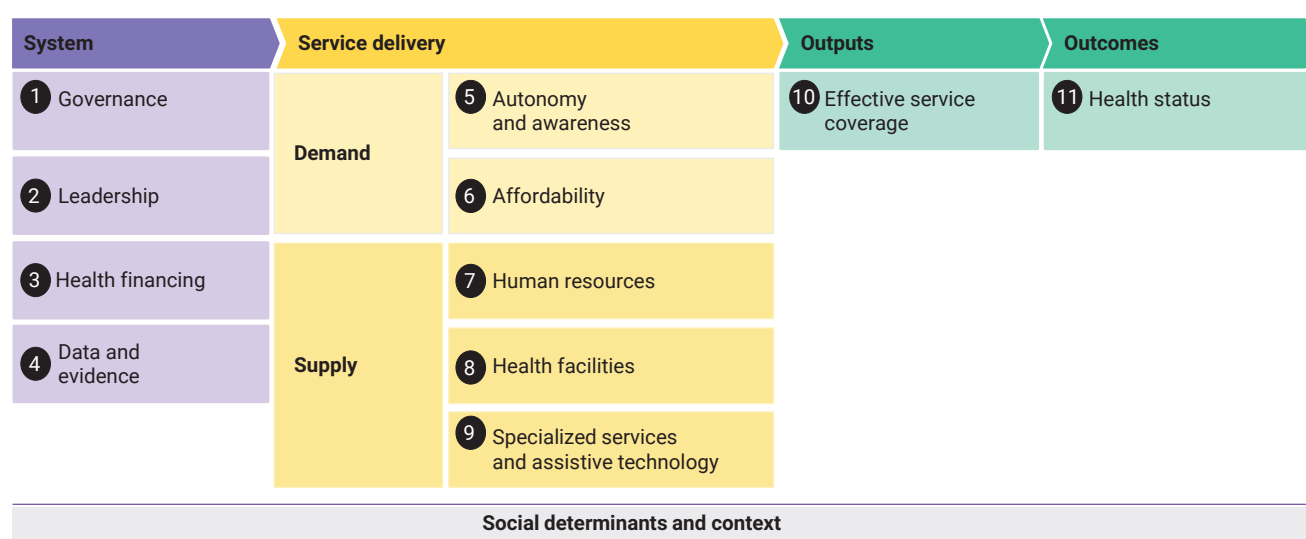


Health system review: framework for disability-inclusive health

A health system framework based upon the WHO six building blocks of the health system (59) and complementary to the Primary Health Care Performance Initiative (PHCPI) performance indicators (60) has been developed and pilot-tested. Health system indicators and national health plans can be reviewed against this framework to identify areas for strengthening disability inclusion (Fig. 2). This review framework can be used by ministries of health and other government policy-makers to drive action in three main steps.

- ◆ **Learn:** use of the health system elements to review the current situation.
- ◆ **Consult:** consult people with disabilities and technical experts.
- ◆ **Make changes:** prioritize a few tangible changes, make a plan, including a budget, for them and start executing.

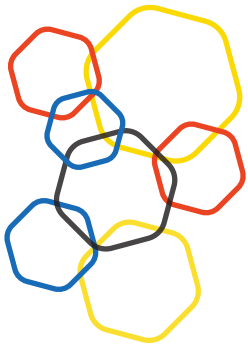
Fig. 2. Health Systems Framework



Source: Kuper & Heydt (4).

For each of the components described in the “System” and “Service delivery” columns of the framework, the following sections describe:

- ◆ the overall objective (“must ensure”) and some context
- ◆ a starting point for review (“good questions to ask”), indicating areas for action
- ◆ good practice examples from the WHO Regional Office for Europe.



Nothing about us, without us! People with disabilities have unique insight into their health-care needs, and the acceptability and feasibility of different solutions. It therefore is vital to ensure their inclusion throughout this exercise.

