



INCLUSIVE SOCIAL PROTECTION FOR EMPOWERMENT OF PERSONS WITH DISABILITIES

BACKGROUND PAPER #4

**TOWARDS UNIVERSAL HEALTH COVERAGE, the role of
disability inclusive social protection - a review**

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The UNPRPD project aims at developing practical guidance for countries, development agencies and OPDs for reforms towards inclusive social protection systems fostering empowerment of persons with disabilities across the life cycle.

The papers summarize key issues and present policy recommendations and proposal to build inclusive social protection systems supporting empowerment and participation of persons with disabilities across the life cycle. Advanced unedited versions of the papers are disseminated for consultation with experts and activists from social protection and disability rights communities.

Any comments and suggestions on issues highlighted, recommendations and proposals should be sent to [Veronika Wodsak](mailto:wodsak@ilo.org) at wodsak@ilo.org .

Feedback received contributes to the finalization of the papers and the elaboration of a comprehensive guidance document.

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DISCLAIMER

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INTRODUCTION

People with disabilities tend to use more health services on average compared to the broader population, partly because they require the same range of general health services (including immunization, screening, and sexual and reproductive health), as well as additional services specific to their disability (such as specific medicine, assistive devices and rehabilitation). However, people with disabilities overall report a poorer health status, experience greater barriers to receiving care and are more likely to face catastrophic health expenditures than persons without disabilities.

While more and more countries are seeking to achieve universal health coverage by expanding social health protection to all, evidence shows that, often, little attention has been paid to ensuring inclusion of people with disabilities. This has resulted in a lack of capacity of social health protection schemes and more broadly health care systems to provide accessible information and inclusive care, which has been highlighted during the COVID 19 crisisⁱ.

Tackling the diversity of barriers undermining their access to health care requires a multi sector approach, and social protection has a critical role to play in covering the diverse costs that they face.

This paper provides a brief overview of the gaps related to universal health coverage and persons with disabilities and focuses on the different social protection measures that can contribute to more inclusive access to health care.

ⁱ T. Hillgrove and W. Pryor, *Experiences of people with disabilities in COVID-19: A summary of current evidence*, 2020.



1. HEALTH AND DISABILITY: A COMPLEX RELATIONSHIP

1.1. PEOPLE WITH DISABILITIES AND THE HUMAN RIGHTS TO HEALTH AND SOCIAL PROTECTION

Social health protection provides a rights-based pathway towards the goal of UHC (ILO, 2020a). As an integral component of comprehensive social protection systems, social health protection designates a series of public or publicly organized and mandated private measures to achieve (ILO, 2008):

- i. effective access to quality healthcare without hardship, which is the focus of this section; and
- ii. income security to compensate for lost earnings in case of sickness.

The lack of affordable quality healthcare risks creating both poor health and impoverishment, with a greater impact on the most vulnerable. For this reason, the principle of universality of coverage was underlined in human rights instruments within both the rights to health and social security and, further, in global social security standards (UN, 2019, 2008, p. 19, 2000, p. 14).

Social health protection is central for reaching the SDGs. The SDG targets on UHC (SDG 3.8) and universal social protection systems, including floors (SDG 1.3), are complementary and closely linked priority measures aimed at achieving a healthy and dignified life for all. While social health protection is embedded in the human rights framework, important coverage gaps exist worldwide and tend to disproportionately affect vulnerable populations (ILO, 2017).

The human rights framework as well as social security standards state that health services should be acceptable and adaptable, in addition to the already described criteria of available and of good quality. This perspective shows another way in which services are not appropriate for people with disabilities and adds another argument for the need to improve access to healthcare for this group (Box 1).

Box 1. Availability, accessibility, acceptability and good quality of health care ⁹



ACCESSIBILITY

Health facilities, goods and services must be accessible physically as well as financially and on the basis of non-discrimination. Accessibility also implies the right to seek, receive and impart health-related information in an accessible format for all, including persons with disabilities, but does not impair the right to have personal health data treated confidentially.



AVAILABILITY

Functioning public health and health-care facilities, goods and services must be available in sufficient quantity in a timely manner within a country



ACCEPTABILITY

The facilities, goods and services should also be medically and culturally acceptable



GOOD QUALITY

Health facilities, goods and services must be scientifically and medically appropriate and of good quality. This requires, among other things, trained health professionals, scientifically approved and unexpired drugs and hospital equipment, adequate sanitation and safe drinking water.

Poor health of people with disabilities is an important concern. Health is valuable in its own right because it enables a person to have a good life, and a full life expectancy. Furthermore, poor health or lack of access to healthcare can make it more difficult for other rights to be realized. If someone does not have access to the healthcare services that they need, they may be unable to attend school, access jobs, or participate in society in other ways. For all these reasons, health is a disability rights issue, which is why Articles 25 and 26 of the Convention on the Rights of Persons with Disabilities reaffirm the rights of people with disabilities to access healthcare and rehabilitation services.¹⁴

However, this issue has not always received the attention that it should from the disability rights movement, who may sometimes have been reluctant to focus on health and rehabilitation out of concerns about medicalization of disability.

