



# TOWARDS INCLUSIVE SOCIAL PROTECTION SYSTEMS ENABLING PARTICIPATION AND INCLUSION OF PERSONS WITH DISABILITIES

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This is an unedited first version for public consultation which will be finalised in Fall 2023 and will be updated regularly to build on new evidence and lesson learned from ongoing and upcoming programs and reforms.

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## EXECUTIVE SUMMARY

### Introduction

Despite the adoption of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and the Agenda 2030's pledge to leave no one behind, there is a persistent gap in disability inclusion, especially in low and middle-income countries. Data reveals that persons with disabilities face multiple inequalities in education, health, and poverty levels, with children, older people, rural communities, migrants and women being most affected. Humanitarian crises, climate related disasters and conflicts aggravate these disparities, and people with disabilities are disproportionately affected.

The impact also extends to households, affecting family members providing care and support, often women and girls. It can lead to dropout from education or employment, creating a vicious cycle of economic insecurity.

Inclusive social protection systems can play a crucial role in addressing these gaps and enabling the full participation of persons with disabilities across the life cycle. However, globally only a third of people with significant disabilities receive specific support from social protection systems, and still this support is often inadequate. The current guidance aims to address these issues and establish a framework for developing more inclusive social protection systems. It emphasizes the diversity of disability experiences, the importance of dignity, choice, autonomy, universal support, and the crucial role of consultation with people with disabilities. The guidance is a first step, with updates anticipated as further evidence and practices become available.

### What do we mean by inclusive social protection systems?

Historically, social protection policies have viewed disability primarily through the lens of inability to work and care for oneself, leading to policies centred on basic income replacement, rehabilitation and institutional care. Reflecting a paradigm shift encouraged by the UN Convention on the Rights of Persons with Disabilities (CRPD), inclusive social protection focuses on enabling socio economic participation, autonomy and community living of persons with disabilities across the life cycle. This holistic approach goes beyond basic income security as well as interventions aimed at addressing the diversity of disability related costs.

*Disability-related costs encompass direct costs such as additional spending on regular items like healthcare and transportation, and disability-specific spending on assistive devices or human assistance. Indirect costs include lower income due to discrimination and opportunity costs for family members who provide unpaid support.*

*Factors influencing disability-related costs include the individual's characteristics such as gender, ethnicity, age, the nature and extent of impairment and functional limitations, as well as environmental factors, such as physical and attitudinal barriers, location (urban or rural), and the level of participation desired by the person. These factors should be thoroughly considered, including through adequate individual disability and needs assessment to provide tailored support to persons with disabilities throughout their life course.*

**A life cycle and gender responsive** framework is useful for exploring the specific considerations required by inclusive social protection to provide adequate support to persons with disabilities in a diverse range of circumstances.

- **Children with disabilities** face high levels of social exclusion due to stigma, lack of access to education, separation from family, gaps in healthcare, and difficulties transitioning to independent life. Child poverty and disability are closely linked, with disability-related costs pushing families into deeper poverty. Social protection can mitigate these issues by directly addressing extra costs and compensating for the opportunity costs of those who provide care. It can also facilitate access to services like education. Conditionalities may create barriers to social protection, such as

enrolment in inaccessible schools or support in inaccessible locations. Moving away from institutionalization and providing adequate community support services is essential for inclusive social protection.

- **Working-age persons with disabilities** face significant barriers to independent living and economic empowerment, with lower levels of employment, predominantly in the informal economy, and higher likelihood of poverty. Inclusive social protection must acknowledge the income earning potential of persons with disabilities but also the barriers they face and provide adequate, flexible support to cover disability-related extra costs, including those related to employment, and link to labour market policies promoting economic empowerment. It should avoid 'all-or-nothing' schemes and support risk-taking while ensuring the re-uptake of support in case of loss of work. It should also enable development of community care and support services fostering greater autonomy and enabling community living and the diversity of social roles of adults with disabilities such as parenthood.
- **in older age** the increased prevalence of disability significantly impacts income security and personal autonomy. Approximately 38-46% of older persons globally live with moderate to severe disability, compared to 15-16% of the general population. Without effective pension systems and in-home based services, older persons often rely on families for support, potentially leading to household poverty, gender inequalities and limiting their autonomy and social participation. Pensions, while providing income security, often do not cover substantial disability-related costs, including care and support needs. As the global population ages, investments in collaborative care models that integrate healthcare and social services are essential.
- **Women and girls with disabilities** face compounded discrimination due to their gender and disability, resulting in higher rates of exclusion, violence, and poverty. They are less likely to be employed, more likely to be out of school, have unmet health needs, and are often institutionalised. Women with disabilities are three times more likely to be unable to read, have unmet healthcare needs, and twice as less likely to be employed. Moreover, **women and girls often shoulder the primary responsibility of care and support** for persons with disabilities, reducing their educational and economic opportunities. Applying a gender lens to social protection systems is essential, involving women with and without disabilities in decision-making, addressing their specific needs in scheme designs, and reducing the disproportionate burden of unpaid care on them.