Governance

The overall objective (“must ensure”) is that the ratification of international regulations are matched with the creation and adoption of appropriate in-country laws and policies that protect the right to health care for people with disabilities and outlaw discrimination based on disability. Governance mechanisms, particularly those that enable transparency and accountability, must be put in place to enforce this right.

Context: international regulations, including the UNCRPD (articles 25 and 26) (5) stipulate the right of people with disabilities to health care. The political declaration for the United Nations High-level Meeting on Universal Health Coverage also highlights that health systems must be inclusive of people with disabilities (57). The declaration calls on countries to adopt laws and policies that institute a duty around provision of reasonable accommodation (45) and prohibit discrimination in access to health care for people with disabilities (through health insurance eligibility, for instance). These laws and policies must be implemented, improved and extended where necessary. Actionable plans and strategies by ministries of health or other national agencies should also be developed in consultation with relevant stakeholders and made available to the public in understandable formats to ensure and enforce accountability. This enables assessment of whether health systems are compliant with laws and policies with associated accountability.



A starting point for review and action

- Has the country ratified the UNCPRD? When was the last UNCPRD report done? Did the disability movement contribute relevant alternative reports relating to health?
- Is there a national law on the rights of people with disabilities?
- Does the national law prohibit discriminating against people with disabilities (in relation to, for example, health insurance, COVID-19 services, lack of informed consent requirements and opportunities for supported decision-making)?
- Does the national law define a duty to provide a reasonable accommodation for people with disabilities in the field of health care?
- Does the national health policy have a focus on people with disabilities?
- Does the national health plan/strategy for achieving UHC address the particular access barriers of people with disabilities?
- Have people with disabilities and/or their representatives been consulted in developing any elements of the national health plan/strategy?
- Is the national health plan/strategy readily available to the public?
- Is there an accountability mechanism in place to ensure that actions are taken so that health care is inclusive of people with disabilities, including an accessible complaints mechanism?
- Are mechanisms to report/inform on the implementation of law/policies, health-care quality and efficiency, and the experiences of people with disabilities in place?

Good practice examples from the WHO European Region

As an example of an accountability mechanism, the United Kingdom ran an independent inquiry into access to health care for people with learning disabilities in 2008. It revealed that people with learning disabilities have higher levels of unmet need and receive less effective treatment than the general population. A subsequent confidential inquiry in 2013 showed that avoidable deaths of people with learning disabilities were related to quality of care and service provision (52). Recommendations to address these issues included the review of deaths, routine collection of mortality data and the establishment of a national review board for people with learning disabilities, all of which were implemented.

The WHO Regional Office for Europe collaborated with the European Disability Forum to make the WHO European Programme of Work 2020–2025, “United Action for Better Health in Europe” (EPW), disability inclusive. Protecting the rights of persons with disabilities to access the health-care services they need on an equal basis is strongly reflected in the three core priorities of the EPW: UHC (ensuring everyone can use the quality health services they need without financial hardship); protecting against health emergencies; and promoting health and well-being (61).

As another example, a high-level disability forum (HLDF) was held in October 2019 in Dushanbe, Tajikistan, with participation from the Deputy Prime Minister, ministers of health

and social protection, education, labour and finance, dignitaries of other relevant ministries, representatives from committees and agencies from 20 countries and several international organizations (62). Over 200 high-level officials, United Nations agencies, civil society organizations and development partners participated in the forum to celebrate achievements and identify challenges and opportunities related to the rights of people with disabilities in Tajikistan. The HLDF used this opportunity to review the national programme on rehabilitation (2017–2020), the status of implementation of the UNCRPD in Tajikistan and progress made towards its ratification. Following the forum, a roadmap on Tajikistan's accession to and compliance with the UNCRPD was adopted. The HLDF in Tajikistan marked the adoption of a new and empowering declaration on disability issues, contributing to the identification of the priorities for Tajikistan's disability sector until 2030, in line with the SDGs.