1.2. SDG 3.8 ON UNIVERSAL HEALTH COVERAGE (UHC) AND DISABILITY

The achievement of UHC is target 3.8 of Sustainable Development Goal 3 “Good Health and Well-being”.¹ UHC means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services that they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.² Figure 1 illustrates the three dimensions which

can affect the achievement of UHC: coverage of (effective) health services, finance, and population, and highlight the options for expanding coverage along those.^{2,3}

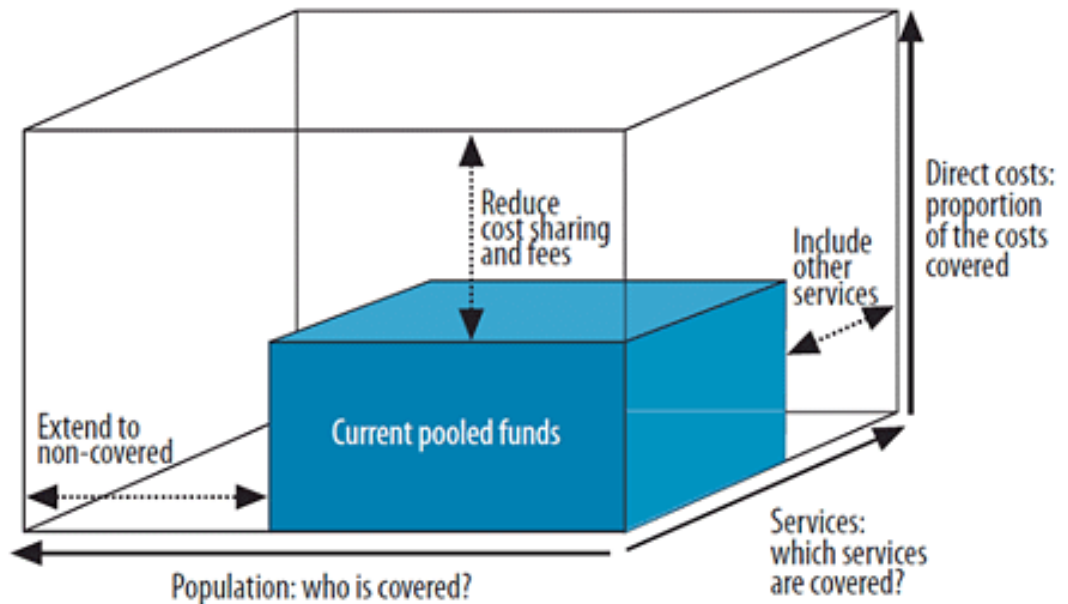


Figure 1: The three dimensions to consider when moving towards universal coverage.²

The SDG 3 on healthcare does not mention disability, including with respect to UHC, in contrast to several other SDGs which do explicitly consider people with disabilities (e.g., SDG 4 on education, SDG 8 on employment and economic growth). However, “universal” means everyone, and so UHC must incorporate people with disabilities.

Nevertheless, people with disabilities are currently being left behind across different dimensions of UHC:



POPULATION COVERAGE

The population coverage axis of UHC focuses on access to health for all, aiming for health care that is available to the entire population. People with disabilities on average experience poorer access to healthcare services and consequently higher unmet needs⁴.



FINANCIAL PROTECTION

UHC achievement depends on financial protection against healthcare costs, inclusive of the poorest in the community. Financial barriers to accessing healthcare are higher among persons with disabilities as they are on average poorer,⁵ yet experience higher healthcare costs.⁴



SERVICE COVERAGE

The full range of healthcare services that people with disabilities may need, both general and specialized, should be available in order to achieve UHC. Crucially, for people with disabilities, rehabilitation and assistive devices must be explicitly included within essential healthcare services and consideration of achievement of UHC.

However, the WHO estimates in many LMICs, only 5-15% of people who require assistive devices and technologies have access to them,⁶ and gaps in access to rehabilitation services are also pronounced.⁷ Public health campaigns and information are rarely provided in accessible format.



QUALITY

Quality of healthcare provision may be compromised for people with disabilities, because of negative attitudes and discrimination, lack of skill of healthcare providers, or inaccessible facilities.⁸

A number of strategies and policies are available at the international and national levels that inform how UHC should be achieved. The 2019 Political declaration of the high-level meeting on universal health coverage includes a commitment 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.”*¹⁰ It also promotes action to implement disability-responsive interventions, improve training about disability, strengthen health information systems with respect to disability, and thereby ensure that people with disabilities are not left behind. This resolution complements both the SDG 3 commitments to universal health and the UNCRPD commitments regarding the right to health and rehabilitation for people with disabilities.¹¹ However, practical guidance is needed on how these laudable aims can be achieved for people with disabilities.

The World Health Organization together with member States, international and professional organizations, nongovernmental organizations and rehabilitation experts issued in 2018 the document *Rehabilitation 2030: a call for action*, to strengthen rehabilitation services with a focus on improving rehabilitation governance and investment; expanding high-quality rehabilitation workforce and services; and enhancing rehabilitation data collection. This followed the adoption of the Priority Assistive Products List in 2016. There is a need for critical assessment of whether and why people with disabilities fall behind in UHC, and what practical interventions are needed to ensure that they are included.