**Disability-inclusive social protection systems** have several key features:

1. These systems ensure accessibility and non-discrimination, allowing persons with disabilities to equally access and benefit from social protection programmes and social services by removing physical, communicational, informational, institutional, and attitudinal barriers.
2. They respect dignity, personal autonomy, and privacy, and provide support without contributing to the stigmatisation, marginalisation, or exclusion of persons with disabilities.
3. They foster consultation with representative organisations of persons with disabilities (OPDs) on the design, implementation, and monitoring of social protection, to provide a lived experience perspective, promote ownership, and sustain demand for necessary reforms.
4. they provide both basic income security and covering health and disability-related costs through a flexible combination of inclusive mainstream, and disability specific cash transfer, concessions and services to support socio-economic participation and inclusion,

**Building universal and inclusive social protection systems for participation of persons with disabilities** requires making the most all instruments available. Cash benefits can replace or supplement income and help offset disability-related costs. Concessions and community services, like support services and subsidies, can reduce out-of-pocket expenses. Social health protection mitigates financial barriers and risk of poverty due to health expenses. Disability and needs assessment and case management mechanisms, and linkages to education and economic empowerment programs are critical for targeted support and inclusion. The mix of these components will vary per country, based

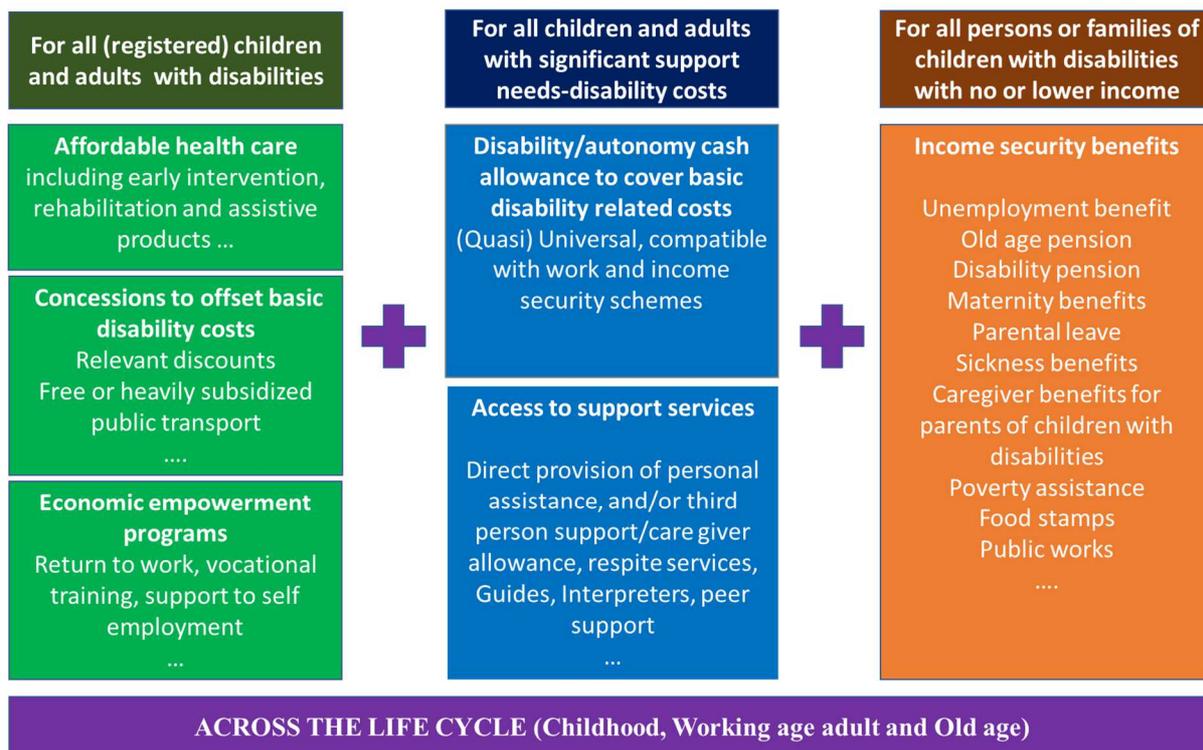
on the maturity of the social protection system, availability of goods and services, fiscal space, and institutional capacity.

The table below sets out examples of different social protection schemes in terms of the category of social protection instruments that can be combined, the functions they mostly support, and how they relate to the lifecycle.

CATEGORIES OF INSTRUMENTS	EXAMPLES OF TYPES SCHEMES ACROSS THE LIFE CYCLE			MAIN FUNCTION
	CHILDHOOD	WORKING AGE	OLD AGE	
CASH BENEFITS <sup>1</sup>	Poverty assistance cash transfer, cash for work			INCOME SECURITY
	Child grant/family benefits/	Unemployment, maternity, sickness, parental leave benefits,	Old age pensions	
	Care giver benefits	Disability related income replacement benefits		
	Child disability benefits	Disability costs basic allowance/top up schemes		COVERAGE OF HEALTH CARE AND DISABILITY-RELATED COSTS
	Third person support / caregiver benefits			
IN KIND BENEFITS	<b>Concessions</b> Health insurance/cost coverage including early intervention, rehabilitation, assistive technology, free or discounted public transport, subsidised utilities, tax exemptions, food distribution...			COVERAGE OF HEALTH CARE AND DISABILITY-RELATED COSTS
	<b>Services</b> Health care, Case management Community care and support, social housing, personal assistance, interpreters, counselling, point to point transport, respite care			
INTERLINKAGE	Early childhood development, child care, education	Economic inclusion/ empowerment programmes, decent work programmes, return to work programmes, women's empowerment, protection services, financial inclusion services		CONNECTION TO OTHER SERVICES