An analysis of the status of disability discrimination with regard to health care in 27 EU countries showed that 14 have legislation in place that both prohibits disability discrimination and requires a reasonable accommodation (Table 3 (45)).

Table 3. Status of EU countries with respect to legislation prohibiting disability discrimination and/or requirement of reasonable accommodation in health care

		Legislation requires a reasonable accommodation	
		Yes	No
Legislation prohibits disability discrimination	Yes	14 (Austria, Belgium, Bulgaria, Croatia, Czechia, Finland, Germany, Hungary, Ireland, Malta, the Netherlands, Slovakia, Spain, Sweden)	7 (France, Italy, Latvia, Lithuania, Luxembourg, Romania, Slovenia)
	No	1 (Cyprus)	5 (Denmark, Estonia, Greece, Poland, Portugal)

Source: Waddington (45).

Leadership

The overall objective ("must ensure") is that issues around disability are clearly articulated and represented in the ministry of health, health sector structures and coordination mechanisms. Leadership capacities and structures should be built, strengthened and effectively activated during times of crisis or disasters.

Context: improvement in national laws, policies and plans may depend on the existence of leadership capacity on disability inclusion in the health-care system. In some settings, this means a designated committee or person(s) who is responsible for disability-related issues in the ministry of health. Coordination structures should include representation of people with disabilities to enable and ensure the employment of practical insights, experience and expertise on the issues to be addressed.

A starting point for review and action

- Is there a designated official/cadre in the ministry of health and/or a UNCRPD focal point who is responsible for disability?
- Is there a disability workplan in the ministry of health?

- Is there a budget for the disability workplan and, if so, how is it funded?
- Do leadership and coordination structures have representation of people with disabilities?
- Do any committees, taskforces or other dedicated capacities take care of disability-related health-care issues, including as part of pandemic preparedness plans? Is the ministry of health and/or its designated official or focal point represented in these groups?
- Is there a forum at ministerial level for disability issues?

Good practice examples from the WHO European Region

In March 2020, Ireland announced a National Clinical Programme for People with Disability (NCPDP) (63). The NCPDP seeks to support the provision of effective and efficient assessments, interventions and supports for people with disability that are evidence-informed and context-appropriate, and which are provided within a social and rights-based model of disability. A chief clinical officer for disability will be appointed in the Irish Health Service and a disability advisory group and short-term task groups will be formed.

Health financing

The overall objective (“must ensure”) is that resources are available to ensure health services are accessible to, and affordable for, people with disabilities (in relation to, for example, accessibility of facilities, equipment and communication and costed reasonable accommodations) and disability-targeted services are provided (such as assistive technologies, medical devices and other specialized services).

Context: budgets should enable the provision of disability-inclusive health services, including accessible health services, assistive technologies and specialized services. Coverage policy should ensure people with disabilities do not experience financial hardship due to out-of-pocket payments or indirect costs (such as transport). These budgets may be the responsibility of the ministry of health and/or other ministries (such as the ministry of social affairs) and may operate at central and local government levels, meaning a coordination mechanism may be needed.

A starting point for review and action

- Does the health budget account for disability-related services or adjustments?
- Is accessibility budgeted for when creating and developing new health services and products?
- Do resource allocation formulae account for population needs, including disability?
- Does the publicly financed benefits package include disability-related services such as rehabilitation and assistive technologies?
- Are user charges (co-payments) for publicly financed health services designed to reduce unmet need and financial hardship, particularly for people at risk of poverty and social exclusion and people who are regular users of health services?

- Are social protection programmes inclusive of people with disabilities and do they provide financial support to minimize out-of-pocket payments for health services?
- Do provider payment mechanisms account for the needs of people with disabilities (for example, longer consultations, home visits or pain relief for dental care for a person with intellectual disabilities)?
- Are there efforts to ensure people do not face administrative barriers to accessing health services or social protection?