1.3. NEED OF HEALTHCARE OF PEOPLE LIVING WITH DISABILITIES

Of course, people with disabilities can be healthy. However, on average people with disabilities are more likely to experience poor health than people without disabilities.¹⁵⁻²¹ For instance, a study in Guatemala showed that people with disabilities were almost three times more likely to report a serious health problem (aOR 2.8, 2.2-3.7) or doctor-diagnosis of one of 17 general health conditions (aOR 2.9, 2.2-3.8) as compared to those without disabilities.²⁰ Similarly, a study across 30 low and middle income countries (LMICs) showed that children with disabilities were around five times more likely to report a serious illness in the last year as compared to children without disabilities.¹⁸

There are different possible pathways for the link of disability and poor health. First, people with disabilities often occupy a disadvantaged and marginalised structural position in society,²² and are on average older, and both these traits are linked to poor health. A separate pathway is that, according to the International Classification of Functioning, Disability and Health, people with disabilities by definition have a health condition and an impairment, and these conditions may produce further health consequences. For instance, diabetes is a health condition that can cause blindness through diabetic retinopathy, but also increases the risk of heart and kidney disease. An impairment may cause secondary health conditions, as in the case of a person with a spinal cord injury who is more vulnerable to pressure sores and urinary tract infections. Another mechanism for the link between disability and poor health is that access to preventive and curative interventions may be worse for people with disabilities because of a range of barriers. For instance, women with disabilities are less likely to attend for breast or bowel cancer screening,²³ and so are less likely to receive timely preventative health care.

People with disabilities have the same health needs as every other member of the population, including immunization, screening, sexual and reproductive health, and all other aspects of regular healthcare. However, as discussed above, people with disabilities may have additional general healthcare needs, because of their greater vulnerability to health conditions.^{18,21,24,25} A systematic review was conducted of access to general healthcare for people with disabilities in LMICs and showed that utilization of healthcare service was higher for people with disabilities than those without for 17 out of the 20 included studies.²⁶ Additionally, by definition for there to be disability there must be an underlying impairment, and so people with disabilities will also have a greater need for rehabilitation and specialist services.²⁷ These services include medication, surgery, assistive devices, and therapeutic rehabilitation (e.g. physical therapy).

1.4. BARRIERS TO HEALTHCARE OF PEOPLE LIVING WITH DISABILITIES

People with disabilities face a range of barriers that reduce their capability of accessing quality healthcare.²⁶ People with disabilities are, of course, a diverse group and the barriers faced will vary by impairment type, gender, age, geographic location and so on. However, universally, a few key barriers

are common. Accessibility barriers, whether physical or financial are widespread. Not only are people with disabilities on average poorer, but they also experience greater healthcare costs both because they are heavier users of healthcare, on average, but also because they incur higher costs when seeking healthcare (e.g. the need for accessible transport, paying for an accompanying adult, or being targeted for bribes).^{26 28}

The World Report on Disability reported that half of people with disabilities could not afford health care and that they were also 50% more likely to experience catastrophic healthcare expenditure.²¹ Physical access barriers to healthcare facilities, equipment and transport are also common. Likewise, communication difficulties, particularly for people with hearing or cognitive impairments. Availability of services is also a widespread issue for everyone, particularly in LMICs. However, this issue may be a particular concern for people with disabilities, who may have more complex health needs, and so may not be adequately served by community health workers, but will require attention from doctors, who are often less available.

People with disabilities may experience greater difficulties receiving good quality services. Negative attitudes can be common, including from the perspective of the healthcare providers. There is often a lack of knowledge among staff about the specific health concerns of people with disabilities. Equipment may also be inadequate to undertake diagnosis or treatment for people with disabilities to a sufficient quality (e.g. MRI scanners suitable for people with certain mobility impairments may be unavailable). Barriers will also vary by context. For instance, people with disabilities may face particular difficulties acquiring health services in humanitarian settings.²⁹

1.5. EFFECTIVE HEALTHCARE OF PEOPLE LIVING WITH DISABILITIES

Healthcare coverage and quality is therefore likely to be worse for people with disabilities, as a result of these barriers. The World Report on Disability showed that people with disabilities were twice as likely to say that they found healthcare providers skills and facilities inadequate, three times as likely to be denied healthcare and four times as likely to report being treated badly in the healthcare system.²¹ Furthermore, both men and women with disabilities were significantly more likely to report needing healthcare services but not receiving them, compared to people without disabilities (women: 5.8% versus 3.7%; men: 5.8% versus 4.1%). The two recent systematic reviews also showed that people with disabilities experience greater barriers and costs when seeking healthcare, reported problems with quality of services, and had issues with access, in particular to rehabilitation/specialist services.²⁶⁷ People with disabilities therefore fall behind in terms of access to general healthcare, access to specialist services that they need on account of their impairment, and receiving care that is of sufficient quality and does not result in financial hardship. These elements are the fundamental components of UHC, as well as international legal frameworks, such as the UN conventions.

It is clear that, on average, people with disabilities have higher healthcare needs, but fall behind in critical aspects of UHC: receiving the services that they need, of sufficient quality and without incurring financial hardship. Yet it is also clear that guidance on how to tackle this issue is lacking from a UHC perspective. The question therefore remains as to what are potential solutions to improve access to healthcare services for people with disabilities?

Development of interventions to improve access to healthcare services for people with disabilities must reflect the complexity of the barriers faced. First, we should consider both the barriers faced by the person with disabilities (demand perspective), as well as the care provider – the healthcare service (supplier perspective).³⁰ Furthermore, it is clear that the barriers to accessing services can occur at different stages in the healthcare seeking journey – from when identifying there is a health condition,

making the decision to seek care, travelling to care, experiencing the healthcare interaction, or receiving follow-up care. Additionally, barriers should be considered across the spectrum of healthcare services needed (promotive, preventive, curative, rehabilitative, palliative). People with disabilities are a heterogeneous group, and so interventions will need to vary for people with different impairment types and living in different geographic regions.