Universal and inclusive support doesn't mean every person with disabilities receives all disability related benefits. All individuals with disabilities should have access to affordable healthcare, housing, assistive technology, rehabilitation, meaningful concessions to offset disability-related costs, adequate education, economic inclusion, and necessary human assistance. However, in line with progressive realisation, those most in need should receive further support first. A CRPD-compliant approach requires factoring the extent and type of support needed for independent living and community inclusion. While means testing is often a first option for targeting benefits, its use for disability related support should be carefully considered due to compounded risk of exclusion errors and limited consideration for disability-related costs. A prioritisation based on age and level of support needs and disability related costs might be more effective and equitable.

The Figure below proposes an initial distribution of social protection benefits and services according to the level of need of different groups of persons with disabilities. To enable such a distribution, it is critical that disability assessment and determination mechanisms meaningfully take support needs into consideration.



To make the most of all social protection instruments – and identify different starting points and pathways to extending social protection, research is required to identify the diversity of disability-related costs across different socio-demographic groups, genders, and settings to inform the scope of support required and what can be covered by cash transfer and what require subsidies or direct support services.

### Contributory and tax-financed cash transfers

Extending cash transfers in low- and middle-income countries to support persons with disabilities requires a flexible approach, recognising their diverse needs. Cash transfers are critical for income security and addressing disability-related costs. However, low coverage and inadequate benefit levels often limit their effectiveness. A shift from a 'one-size-fits-all' approach is necessary, moving from disability being equated to an incapacity to work towards recognising individual needs, abilities and barriers.

Ensuring inclusive access to a broad package of schemes, including disability benefits, child benefits, maternity benefits, sick leave, old-age pensions, employment injury benefits, and unemployment insurance, can ensure universal coverage and adequate benefits.

Contributory schemes should extend beyond public sector workers to include self-employed workers, private sector employees, and leveraged to foster formalization of those in the informal economy. Innovations such as pension credits or contribution catch-up programmes can accommodate career breaks, thereby also addressing gender gaps. Additionally, contributory schemes should be comprehensive, including maternity protection, paternity leave, and family sick leave which can be particularly relevant for parents of children with disabilities among others.

However, given the limited reach of contributory disability benefits, countries should complement efforts to facilitate formalization with **non-contributory mainstream and disability-specific benefits** addressing income security and disability-related extra costs.

Persons with disabilities and their families should have access to mainstream social assistance programs. Where household poverty targeted schemes<sup>1</sup> are in place, **certain design features can be introduced so that schemes better address income security of household members with disabilities**. This includes:

- adjusting eligibility criteria to higher thresholds for persons with disabilities to account for their greater consumption needs,
- increasing benefit levels for households with persons with disabilities as their capacities to generate additional income is reduced and to compensate for higher expenditures,
- excluding benefits that address disability related costs benefits when assessing household income status,
- providing top-ups to incentivize increased investments in education and health services for boys and girls with disabilities, for example by designing soft conditionalities such as labelling and messaging to encourage school enrolment and attendance in particular of girls with disabilities,
- for working adults and older persons with disabilities, make them individual rather than household benefits.

To cover basic disability-related costs, countries should seek to **introduce (quasi) universal disability-specific cash benefit which are compatible with work and with other benefits** providing income security.

**In countries where no mainstream non-contributory income security schemes** exist (e.g., household poverty assistance, old age social pension), a starting point can be to **introduce a sole hybrid disability benefit** which are provided to persons with disabilities regardless of their employment status. For people out of work, it provides basic income security and for those in work it covers part if disability related costs. While not ideal, it is a first step towards flexible support needed to facilitate socio economic inclusion and empowerment.

Non-contributory disability support programmes should be designed to **limit exclusion errors** by moving away from a narrow poverty-targeting of disability benefits, towards higher-coverage schemes. While shifting to universal benefits is more aligned with the rights-based approach it may not be politically feasibility. An alternative to poverty-targeting in the short term may be focusing schemes on children and those with more severe disabilities, possibly combined with affluence or benefit testing.

### **Concessions**

Concessions and discounts can ease the financial burden of persons with disabilities by reducing or offsetting disability related costs. Most high-income countries, and countries like Nepal, India, Vietnam, Philippines, Georgia, Kenya, and South Africa provide concessions as part of their social protection systems, complementing cash transfers. Concessions can be effective for all but especially for those not eligible for other schemes. These can include tax exemptions, discounts, fee waivers, and subsidies.

However, concessions may disproportionately benefit those with formal employment or higher incomes. Rural and marginalized persons with disabilities often struggle to access concessions, due to limited service availability, informal employment or restrictive social norms. Designing effective concessions requires understanding the diverse needs of persons with disabilities based on their employment status, functional limitations, and residence.