Good practice examples from the WHO European Region

The Irish Health Service established the NCPPD in March 2020 (63). As part of this work, the Minister for Health and Minister for Disability announced a €20 million fund to reform disability services, build the capacity of disability organizations and improve the quality of life of those who rely on these services. This funding is additional to the €100 million extra baseline allocated for disabilities services for 2021.

In Germany, the benefits package of the national health insurance programme recognizes the particular needs of people with disabilities in some areas. For example, home visits for simple dental care procedures are reimbursed and patients are entitled to more frequent oral health examinations and preventive measures.

Data and evidence

The overall objective (“must ensure”) is that routine data showing the health situation of people with disabilities and how their health can be improved are available, and evidence is generated to understand and improve delivery of health services.

Context: health information systems should generate data to describe the access to health care of people with disabilities in comparison to others. These data should be compiled, analysed and communicated to relevant stakeholders, who can then use them to identify actions to promote inclusion, set priorities and allocate resources. As Margaret Chan, the former WHO Director-General, has said repeatedly, “What gets measured gets done”.

There are three potential sources of information.

- **Household surveys on health:** inclusion of measures of disability within the data-collection efforts of health surveys allows disaggregation of health indicators by disability. For instance, national health surveys could include measures of disability in their nationally representative household surveys and thereby establish differences in mortality, morbidity and key health outcomes (such as prevalence of noncommunicable diseases) by disability status.
- **Routine health information systems:** use of routine health information systems to identify exemplar groups (such as people with intellectual disabilities) allows comparisons of their health-care utilization and coverage with the entire population.
- **Disability-specific surveys:** each country should conduct disability-specific health-care surveys on a 5–10-year basis to help them understand the health status and health-

care-seeking behaviour of people with disabilities compared to the wider population. WHO's Model Disability Survey is one such example.

Where possible, data on disability and health should be disaggregated by disability type and by gender and age to explore gaps and needs for different groups. This data collection should complement, and not duplicate, other data-collection efforts, such as those using the systematic assessment of rehabilitation situation tool recommended by WHO or PHCPI data-collection initiatives.

Evidence is also required on which interventions are needed to improve access to health care for people with disabilities. Research should therefore be undertaken to assess the effectiveness, and cost-effectiveness, of different approaches. New innovations may be needed to facilitate health-care access; these should be developed in an evidence-based manner, ideally using a human-centred design, working in partnership with people with disabilities. Collection of evidence should always comply with ethical standards, including in terms of seeking consent and ensuring confidentiality of data.

A starting point for review and action

- Do data exist on the number of people with disabilities and type?
- Is it possible to disaggregate health data by disability? If so, can health data be further disaggregated by disability type, gender and age?
- Has there been a survey on health needs, outcomes and/or access for people with disabilities in the last 10 years (for instance, the WHO Model Disability Survey)?
- Has there been a national consultation on health with people with disabilities to identify priorities and gaps?
- Are data on needs for and access to specialist services (such as rehabilitation and assistive technology) available?
- Does a monitoring framework for disability-inclusive health services exist in the ministry of health?
- Are there any operational research projects or pilots underway that address particular access challenges for people with disabilities?
- Has any mapping been done of the human experience of people with disabilities as a basis for designing interventions/adaptations?
- Has there been a mapping of disability service provision coherence across different sectors such as health, social care and education?

Good practice examples from the WHO European Region

Household surveys on health that have included measures of disability (such as the European Health and Social Integration Survey) have been undertaken in several European countries, allowing data disaggregation. Disability has been included in regular household budget surveys in, for example, Tajikistan (64).

Disability-specific surveys have been undertaken in a number of European countries, including Malta (2005), Ireland (2006), Kyrgyzstan (2008), Serbia (2008), Spain (2008), Croatia (2009), Latvia (2009), Romania (2009) and Tajikistan (2018).