Keeping these caveats in mind, methods to improve inclusion of people with disabilities in scale up of UHC may include the following:

1. Provision of accessible healthcare infrastructure and transport
2. Training of healthcare staff on disability awareness and knowledge
3. Scaling up the availability of rehabilitation, assistive devices and specialist services that may be needed by people with disabilities
4. Providing outreach services to people with disabilities in the community including accessible public health messaging
5. Improving plans, legislation and policies, and implementing incentives and penalties to ensure that they are met
6. Collecting data on access to healthcare for people with disabilities, and monitoring disability inclusion and accessibility of services
7. Improving management and budgeting of disability inclusive healthcare services
8. Overcoming financial barriers to the uptake of healthcare services

Currently, the evidence base on what works to improve access to healthcare without hardship for people with disabilities in LMICs is very poor.^{7,26} Another complexity is that implementation of these solutions will often go beyond the remit of the Ministry of Health, for instance the Department of Transport is needed to ensure that transport is accessible while the Ministry of Social Welfare may give oversight on personal assistants and, lastly, income replacement may be needed to cover the loss of income due to the time and cost of seeking care. A critical element is to what extent the provision of assistive devices is the task of the healthcare system, and how other agencies, and the private sector, can share responsibility. Social health protection schemes are an example of interventions that require non-healthcare actors in order to be implemented effectively. In the remaining sections, we will focus on the implementation of social health protection schemes to overcome financial barriers to accessing services. This emphasis is important as financial barriers are widespread,²¹ and the provision of social health protection is an ever greater focus of the development community.



2. SOCIAL HEALTH PROTECTION TO IMPROVE ACCESS TO HEALTHCARE FOR PEOPLE WITH DISABILITIES

Social protection is a set of policies and programmes designed to reduce poverty and vulnerability throughout the life cycle.³¹ Social protection, specifically social health protection, may help people with disabilities cover a range of costs they face while accessing needed healthcare such as:

DIRECT MEDICAL COSTS

such as for general healthcare services, rehabilitation and specialist health services, assistive devices and community/home-based long-term care;

DIRECT NON-MEDICAL COSTS

such as transportation, housing and personal assistance required when accessing healthcare;

INDIRECT COSTS

such as loss of income or time people with disabilities face while seeking care, or for other family members who provide personal assistance or caregiving support.

Most social health protection schemes focus on direct medical costs. Financial coverage of direct medical costs may include the following types of schemes: ^{32,33}

TAX-FINANCED SCHEMES	<p>Schemes are non-contributory and financing is derived from government budgets (mainly taxes).</p> <p>Such scheme encompass: i) national health service systems where affordable or free healthcare is provided in all public providers; ii) fee exemptions programmes for specific vulnerable groups (children under 5, pregnant women, the poor, etc.); and iii) other types of social assistance (health voucher schemes, etc.).</p>
SOCIAL HEALTH INSURANCE SCHEMES	<p>Schemes are mandatory and fully or partially contributory: for example, workers and/or employers pay progressive contributions through payroll taxes. In some cases, governments will match the contributions and / or cover or subsidise contributions for certain groups (e.g. people living in poverty, people with disabilities).</p>

In addition, some countries use voluntary health insurance schemes, which may include government or commercial schemes in which individuals opt in and pay regular contributions or premiums. Governments may directly or indirectly subsidise some voluntary schemes (e.g. tax credits). Voluntary schemes alone are unlikely to achieve UHC due to limited risk pooling and adverse selection.

In practice, most countries that have achieved universal coverage use a mix of taxes and social contributions to finance their social health protection systems (ILO, 2020b). Social protection is therefore a potential mechanism by which financial protection against healthcare costs can be achieved. For instance, social protection could help with the improvement of coverage of essential health services (SDG UHC indicator 3.8.1) through covering direct medical costs (e.g. drugs), direct non-medical costs (e.g. transportation), while also reducing the risk of large expenditures on health (SDG UHC indicator 3.8.2).

It is important to note that the above schemes may not cover all needed direct medical costs, as schemes will typically have a defined package of services covered and may include some level of co-payments or small user fees to encourage responsible use of services. Further, indirect and direct non-medical costs are rarely covered in the above programmes. However, they may be partially or indirectly covered through other social protection schemes. For example, cash transfers can improve an individual's capacity to pay for other costs associated with seeking medical care, while some in-kind transfers (e.g. transportation discounts) may offset indirect costs of seeking care.

Some examples of social health protection are given in Box 2.



BOX 2: SOCIAL HEALTH PROTECTION TO ENHANCE UHC FOR PEOPLE WITH DISABILITIES

FREE OR SUBSIDISED SOCIAL HEALTH INSURANCE

Some countries provide subsidised social health insurance to people who are registered as having a disability.

For example, in Vietnam, people with disabilities receive a full waiver on the contribution for the social health insurance programme Compulsory Health Insurance (usually individual contribution is 1.5% of salary).³⁴ People with disabilities also receive subsidies on co-payments, reducing out-of-pocket payments on eligible medical expenses to 5% from 20%. These benefits are available to people with disabilities who are assessed by commune-level Disability Degree Designation Council as having a 'severe' or 'extremely severe' disability. Further, in some districts of Vietnam, children with disabilities (<18 years) with a 'mild' classification can receive this benefit. Subsidised Compulsory Health Insurance is bundled with other disability-targeted social protection benefits given to people who are registered as having a disability, including a non-contributory, non-means

tested cash transfer (Disability Allowance) and other in-kind benefits (e.g. discounts for transportation, educational scholarships).