Concessions can take various forms, including:

- Income taxation exemptions or reduced rates, increasing disposable income to cover disability-related costs.

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<sup>1</sup> Poverty targeted schemes can not only be poverty assistance schemes, but also categorical schemes that include means-testing, such as child benefits or old age pensions that target households below a poverty threshold.

- Sales tax exemptions and import duty exemption on disability-specific items, reducing prices for these goods.
- Discounts and fee waivers on healthcare, transportation, utilities, education, training, livelihoods, and arts and leisure. However, these require the services to be available, accessible, and safe, especially for women, girls, and those living in remote areas.

Some concession while useful for many, might be irrelevant for others such as public transport systems that may not be accessible, or discount on goods provided by providers in the formal economy (due tax related compensation with government) more present in urban setting than rural settings.

Concessions should be progressive, meaningful, and preferably target the first dollar spent or earned. However, few countries have adopted consistent, evidence-based strategies when designing and implementing concessions. Having good insights on the extent and structure of disability related costs can help government design effective concessions.

### **Community care and support services**

Community care and support services, encompassing various forms such as human assistance, assistive technology, transportation, housing, and more, are essential for people with disabilities. The requirements for these services are specific to each individual's circumstances and needs. Combined with cash transfers, these services can facilitate independent living in the community, contributing to social participation and dignified living.

The absence of adequate formal and publicly funded community support services, particularly in low and middle-income countries, creates financial strains on households, foregone opportunities, low choice and autonomy of persons with disabilities, overreliance on unpaid assistance from family members which may lead to burn-out of care givers, and even neglect, abuse, abandonment, and institutionalisation. This gap in support services carries significant gender implications, as girls and women most often provide the unpaid support.

Challenges limiting access to community support services include a lack of awareness about their importance, lack of data on diverse needs for support services, low investments in these services, shortages of service providers and trained workforce, and existing services being fragmented, unsustainable, and of low quality. These challenges are particularly acute in rural areas.

While development and expansion of publicly funded community care and support services require cross sectoral coordination, social protection systems and reforms can support by

- Fostering change in legal and policy framework, integrating community support services in addition to cash in basic benefit packages,
- Supporting awareness-building and collecting comprehensive data on support needs
- Including basic assessment of support needs in Disability identification and determination mechanisms to enable case management
- mobilising community resources, using social protection regulatory frameworks facilitating public-private-non-profit partnerships and encouraging involvement of disability and community-based organisations and volunteers
- Addressing workforce shortages, especially social services workforce and innovating on the profile and training of available community workers.
- using public employment/works programmes compensate community care and support work, while considering gender equality and quality of support issues.

### **Coverage of health care costs**

Persons with disabilities often face increased healthcare needs and barriers to access health care, leading to greater associated costs. They frequently require access to both general and specialist health services due to underlying conditions and specific impairments.

Access to healthcare is often hindered by physical and informational inaccessibility, discrimination, and lack of specialised care. Women and girls with disabilities face additional prejudices, particularly in seeking sexual and reproductive health care. The quality of care received may be compromised, necessitating travel to major cities or even abroad.

Health care related costs for persons with disabilities and their families include;

- direct medical costs for general and specialist health services, assistive devices, and long-term care;
- direct non-medical costs like transportation and personal assistance;
- indirect costs like loss of income of person themselves and their accompanying family members especially when frequent medical visit are required.

Consequently, they report poorer health status, face increased barriers to care, and are more likely to encounter catastrophic health expenditures. Social protection systems can alleviate these financial barriers, thus enhancing healthcare access.

Given that persons with disabilities often have higher healthcare needs and face barriers such as poverty and limited labour market access, prioritising them in the extension of universal health coverage is essential. This could mean extending subsidized social health insurance to them, and even waiving means test requirements for this group. If coverage is expanded progressively via a tax-financed approach, persons with disabilities should be considered a priority.

For persons with disabilities, the burden of healthcare co-payments should be reduced or eliminated, given their higher usage of health services and the potentially higher cost of these services. Furthermore, addressing direct non-medical costs (like transport or personal assistance) and indirect costs (like lost income while seeking care) is also essential. This could be managed through concessions, community support services, cash benefits, income security measures, and benefits addressing opportunity costs.

In any case, the inclusion of disability-related services, such as assistive devices and rehabilitation, in guaranteed benefit packages is critical. Outreach, simplified application processes, and physical access must be improved. Importantly, persons with disabilities should be actively engaged in the development, implementation, and monitoring of social health protection systems to ensure these are responsive to their needs.

### **Identification, assessment and certification of persons with disabilities and their needs for social protection purpose**

Universal and inclusive social protection systems could theoretically offer tailored support to diverse members of society without labelling them as poor, old, or disabled, by assessing individual vulnerabilities and needs at life stages. Such a system, although ideal, has yet to be developed due to historical policies, technical and financing challenges, and the politics of resource allocation and social protection reforms.

While the Convention on the Rights of Persons with Disabilities (CRPD) doesn't necessitate identifying specifically persons with disabilities for inclusive mainstream services, provision of individual disability related support requires states to develop mechanism to identify those requiring such disability-related assistance.