Routine health information systems have been used to collect data on the health status and outcomes of people with disabilities. A specific initiative in the United Kingdom, Health and Care of People with Learning Disabilities (65), monitors mortality, certain health conditions (such as epilepsy and dysphagia) and cancer screening, and compares these to figures for the general population. Data are compiled through electronic databases from general practitioners. In Sweden, the health-care utilization and mortality of people with intellectual disabilities is tracked through a national registry.

Autonomy and awareness

The overall objective (“must ensure”) is that people with disabilities make their own decisions about health care and are aware of their rights and options.

Context: people with disabilities may be denied the autonomy to make decisions about their own health care (informed consent may not always be sought for interventions, for instance) and may not be provided with health information on areas such as when and how to seek care when needed in accessible formats. These fundamental barriers must be addressed, otherwise making changes in the supply side alone is unlikely to equalize health-care access.

A starting point for review and action

- Is key health information for the general public (such as radio messages on HIV or general information about COVID-19 on TV) accessible for people with different impairment types (EasyRead for people with intellectual disabilities, sign language interpretation/captioning for people with hearing impairment or braille for people with visual impairment, for instance)?
- Are education materials available for children with disabilities (such as materials for children with intellectual disabilities about going to the doctor and on informed consent)?
- Are there any peer education programmes for people with disabilities on their rights to health and particular health topics (like COVID-19 and cancer)?
- Are there any support groups for parents of children with disabilities, and does the ministry of health engage with these groups?

Good practice examples from the WHO European Region

The WHO Regional Office for Europe has collaborated with the European Disability Forum, a regional organization of persons with disabilities, regarding COVID-19 communication. Together, they created two videos to provide information on how to make COVID-19 messages disability-inclusive (66), with examples of COVID-19 information in alternative formats (such as sign language (67)). The Regional Office and the Forum also prepared two guidance notes, one for health ministries and WHO offices (68) and one for disabled people’s organizations (69), to guide them on disability-inclusive information during COVID-19.

Beyond Words has created EasyRead information for people with intellectual disabilities about going to the doctor and other health-related issues.

Affordability

The overall objective (“must ensure”) is that people with disabilities must be able to afford health services.

Context: people with disabilities are on average poorer yet incur greater direct and indirect health-care costs. For example, travel may be more expensive for people who require accessible transport modes. People with disabilities may seek services from private providers if public services are not accessible.

People with disabilities may therefore need additional protection from out-of-pocket payments and additional financial support to cover indirect costs when using health services. Depending on context, this may be provided through the health system or through broader social protection programmes. Social protection eligibility and benefits packages vary widely across the European Region.

A starting point for review and action

- Is there a social benefit programme or a disability allowance for people with disabilities?
- Is there any financial support for attending health services (such as reduced costs for services and transport vouchers)?
- Are affordable assistive technologies made available to persons with disabilities?

Good practice examples from the WHO European Region

Persons with disabilities in Sweden have been eligible since 2019 for an allowance when they incur additional costs due to disability. They are eligible if 18 years and over, have a disability that would last for at least one year, are insured in Sweden and have additional disability-related costs of at least SEK 11 900 per year (approximately €1190). The Försäkringskassan government agency administers social insurance and is responsible for determining what counts as additional costs.

Generally, these costs are in addition to common expenses of same-age persons without disabilities, can be one-off or recurring, and are divided by law into seven categories: health care and food; wear and tear and cleaning; travel; assistive devices; personal assistance; housing; or others. Depending on the amount of additional costs per year, persons can receive an allowance of between SEK 1190 and 2777 per month (approximately €119–278). Applications can be made online; guidance is available for calculating additional costs and a medical statement is required to certify disability.

Human resources

The overall objective (“must ensure”) is that the health-care workforce is knowledgeable about disability and has the skills and flexibility to provide quality care to people with disabilities.