Similarly, the National Health Insurance Scheme in Ghana waives some individual contributions for people with disabilities who register with the Social Welfare Department.³⁵ People with disabilities can also gain waivers if they are recipients of the Livelihood Empowerment Against Poverty (LEAP) cash transfer.³⁶ This cash transfer is targeted to households living in poverty who have at least one household member belonging to a designated vulnerable group (e.g. older adult, person with a disability who is unable to work). People need to reapply annually for the extension of contribution waivers.

Other countries that waive or subsidise social health insurance fees for people with disabilities include Algeria, Nigeria, Moldova, Kyrgyzstan, China, Serbia, Bosnia & Herzegovina, Macedonia, Albania, Romania and Bulgaria.^{35,37,38} These countries are all classified as middle income countries and all require people with disabilities to undergo a registration process to determine if they have a disability according to programme criteria to receive the waiver or subsidy.

FREE OR SUBSIDISED ASSISTIVE DEVICES AND OTHER DISABILITY-SPECIFIC HEALTHCARE

Some countries have implemented programmes for providing people with disabilities with assistive devices. For example, people with disabilities in Kenya can apply for assistive devices through the National Development Fund for Persons with Disabilities run by the National Council of Persons with Disabilities.³⁹ Requests are granted on an ad hoc basis, although the Fund states that it is unlikely to cover certain expensive assistive devices (e.g. computer software). People must also be registered with the National Council as a person with disability to apply for this fund. However, it is estimated that only about 7% of people with disabilities nationally are registered with the National Council and issues around long wait times, complicated applications and low awareness have been reported as barriers to accessing assistive devices through the Fund.

Similarly, people with disabilities in the Maldives can receive assistive devices, medication and other health services not covered under the national social health insurance (Aasandha) through Medical Welfare. Medical Welfare is a government programme that is open to all citizens and provides subsidies or waivers for the cost of health services not covered in Aasandha on an ad hoc basis. People with disabilities are supposed to be assessed and referred for assistive devices and other medical needs when they enrol in the Disability Allowance (unconditional cash transfer). Referred devices and services may either be provided directly by the National Social Protection Agency, if available, or people may be referred to apply for Medical Welfare. For Medical Welfare, applicants must submit a letter, medical documentation verifying the need for the assistive device or medication and three price quotations from different vendors. Assistive devices provided through Medical Welfare can be replaced, but only on a fixed schedule rather than on request (for example, every three years for hearing aids or annually for wheelchairs).

Other countries with social protection programmes to provide free or subsidised assistive devices include Lebanon, Palestine, Yemen and Lesotho, although the scope and coverage of these programmes is not clear.

OTHER HEALTH BENEFITS

People with disabilities may be provided with other health discounts. For example, people with disabilities in Cape Verde enrolled in the means-tested cash transfer programme Pensão Social (Social Pension) also have access to the Mutual Health Fund, which subsidises medicine purchases up to CVE 2,500 (US\$25) per year. Similarly, people with disabilities in Nepal who have a disability identification card can access certain additional health benefits, such as waivers for an expanded list of 70 drugs not covered in the public sector (primarily general medicines, psychiatric medicines not covered) and certain services at tertiary health facilities (e.g. waivers of registration fees, X-rays).⁴⁰

SOCIAL PROTECTION FOR DIRECT NON-MEDICAL COSTS AND INDIRECT COSTS

Some social protection schemes may cover direct non-medical costs or indirect costs. For example, in Nepal and Vietnam, people registered as having a disability are eligible for discounts on public transportation, which may offset costs associated with traveling for healthcare – if public transportation is available and accessible.^{40,41} In South Africa, Dial-a-Ride offers subsidised, accessible transportation for people with disabilities. However, this service only runs in certain areas, on certain routes and is highly oversubscribed.^{42,43}

Some countries also have cash transfers for caregivers of children and for adults with disabilities often to offset the loss of income arising from caregiving support provided by family members. For example, South Africa provides a Care Dependency Grant to caregivers of children with severe disabilities who are also living in poverty, while Vietnam provides a cash transfer to caregivers of adults and children with severe disabilities.^{41,44} Finally, sickness benefits may cover loss of income due to long-term poor health, while cash transfers (disability-targeted or non-disability targeted) may improve ability to pay for the range of costs associated with accessing healthcare.

Little evidence is available on the effectiveness of social health protection schemes for people with disabilities, or social protection more broadly on improving health outcomes and health financing amongst people with disabilities.^{45,46} Some studies have found a positive link between having social health protection and utilisation of health services. For instance, insured people with disabilities were more likely to access outpatient care in Vietnam,⁴⁷ Pap tests/mammography in Chile,⁴⁸ and mental health services in China,⁴⁹ compared to people with disabilities without insurance. Less is known on the impact of social health protection on financial protection.⁵⁰ However, there are concerns that financial protection may be inadequate. For example, 30% of people with disabilities in Vietnam covered through social health insurance still faced catastrophic health expenditure spending (at least 20% of their non-food expenditures spent on healthcare), which was significantly more frequent compared to other insured groups.⁵¹

An additional concern is that coverage of people with disabilities in available schemes appears to be low.^{50,52} Table 1 presents enrolment estimates of people with disabilities in different social health protection schemes from LMICs, using data from representative surveys. While there are variations between countries, these estimates indicate that many people with disabilities are currently not being

SOCIAL HEALTH PROTECTION TO IMPROVE ACCESS TO HEALTHCARE FOR PEOPLE WITH DISABILITIES

covered through available schemes and despite higher health needs, enrolment levels did not significantly differ compared to people without disabilities.^{47,53-56} Although universal coverage is needed to ensure that all people are financially protected when seeking health care, and is important for risk pooling and sustainable programme financing, people with disabilities are likely to face a higher burden from the lack of coverage due to higher health needs.