In all countries that have fairly mature social protection systems, while access to mainstream social protection schemes such as poverty assistance, old age pension, health insurance, public housing might not require identification of persons with disabilities (assuming that they are made accessible), providing disability specific support (cash transfer for income replacement and/or disability related costs, costly assistive devices, personal assistance, among others) require such identification to ensure that programmes reach those for whom they are designed.

Disability assessment and determination mechanisms potentially serve a three-fold purpose:

- identifying children, working age adults and older persons (and their support need) who may require and want disability-related support to live independently,
- enabling targeting, prioritization and access to available programs providing such support, and
- providing data to design, plan, and cost required services to respond to unmet support needs

An important caveat is that disability assessment and determination mechanisms cannot be used to estimate how many people experience disability within the total population. Indeed, many people who may be experiencing functional limitation and disability related participation restriction may not self-identify as persons with disabilities in the first place and would not seek disability status. However, Disability registry can provide data contributing to such endeavor, but they will only provide information about people who access the system.

Issues with disability assessment often arise, including lack of accessibility, costs, complexity, or the lack of qualified assessors. Disability assessment often focuses on medical conditions and impairments, rarely considering the diverse support that people need, which can limit access to benefits, especially in low- and middle-income countries.

Reforming or developing disability assessment and determination procedures is a complex task involving multiple stakeholders. Persons with disabilities require clear, accessible and predictable processes, while governments seek cost-effective, legally robust systems with minimal fraud potential. Reform is often seen as a risk by those with disabilities due to possible service limitations.

The CRPD committee recommends a disability determination process based on universal access, focus on support requirements and barriers, and meaningful participation of individuals with disabilities. However, while high-income countries have well-established mechanisms, they may fall short of these standards, and face legal claims or controversy. Low and middle-income countries, while increasing social protection, face resource and administrative capacity challenges.

Therefore, stakeholders are working towards solving an equation combining accessibility, comprehensiveness and reliability in disability assessment and determination procedures:

- **Accessibility** involves ease, transparency, and minimal burden in application so that the procedure is available, free and accessible to all everywhere in the country
- **Comprehensiveness** requires inclusion of all disabilities, assessment of individual limitations and support needs, age and gender sensitivity, and respect for privacy
- **Reliability** entails transparent evaluation procedures, standardized processes, trained staff, grievance mechanisms, fraud minimization, and involvement of organizations of persons with disabilities.

To solve the equation of CRPD compliant disability assessment and determination mechanisms, there is no one-size fits all approach and governments should develop processes, mechanisms and tools that:

- Are tailored to be used and managed effectively by the most relevant staff available at local level across the country so that all persons with disabilities are in position to access the mechanisms,
- Are easily accessible, understandable and manageable by all persons with disabilities and parents of children with disabilities, considering social norms around gender and disability.
- Can capture to the best extent possible evidence of impairment and/or type and level of functional limitations, support requirements, barriers, and level of participation
- Have effective and adapted quality control, fraud prevention and safeguard mechanisms which do not complexify and make the process cumbersome while ensuring consistent outcomes.

Disability assessment information has traditionally been used primarily for determining disability status, but advancements in management information systems in sectors like health, education, and social protection have opened new avenues for its usage. A rising number of nations, such as India, Senegal, Djibouti, or Cambodia, have adopted a national disability registry linked to a disability/equal opportunity card, providing official proof of disability across government services.

These digital registries have started evolving into **Disability Management Information Systems (DMIS)**, offering several benefits:

- Digitization allows community worker to carry out computer assisted assessment more comprehensive than they would with paper-based tools and provides possibilities for fast verification validation and oversight
- When linked to single-window assessment systems, DMIS can reduce administrative burdens on disabled individuals and their families, preventing repeated assessments and reducing administrative costs.
- They facilitate case management and access to diverse social protection benefits like cash benefits, healthcare, assistive devices, support and concessions. If skills and occupation information is included, they can aid job placements.
- DMIS make social protection systems more shock responsive, supporting expansion of existing disability benefits, and help create new ones during crises, as seen during the COVID-19 pandemic.
- Aggregated data from DMIS can help priorities, plan, and cost service and scheme extensions or development at local and national levels based on assessed needs, especially when combined with national statistical data.

Several low and middle-income countries have invested in developing such registries and information management systems. Cambodia's DMIS has been used to improve cash transfer targeting and prioritise registered disabled people for COVID-19 vaccines. Senegal used their registry for its equal opportunity card to ensure registered disabled people had access to COVID-19 related relief. India is building a National Database, issuing a Unique Disability Identity Card to facilitate access to various government schemes. Rwanda is piloting a national DMIS based on individual disability assessments capturing support needs. Togo has embarked on a digitization drive to register all persons with disabilities.

Digitization increases accessibility comprehensiveness and reliability. However, data privacy and protection must be considered, given the broad scope of individual information collected.

#### **Data for inclusive social protection**

High-quality data is crucial in the design, monitoring, and evaluation of social protection policies and programs, especially for disability-inclusive social protection. Unfortunately, data collection often falls short in supporting disability-inclusive efforts, hindering the development and adjustment of effective schemes for persons with disabilities.