Context: health-care workers must have the knowledge to provide quality care for people with disabilities. They require information about the health-care needs people with disabilities may experience, both in terms of specific vulnerabilities (such as pressure sores among people with mobility impairments) and additional needs when accessing general health care (challenging false assumptions that people with disabilities are asexual and therefore do not need access to sexual and reproductive health services, for instance). Health-care workers need the skills to be able to communicate with people with different impairment types (including how to interact with someone with a visual or cognitive impairment, obtaining free and informed consent to health care and respecting the privacy and dignity of the person) and ensure their services are accessible for persons with disabilities (by explaining health issues in simple language to patients with intellectual disabilities, for instance). In addition to clinical staff, it is important that all staff working in the health-care sector (including administration, cleaning and maintenance staff, IT staff and management) are well trained and informed on disability-inclusive health provision, including accessibility.

Disability awareness and knowledge training should be incorporated within the health-care curriculum for different types of professionals and should form a part of ongoing training. Ideally, any training should be delivered by people with disabilities. Training people with disabilities to become health-care professionals is also important.

A starting point for review and action

- Do the curricula of all health-care professionals (including doctors, nurses, midwives, counsellors, physiotherapists, social care professionals and community health workers) include training on disability (such as disability rights, communication skills and accessibility)?
- Have health-care professionals received any on-the-job training about disability?
- Is training on disability provided to other staff working in the health sector?
- Are rehabilitation workforces specifically addressed in national human resources for health planning?
- Are people with disabilities leading and/or involved in the training of health workers?
- What proportion of the health workforce has a disability?

Good practice examples from the WHO European Region

The number of good practice examples on integrating disability within curricula for health-care professionals in Europe is limited (70). Approaches include: clinical or community placements with disabled people (Leicester, United Kingdom; Lund, Sweden; Leipzig, Germany; Zurich, Switzerland; Angers, France); disability and/or communication skills training (Leicester, United Kingdom; Wolverhampton, United Kingdom; Angers, France; Leeds, United Kingdom; Bradford, United Kingdom; Glasgow, United Kingdom); and interactive workshops or interaction with disabled users (Staffordshire, United Kingdom; London, United Kingdom; Bristol, United Kingdom). These case studies included people with a range of impairment types (hearing, intellectual and physical) and often were conducted in partnership with people with disabilities.

There is a need for greater support for health professionals with disabilities. The British Medical Association report *Disability in the medical profession – survey findings 2020* showed low levels of support for doctors and medical students with disabilities (71). Of 705 doctors and medical students with disabilities surveyed, 35% reported being bullied or harassed in their current workplace as a result of their disability, 45% reported not obtaining reasonable adjustments and 77% reported they were worried about being treated unfavourably if they disclosed a disability or long-term health condition. The lesson learnt is that greater support services and anti-discrimination measures should be put in place for health professionals with disabilities.

Health facilities

The overall objective (“must ensure”) is that health-care services, including health-care facility infrastructure and information, are accessible for people with disabilities.

Context: health-care facilities, including the entrance, examination rooms, bathrooms and equipment, must be physically accessible for people with disabilities. A number of accessibility standards list the required features. It will be most cost-efficient for facilities to be built to these standards, rather than retrofitting them at a later date. Measures must be in place to ensure accessibility for people with other access needs, including visual (by offering braille signage and good lighting, for instance), hearing or communication (such as offering access to alternative forms of communication).

Information, including digital health services (such as online consultations and mobile apps) must also be fully accessible to people with disabilities (offering EasyRead texts and communicating in simple language for people with intellectual/cognitive impairments, for example).

There should be compliance with the European standards for accessibility of the built environment (EN17210 and ICT services/products (EN301549)). Appointing an accessibility expert in each health facility can help ensure these accessibility features are in place and maintained. Consulting locally with organizations of persons with disabilities will help to highlight the specific local accessibility barriers and how they can be overcome. Additionally, routine monitoring of accessibility of health services is recommended, with consequences for those who fail accessibility standards.

A starting point for review and action

- Are there any national accessibility standards for health-care facilities?
- Are there rules to follow existing European standards on accessibility of health-care facilities, buildings (EN17210) and accessibility of digital health-care services and products (EN301549)?
- Are there any local institutions that have developed/adapted practical guides/tools that are available for the use of accessibility audits?
- Has an audit of the accessibility of clinics (physical and information) been undertaken?
- Has an audit of the accessibility of e-health services been undertaken?