Table 1. Estimates of social health protection coverage amongst people with disabilities from population-based surveys in LMICs

COUNTRY (year of data collection)	TYPE OF SCHEMES	POPULATION	ENROLMENT (disability)	ENROLMENT (no disability)
Mexico, nationally representative (2012) ⁵⁷	SHI, tax-financed	18,847 older adults (age 60+)	66.5%	82.2% (total population)
Vietnam, Cam Le district (2016) ³⁴	SHI, voluntary public, commercial	6,379 people (age 2+)	96.0%	88.3%
Vietnam, nationally representative, (2001-2002) ⁴⁷	SHI, voluntary public	158,000 people (age 5+)	19.4%	18.8%
China, nationally representative (2006) ⁵⁸	SHI	114,485 people with disabilities (age 18+)	28.0%	n/a
Peru, nationally representative (2012-2013) ⁵⁹	SHI, tax-financed, commercial	37,117 people with disabilities (all ages)	61.6%	n/a
Peru, nationally representative (2012) ⁵⁵	SHI, tax-financed, commercial	3,869 people (65-80 years)	65.1%	63.3%
Tanzania, 3 districts, (2014) ⁵³	Voluntary public (Community Health Fund)	4,475 people (age 5+)	12.0%	9.0%
Rwanda, nationally representative (2005-2006) ⁵⁴	Voluntary public ⁱⁱ	34,785 people (all ages)	47.8%	39.4% (total population)
India, Tamil Nadu (2013-2014) ⁵⁶	SHI, tax-financed, private	39,245 people, no disability and people with cognitive/intellectual impairments (all ages)	25.7%	23.2%
South Africa, nationally representative (2008) ⁶⁰	Unclear	14,455 people (age 18+)	10%	18%

SHI=social health insurance

Several factors can affect the effective inclusion of people with disabilities in social health protection schemes in LMICs. These factors are discussed below.

ⁱⁱ Data from before enrolment in Rwanda's Mutual Health Insurance (*Mutuelles de Santé*) became compulsory.

2.1. PROGRAMME DESIGN

Scope of coverage: financing design and eligibility

People with disabilities may face difficulties enrolling in social health protection, including programmes targeted to people with disabilities, due to programme eligibility criteria.

Historically, social health protection schemes have been tied to formal sector employment in many countries.⁶¹ Some governments – such as in Kenya, Burundi, Vietnam and several Latin American countries – initiated contributory social insurance models by first covering civil servants and workers in the formal sector.⁶¹ For instance, it is mandatory for formal sector workers to enrol in the National Hospital Insurance Fund in Kenya, but voluntary for other groups.⁶² In Moldova, it is mandatory for all residents to enrol in social health insurance, however in practice, enforcement is limited to the formal sector.⁶³ Some countries have made proactive efforts, like Vietnam, and now cover the entire population with their national health insurance system. People with disabilities, however, are less likely to be employed and more likely to work in the informal sector compared to people without disabilities,^{64,65} and so may be excluded from these types of schemes when they focus only on the formally employed. Although some countries have voluntary enrolment for people who are not working or working in the informal sector, voluntary enrolment has proven ineffective to reach broad coverage for any type of scheme (contributory or not).

In some countries, people are eligible for free or subsidised social health insurance if they meet certain eligibility criteria, such as being an older adult, unemployed, living in poverty or being classified as a person with disabilities. As an example, contributions for National Health Insurance Scheme in Ghana are waived for people with disabilities, older adults (age 70+), pregnant woman, child (<18 years) and recipients of the Livelihood Empowerment Against Poverty cash transfer (eligibility based on poverty and vulnerability).^{66,67} Still, people often need to apply for these subsidies and some criteria can be complex to assess. In particular, eligibility criteria defining disability or poverty may be restrictive or poorly defined.^{35,41} For example, poverty assessments rarely take into account the additional costs that people with disabilities require in order to participate (e.g. for personal assistance, additional transport, assistive devices).^{68,69} Similarly, definitions of disability used in eligibility criteria and means of assessment may exclude many people with disabilities, particularly if they focus on capacity to work or are skewed towards more visible impairments.^{52,70,71}

Finally, commercial health insurance schemes exist in many countries. However, they are likely to cover only a minority and exclude many people with disabilities, due to discriminatory eligibility criteria. For example, some plans exclude applicants or charge higher premiums for coverage of “pre-existing conditions” such as disability.⁷² In Moldova, private health insurance plans offered by employers exclude coverage for people with disabilities.⁷³

Adequacy of health care benefits

Benefit package

A key challenge for people with disabilities is the scope of the benefit package provided through health insurance, as many plans do not cover or charge high co-payments for disability-related health services, such as long-term care, rehabilitation and assistive devices. For example, the National Health Insurance Scheme in Ghana and the Voluntary and Compulsory Health Insurance Schemes in Vietnam only cover a limited range rehabilitation services and mental health services, and provide no coverage for assistive devices.^{34,74} Similarly, people with disabilities in Iran reported that their health insurance did not cover many disability-specific health services and assistive devices, or that they had to pay

prohibitively large co-payments for them.⁷⁵ Consequently, people with disabilities with social health protection may still face impoverishing healthcare spending or forgo essential healthcare.