To strengthen the collection of relevant disability data, attention should be paid to national surveys, social protection administrative data, and other pertinent methods to provide data on disability prevalence and demographic patterns, inequalities as per disability status, environmental barriers that foster exclusion, and the extent of met and unmet support needs of disabled individuals and estimate the economic impact of disability-related expenditures. In all those efforts safeguarding the confidentiality of private information, particularly sensitive medical and personal data, is paramount in data collection and processing.

To enhance national censuses and surveys, internationally comparable questions on disability status such as the Washington Group set(s) should be used. While this would allow for disability disaggregation, there is also a need to consider specific modules or even surveys, to collect data on the diversity of disability-related barriers and support needs across the life cycle and for women and girls with disabilities.

Administrative data is also essential for assessing the inclusivity of social protection policies for people with disabilities. This data typically includes recipient demographics and, for more complex schemes, detailed information about income, assets, and household composition. Such data can be compared with demographic information to estimate coverage and identify issues of accessibility, like low coverage in a certain group or geographical location. When used with survey data, administrative data can provide a comprehensive understanding of the situation and needs of disabled individuals. To strengthen administrative data, it's crucial to collect information on disability status and support needs. For disability-

specific schemes, this involves confirming disability status as part of eligibility determination, ideally by using functional limitations questions as a reference. Mainstream schemes should include questions on disability to assess inclusivity and allow inclusive targeting. In addition, data on support needs should be collected to ensure appropriate support delivery or referral.

National surveys and administrative data can be enhanced with qualitative research, impact evaluations, Knowledge, Attitudes, and Practices (KAP) surveys, and Goods and Services Required (GSR) methods to promote inclusive social. Qualitative research provides insights into attitudinal, institutional, and structural barriers that create exclusion, aiding in policy design. Impact evaluations measure the effect of social protection schemes. KAP surveys shed light on attitudes towards persons with disabilities, influencing policy development. Lastly, GSR methods assess the costs of goods and services required for equal participation or disability-related extra costs, thus informing the design of social protection measures.

### **Meaningful participation of persons with disabilities**

Engaging meaningfully with Organizations of Persons with Disabilities (OPDs) is pivotal for designing, monitoring, and evaluating inclusive social protection policies and programs. Despite historical misunderstandings and unease within the disability movement about social protection, perceived as perpetuating the charity and medical models, shifts in perception are occurring. The impact of the 2008 financial crisis and the COVID-19 pandemic, both of which underscored the critical importance of robust social protection systems, has led to growing awareness about the necessity of such measures for persons with disabilities.

OPDs play three key roles in inclusive social protection systems. First, they offer unique perspectives based on lived experiences, filling data gaps, and providing context. They can highlight the barriers faced by marginalized groups that are often overlooked in national data. Second, they contribute to inclusive design and delivery, raising awareness about disability inclusion among social protection teams in national governments and international agencies. Third, they build ownership, fostering the commitment and advocacy required for sustained and effective reforms. Engagement with OPDs should therefore be extended to the design and implementation phases of social protection policies and programmes.

Mutual capacity building and creating a space for meaningful consultation are equally important. Given that social protection is an emerging field of advocacy for many OPDs, there may be limited understanding of social protection policies. Conversely, social protection professionals might lack understanding of disability rights and inclusion. Therefore, investing in mutual capacity development is necessary to enable meaningful participation in inclusive spaces. The "we want jobs, not charity" motto prevalent within part of the disability movement underscores the need for social protection professionals to adopt a human rights-based, inclusion-focused approach.

To meaningfully engage with OPDs, considerations should be given to accessibility of venues, information, and communication, diversity of persons with disabilities, including women with disabilities and under-represented groups, and the capacity and resources required for engagement.

Different consultation and engagement mechanisms can be used depending on the purpose of engagement, such as advisory or steering committees at the program level, or national disability coordination mechanisms for policy or national reforms. Despite these mechanisms not being perceived as effective by some OPDs, it is essential to leverage them to increase their relevance and capacity.

### **Accessibility of social protection delivery mechanisms**

People with disabilities often face significant barriers in accessing social protection schemes and cash transfer programs. While barriers related to distance to administration and payment points, financial illiteracy or complex administrative processes impact a lot of groups, they are magnified for persons with disabilities.

These barriers stem from a combination of physical, information and communication, and attitudinal factors. For example, they might have to travel long distances or navigate difficult terrains to access enrolment or payment centres, or face difficulties in accessing information in suitable formats. Discriminatory attitudes and lack of engagement from staff involved in the schemes further compound these issues. Additionally, people with disabilities may face additional costs such as transportation or assistance-related expenses. These obstacles can be present even before enrolment, for instance, as obtaining necessary ID cards may prove challenging.

Accessibility plays a crucial role in the successful implementation of cash transfer schemes and more broadly social protection system. Often, individuals with disabilities are overlooked due to staff unawareness, lack of inclusive regulations and data visibility. To rectify this, accessibility and inclusive design needs to be integrated into various operational areas of social protection programs including training and data disaggregation, standard setting, administrative processes, and organisational systems and management arrangements.