Good practice examples from the WHO European Region

The European Disability Forum campaigns for the European Commission to ensure that e-health services and mobile health devices and services are fully accessible and safe to use for disabled patients, family members, personal assistants and health-care staff.

A range of accessibility audits have been developed for European contexts to allow assessment of health-care facilities (including from the United Kingdom (Scotland) (72)).

In Georgia, requirements are stipulated for the physical accessibility of health-care facilities. Fulfilment of access requirements is checked locally, and non-compliance can be grounds for closing facilities.

Rehabilitation and specialist services

The overall objective (“must ensure”) is that rehabilitation (such as physiotherapy, assistive technology and medical devices) and specialist health services (like ophthalmology, medical appliances and assistive technology) are available, affordable and of good quality for people with disabilities.

Context: people with disabilities may require rehabilitation and specialist health services. Need far outstrips supply in many countries, so global initiatives such as WHO’s *Rehabilitation in health systems: a guide for action* (73) and ATscale, a global partnership for assistive technology, have been launched to scale up these services.

WHO’s rehabilitation guide for action encourages countries to strengthen the capacity and performance of rehabilitation in their health system through a four-step process: assessment of the situation in the country; development of a rehabilitation strategic plan; establishment of monitoring, evaluation and review processes; and implementation of the strategic plan by

increasing capacity of rehabilitation leadership and governance. Supportive documents are available to guide the conduct of the four steps.

ATscale works with partners to support governments in scaling up assistive technologies and address market failures.

A starting point for review and action

- Does the national essential services package include rehabilitation and assistive device provision?
- Are there any national rehabilitation and/or assistive technology plans or committees?
- Has there been any assessments of rehabilitation services and capacity in the country (for instance, the WHO Systematic Assessment of Rehabilitation Situation)?
- Are there any prioritized activities to improve rehabilitation (including assistive technology) in the health sector national plan?
- Do specialized rehabilitation service centres for complex rehabilitation exist, in particular for spinal cord and traumatic brain injuries?
- Do rehabilitation services (therapy, rehabilitation medicine and assistive devices) exist in primary, secondary and/or tertiary health facilities?
- Does a continuum of care exist that includes rehabilitation services through discharge planning, clinical guidelines, multi- and transdisciplinary teams, referral pathways, service directories and case management?

Good practice examples from the WHO European Region

The Cerebral Palsy Follow-Up Programme was established in Sweden in 1994 and has included all habilitation units since 2007 (74). Children with cerebral palsy are identified through the national register and are supported to maintain good health and maximize functioning through access to physical therapy, occupational therapy and orthopaedic care. The programme is also used in Denmark, Norway, the United Kingdom (Scotland) and parts of Iceland.

Rapid assistive technology assessments were conducted for Azerbaijan, Georgia, Italy, Poland, Tajikistan, Ukraine and the United Kingdom in 2021 to estimate the met and unmet need for assistive technology. These surveys will help ministries and other health agencies to plan to strengthen assistive technology services. In addition, assistive technology policy and services were strengthened in Azerbaijan, Georgia, Tajikistan and Ukraine.



Summary

The current situation of people with disabilities in the WHO European Region is that on average, they have greater health-care needs yet face more barriers in accessing services due to failures in systems and service delivery (Table 4). As a consequence, they tend to have lower coverage and quality of services and worse health-care outcomes.