The scope of the benefit package can significantly impact access to needed services. In Peru, people with disabilities on the more limited coverage tax-financed programme for the vulnerable (Seguro Integral de Salud) were much less likely to access rehabilitation (9.1%) compared to people with disabilities enrolled in the more extensive coverage commercial health insurance (26.9%) or Social Security (social health insurance for people in salaried positions) (20.6%).^{59,76} Similarly, in China, the likelihood of accessing inpatient mental health services amongst people with mental health conditions was linked to the type plan: people with plans that offered higher reimbursement rates were more likely to utilise needed mental health services.⁴⁹

Level of financial protection

Voluntary health insurance (public or private) and social health insurance typically require payments from participants, such as annual/monthly contributions (enrolment fees, paid regardless of service use) and co-payments (fees incurred at the point of use when accessing health services, may be flat rates or a proportional to the cost of service). Tax-financed programmes do not have contributions, but may have co-payments. In addition to official payments, people may also have to pay unofficial fees when accessing care (e.g. bribes, gifts, informal payments to access services the individual is already entitled to).⁷⁷

The magnitude of these costs varies by programme and country. For example, in Vietnam, government health insurance programmes require individual contributions between 1.5-4.5% of an individual's salary: the Compulsory Health Insurance scheme for formal sector employees has contributions set to 1.5% of the individual's monthly salary (with a further 4.5% contribution by the employer), while Voluntary Health Insurance has individual contributions of 4.5% of monthly salary with no employer contribution.³⁴ Although contributions are progressive - as they are set as a proportion of income - the contribution rate is higher for Voluntary Health Insurance. For many informal sector workers, who work low-paying or unstable jobs, even a 4.5% monthly contribution may be prohibitive. Additionally, co-payments are set at the same level for all participants of both plans (20% of eligible medical expenses) and so the cost will be more burdensome to people living in poverty. People with disabilities are more likely to be living in poverty and informal or no employment,^{78,79} and often require more health services, and so meeting contributions and co-payments may be particularly challenging.

Some countries – such as Vietnam, Ghana, Kenya– offer subsidies on contributions or co-payments for people living in poverty or meeting other eligibility criteria (e.g. young children, older adults, people with disabilities). These subsidies may improve access to and affordability of available schemes for people with disabilities, if participants can successfully register for them. For instance, in Vietnam, a study using data from 2001-2002, found that 66-80% of people with disabilities living in poverty were not covered by social health insurance⁴⁷ while the 2016 National Disability Survey 98% of poor disabled people were insured compared to 97% of the non-disabled population.

Finally, even when direct medical costs are well covered through social health protection, direct non-medical costs and indirect costs associated with accessing health services can limit the financial protection offered by schemes and in some instances, prevent people with disabilities from accessing needed healthcare.⁸⁰⁻⁸⁵ For instance, women with disabilities in Kenya who were enrolled in the Health Insurance Subsidy Programmeⁱⁱⁱ reported forgoing needed healthcare because they could not afford

ⁱⁱⁱ The Health Insurance Subsidy for the Poor waives contributions for the National Hospital Insurance Fund, a contributory social health insurance programme that is the dominant form of health insurance in Kenya, for households deemed to be living in poverty

the costs of transportation, take time off from work and other responsibilities, or find someone to assist them in getting to services.⁸⁰ These indirect costs have also been cited as barriers for people without disabilities,^{86,87} however, the magnitude is likely greater for people with disabilities. For instance, travel to health facilities can be costly for many people, particularly people who live in areas that are far from needed health services or lack transportation links. Still, people with disabilities may face higher travel costs, as they may not be able to use available public transportation if it is not accessible, take longer to reach facilities or have to pay for the additional transport of a family member or caregiver to accompany them. Additionally, disability-related health services are often in short supply and therefore tend to be urban-based, resulting in greater costs to reach them.⁸⁸

In summary, many social health protection programmes may not offer adequate financial protection to people with disabilities due to the lack of coverage of many needed health services (rehabilitation, specialist services) and direct non-medical and indirect costs, as well as difficulties managing contributions, co-payments and non-official payments.

2.2. GOVERNANCE AND ADMINISTRATION

Governance and participation

People with disabilities must be actively engaged in the development, implementation and monitoring of social health protection systems.⁸⁹ States are obliged under the United Nations Convention on the Rights of Persons with disabilities (UNCRPD) to promote the effective participation of people with disabilities in legislation, policies and decision-making processes that concern them.^{89,90} However, there is frequently little, if any, consultation of people with disabilities in decision-making, including for social health protection.⁸⁹ Effective consultations with people disabilities could improve design and delivery of social health protection systems so that they are more responsive to the needs and concerns of people with disabilities.