Awareness training and data disaggregation involve providing disability awareness and gender equality training to staff, thus equipping them with the skills to develop inclusive delivery mechanisms. Additionally, data utilized for design, monitoring, and evaluation should allow for disability disaggregation, helping anticipate potential barriers for those with disabilities.

Minimum standards for operations should be developed with people with disabilities and their representative organizations. These standards, including accessibility requirements, should be published in accessible formats and incorporated in contracts with private sector contractors. The schemes should also publish annual reports on their compliance with these standards.

Administrative processes involve several steps to ensure accessibility. Communications should be accessible, with staff trained to interact effectively with people with disabilities. Registration and enrolment processes should be streamlined, considering the mobility and communication limitations of the disabled. Cash withdrawal mechanisms should be electronic and flexible, accounting for the diverse needs of people with disabilities. Changes in the circumstances of beneficiaries should be easy to report, with options that minimize travel. Conditions and sanctions should be managed sensitively, ensuring accessibility in facilities associated with social protection schemes. Grievances and redress should be available through multiple channels, adapted to accommodate different types of impairments and communication forms.

Organisational systems and management arrangements must include suitable institutional and human resource arrangements, with a specialist disability unit within the implementing ministry or agency. Training on disability inclusion should be provided to all staff, and recruitment processes should be open to employing people with disabilities. Operations manuals should provide comprehensive guidance on ensuring accessibility. Management Information Systems should allow the identification of persons with disabilities and their accessibility requirements. Payment systems and financial management systems should be adapted to promote access and autonomy and to track spending related to accessibility. Social accountability mechanisms and monitoring and reporting mechanisms should incorporate key indicators on accessibility and disability inclusion.

Evaluations of cash transfer schemes should review the accessibility experiences of people with disabilities at each mechanism of the cash transfer process. This includes incorporating the Washington Group Short Set of Questions in all quantitative evaluations and national household surveys. Moreover, qualitative surveys should ensure the inclusion of people with disabilities. Specific evaluations of national disability-specific and old age pension schemes are needed to expand knowledge on the access and impact of such cash transfer schemes.

### **Financing inclusive social protection**

Financing inclusive social protection schemes for people with disabilities is context-specific, with a strong link to the broader economic, fiscal, and political conditions of a country.

Understanding current spending levels and distribution can inform if allocations are adequate relative to the needs of people with disabilities. Challenges include identifying what is "disability-related", discerning what constitutes "social protection", and distinguishing between different types of schemes.

Internationally-recognised statistical frameworks like the OECD Social Expenditure Database (SOCX), European System of Integrated Social PROtection Statistics (ESSPROS), and the Classification of the Functions of Government (COFOG) can help in classifying disability-related social protection expenditure. They allow the identification of disability-specific expenditure and disaggregation by benefits in cash and kind, and between different benefits. These classification systems have comprehensive documentation and guidance on how benefits should be classified.

However, these classifications don't perfectly correspond to all benefits within inclusive social protection for persons with disabilities. A way to address this would be developing a framework to collect data on a broader range of disability-related expenditures. The System of Health Accounts, developed by the OECD, Eurostat, and the WHO, is another useful framework, as it can identify some key types of disability-related expenditures, such as long-term care.

Data on disability-specific social protection expenditure is generally weak in low- and middle-income countries. Often, the information is not available or hard to find in budget documents and statistical reports. To improve this, national governments should report all disability-related social protection expenditures, and organizations representing persons with disabilities (OPDs) could play a greater role in budget monitoring. Such monitoring provides a platform for OPDs to engage with governments on social protection policy and hold them accountable for their spending commitments.

Costing proposed disability-related social protection schemes is another critical step. Costing requires defining the parameters of different schemes, such as eligibility, benefit level, administrative costs for cash benefits, and complex factors for in-kind benefits, such as price of goods, wages, uptake, etc. These costs can then be tested under different scenarios to understand how adjustments affect total costs. However, existing costing models focus mostly on cash transfers and are limited in scope, necessitating the development of more comprehensive models.

Social protection reforms, particularly disability-related expenditures, can be implemented and financed through various tools and strategies. The process begins with understanding a country's fiscal context, where social protection financing often involves identifying "fiscal space". Fiscal space refers to the budgetary room a government has to allocate resources without harming financial stability or economic growth. This usually involves analyzing revenue sources, debt sustainability, and expenditure allocation in the national budget.

The feasibility of such reforms relies on a comprehensive assessment of the fiscal context using sources like budget documents, IMF consultation documents, Public Expenditure Reviews, and analyses by various institutions. However, the fiscal context also involves predicting changes in revenues, expenditure, and debt in the short, medium, and long term, and how these might affect the potential for social protection investment.

Given that establishing an inclusive social protection system is likely to be a gradual process, it's important to consider long-term investment plans. Gradual expansion may occur organically or be integrated into strategic budgeting plans to create a forward-looking vision. Expansion typically occurs through adjusting scheme parameters, such as eligibility criteria and benefit levels. This might involve initial targeting of specific groups, followed by subsequent expansion, or starting with a lower benefit level and increasing it over time. This gradual, strategic approach allows for manageable, sustainable growth in social protection benefits.