Table 4. Summary of health systems failure, coverage and outcomes for people with disabilities

Failures: systems	Failures: service delivery	Results: poor health and financial hardship for people with disabilities
Lack of political leadership and management at national and local level	Transport not affordable Health clinics not accessible	Unmet need and financial hardship due to poor coverage of services
Lack of adequate funding and weak financing	Health information inaccessible	Poor quality of services
Poor legislation and policy, or lack of implementation	Rehabilitation and specialist services not available	Worse outcomes: higher mortality, high prevalence of conditions
Gaps in data and evidence	Health workers lack information and skills about disability	

These gaps are important as:

- people with disabilities will fail to maximize their functioning and quality of life;
- it is a violation of the right to health care of people with disabilities as set out by the UNCRPD and the laws of most countries;
- continued exclusion of people with disabilities will mean that UHC and other SDG and health targets will not be met; and
- health systems that include people with disabilities will work better for all.

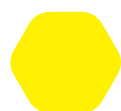
A range of health system failures therefore need to be addressed to improve health-care coverage and outcomes for people with disabilities. These include strengthening:

- governance;
- leadership;
- health financing mechanisms;
- data and evidence;
- demand-level variables (autonomy, awareness and affordability); and
- supply-level factors (human resources, health facilities, rehabilitation and specialized services).

This review framework can be used by ministries of health and other government policy-makers to drive action in three main steps.

1. **Learn:** use the above health system elements and the provided questions (such as using literature and through interviewing key informants) to review the current situation.
 - o *Governments might want to commission a more formal review or situational analysis of the existing system.*
2. **Consult:** consult people with disabilities about their experiences and suggestions, and also consult technical experts.
 - o *Governments might want to create an advisory group on inclusive health for the ministry of health with people with different disability types.*
3. **Make changes:** prioritize a few tangible changes, make a plan, including a budget, for them and start executing.
 - o *Governments might want to create a temporary working group at ministry level to define and drive the execution of these changes.*





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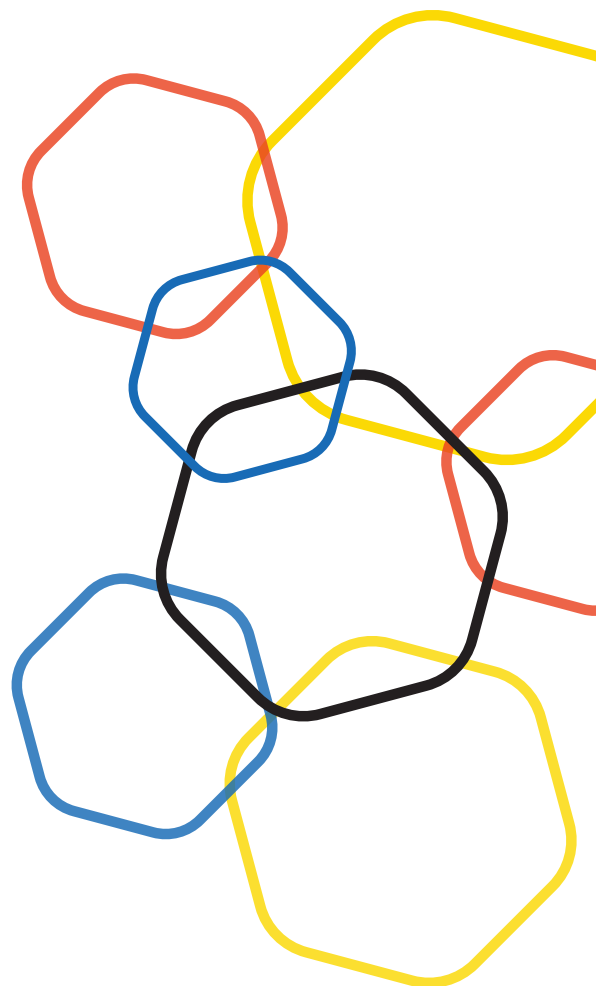
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WHO/EURO:2021-4367-44130-62275

World Health Organization Regional Office for Europe

UN City, Marmorvej 51,
DK-2100 Copenhagen Ø, Denmark
Tel.: +45 45 33 70 00 Fax: +45 45 33 70 01
Email: eurocontact@who.int
Website: www.euro.who.int