Awareness and outreach

People with disabilities may not enrol in social health protection, subsidy/waiver programmes or just claim their entitlement to free care in public facilities when this is provided for by the legal framework due to low levels of awareness on entitlements, available schemes and how to avail themselves of those. For example, qualitative research with people with disabilities in Nigeria highlighted that many people were not aware that they were eligible for a waiver of the National Health Insurance Scheme if they received a letter from the Social Welfare Department certifying they had a disability.³⁵ Similarly, in Nepal, many people with disabilities who were receiving the Disability Allowance were not aware of all the benefits they were entitled to, such as transportation and healthcare discounts.⁴⁰

Accessibility of administrative procedure

The application processes for some schemes can be complex and not accommodating to people with disabilities (e.g. lack of guidelines provide in alternative communication formats, physically inaccessible application offices). Multiple barriers have been reported in registering for even disability-targeted programmes.^{41,52,71} For example, disability-targeted programmes require documentation that the applicant meets the programme's definition of disability. Applicants with disabilities are often required to provide medical documentation of an impairment or undergo assessments of disability by programme staff, which can be time-consuming and costly and may exclude people with certain types of disabilities (e.g. less visible impairments).^{37,38,69}

Further, the coordination of social health protection within the wider social protection system can be fragmented, so that people with disabilities must submit multiple applications to receive different

benefits. For example, people with disabilities in the Maldives who enrol in the Disability Allowance (monthly cash transfer) are supposed to be referred to Medical Welfare for provision of assistive devices and specialist healthcare. However, referrals between programmes is weak and participants must submit a separate application. Similarly, in Kenya, applications for the disability-targeted cash transfer, assistive devices and other disability-targeted benefits are all separate.³⁹ In contrast, almost all recipients of the Disability Allowance in Cam Le, Vietnam reported receiving subsidised social health insurance, as they were automatically enrolled upon acceptance into the Disability Allowance.³⁴ Coordination between social health and other social protection programmes is needed to ensure people with disabilities receive the full package of benefits they are entitled to and do not face a burdensome process navigating different application procedures.

Effective coordination with broader health and social protection systems

Broader health system planning and delivery

People with disabilities may not access health services that are covered through social health protection due to broader health system delivery problems. For example, drug stockouts, long wait times or limited availability of covered service providers can prevent insured individuals from accessing healthcare they are entitled to or lead individuals to pay out-of-pocket in the private sector.^{42,75,85} Further, health facilities are often not accessible to people with disabilities (e.g. inaccessible built environment and medical equipment, lack of adapted communication), which decreases access to and quality of services for people with disabilities regardless of insurance status.⁹¹

Finally, there is poor availability, quality and coordination of healthcare and ancillary services that people with disabilities are more likely to require, including rehabilitation, assistive technology, specialist health services (e.g. ophthalmologists, ear, nose & throat (ENT) specialists, speech & language therapists) and social services (e.g. long-term care).^{31,92} Governments must invest in these programmes to ensure the needs of people of people with disabilities are adequately met.

Coordination with the social protection system

In practice, direct medical costs, direct non-medical costs (i.e. transport for example) and indirect costs (i.e. loss of income due to prolonged care or time spent seeking care) are unlikely to be covered by a single scheme or programme. Lack of coordination among the different schemes can have important consequences for people living with disability and often create a barrier of access to adequate and comprehensive protection.



CONCLUSION

People with disabilities face a dual challenge in that on average they have a greater need for general and specialist healthcare services, yet face more difficulties in accessing these services. As a consequence, people with disabilities are currently falling behind in efforts towards the achievement of UHC, as they have lower healthcare coverage, poor access to specialist services, can incur financial hardship through accessing services and experience worse quality services. This issue is almost entirely ignored within existing UHC guidance. Social health protection, and social protection more broadly, are being promoted as means towards the achievement of UHC, and could potentially help to overcome the financial barriers people with disabilities face in accessing services.

Currently, coverage of social health protection for people with disabilities is inadequate and the packages are often not well-tailored to their specific needs. Furthermore, although social health protection may help to overcome financial barriers, they do not address other challenges in accessing healthcare, such as negative attitudes, inaccessible transport and facilities, and poor skills of healthcare professionals. Social health protection is therefore potentially an important piece of the puzzle of achieving UHC inclusive of people with disabilities, but is not a magic bullet, and needs to be tailored to better meet the needs of people with disabilities.

RECOMMENDATIONS

Propose recommendations are as follows:

DEVELOPMENT OF INDICATORS:

A fundamental concern in discussing healthcare coverage of people with disabilities is that we do not have clear and consistent metrics for how this concept can be measured. A lack of measurement tools is not merely an academic issue; different ways of measuring access will give us different answers as to whether or not people with disabilities are excluded from healthcare, and consequently what our policy and programme response should be. We also cannot monitor change over time without having effective indicators. Disaggregating health data by disability (e.g. if measured through the Washington Group) is helpful, to assess whether there are clear differences for people with disabilities.

However, as discussed above, people with disabilities may face specific or additional issues, such as the need for assistive technology and rehabilitation, and concerns with the quality of care received. It is therefore important to develop and agree on tools for measuring UHC for people with disabilities, as well as approaches for disaggregating existing data by disability. The indicators could be developed along the human rights approach, considering accessibility, availability, adaptability and quality, but also making specific reference to both primary and specialist care services and financial protection. They should be incorporated in both administrative and statistical data systems – for planning, implementation.

DEVELOPMENT OF GUIDANCE ON THE INCLUSION OF PEOPLE WITH DISABILITIES IN SOCIAL HEALTH PROTECTION SCHEMES

Evidence is lacking on the adequacy and inclusiveness of existing social health protection schemes . Operational research is needed to agree and collate good practice examples of disability-inclusive social health protection, and this information should be consolidated in explicit guidelines.

Current social health programme programmes need to be adapted to better meet the needs of people with disabilities, both in terms of encouraging enrolment and ensuring impact of the programme. *At a minimum, in line with international standards, these schemes should not discriminate against or exclude people with disabilities, must cover the costs of assistive technology and rehabilitation services needed, have accessible application schemes with reasonable adjustments made for people with disabilities, and be affordable.*

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