## Conclusion

Recent years have seen a growing emphasis on universal social protection, with particular attention on inclusive, shock-responsive systems. This shift is driven by data showing that people with disabilities face higher risks and barriers which hinder their socio-economic resilience, despite having higher needs for social protection systems. As low- and middle-income nations build or expand their social protection systems, there is an urgent need to prioritize people with disabilities while ensuring conformity with the Convention on the Rights of Persons with Disabilities.

To develop inclusive social protection, certain key elements are essential. Systems should provide income security and cover healthcare and disability-related costs to improve access to services and promote full participation. These systems should combine cash and in-kind benefits, contributory and non-contributory schemes, and inclusive mainstream and disability-specific schemes.

The guidance note outlines practical steps to make social protection systems more inclusive, including:

1. Collecting and analyzing data on the diverse situations of persons with disabilities.
2. Encouraging meaningful participation of people with disabilities and investing in capacity building.
3. Establishing legal frameworks that foster inclusive social protection system development and cross-sectoral interlinkages.
4. Developing disability registries and inclusive management information systems to inform eligibility, facilitate case management, and enable expansion during shocks.
5. Improving income security by considering persistent barriers and disability-related costs with flexible combination of mainstream and disability benefits
6. Prioritizing people with disabilities in Universal Health coverage policies and develop inclusive package with rehabilitation and AT
7. Mobilizing social protection instruments to progressively provide universal support to address disability-related costs.
9. Increasing accessibility across the delivery chain of social protection schemes.

While the guidance refers to several country examples, there are promising ongoing development across regions that will provide in the coming years more elements on conditions, innovation and steps required to build inclusive social protection programs and systems. It will therefore be a living document with a formal update planned in 2025.

## **PART 1: BACKGROUND**

### **1 INTRODUCTION**

While the **UN Convention on the Rights of Persons with Disabilities (UN CRPD)** was adopted in 2006 and has been ratified by 185 state parties as of June 2022, and the Agenda 2030 set the goal to leave no one behind, those aspirations of inclusion still need to be turned into reality.

Latest data on the situation of persons with disabilities in low- and middle-income countries shows a **persistent disability gap** among adults in terms of educational attainment, literacy, food insecurity, asset ownership, health expenditures and multidimensional poverty (Mitra and Yap, 2021). Disability risk grows with age, with older people, rural communities and women being most affected (Mitra and Yap, 2021; Sheppard et al, 2018). Meanwhile, children with disabilities are more likely than their peers without disabilities to be stunted, to have never attended school, to be engaged in child labour, to be multidimensionally poor, to experience severe corporal punishment, among other issues (UNICEF, 2021). For both adults and children, inequalities are more extensive for those with more significant functional difficulties.

**The increasing frequency of humanitarian crises are leaving people with disabilities even further behind.**

In 2022 an unprecedented 247 million people needed emergency aid, of which 41 million were persons with disabilities (UNOCHA, 2021). Armed conflict, violence and persecution have resulted in unparalleled levels of displacement, affecting over 89 million people by the end of 2021 (UNHCR, 2022), with persons with disabilities accounting for an estimated 17 million. A global consultation with persons with disabilities affected by crisis revealed that over half the respondents with disabilities (54 per cent) stated experiencing a direct physical impact, worsening existing functional difficulties owing to injuries, a lack of quality medical care, or the collapse of essential service (Handicap International, 2015). Older persons with disabilities experienced “more difficulty escaping conflict or natural disasters and accessing humanitarian assistance than older people without disabilities because of environmental and other barriers” (Sheppard et al, 2018 pg. 15). Forty-two per cent of respondents with disabilities noted the need for cash assistance, but only 17 per cent received it (Handicap International, 2015).

**The multiple barriers and lack of support faced by persons with disabilities, also negatively impact their household** though direct and indirect costs, especially for family members providing care and support, often women and girls. Family members who provide care and support may end up dropping out of education or employment, increasing their current and future economic insecurity.

**Given the greater exposure to risks and additional vulnerabilities faced by persons with disabilities across the life cycle, the development of inclusive social protection systems is particularly relevant for combatting their marginalisation and promoting their inclusion.** The specific role of inclusive social protection systems for supporting the full and effective participation of persons with disabilities in line with provisions of the UN Convention on Rights of Persons with Disabilities and other international frameworks (see Box 1-2) was set out in the *Joint statement: Towards inclusive social protection systems supporting the full and effective participation of persons with disabilities* (2019) endorsed by a range of international organisations.

**As it stands, social protection systems in most low- and middle-income countries fall far short of addressing the support needs of persons with disabilities.** Latest figures indicate that globally only a third of the people with significant disabilities receive specific support from social protection systems and – even where benefits are provided – adequacy is severely limited (ILO, 2021). Social protection systems, including in some high-income countries, are also often constructed in a way that focuses narrowly on providing a minimum income replacement or consumption floor in relation to the ‘incapacity to work’ rationale. This

fails to recognise the diversity of barriers and costs undermining participation of persons with disabilities across the life cycle and how social protection can effectively support their inclusion by providing income security as well as coverage of health care and disability related costs.

With the combined momentum of expansion of social protection and implementation of the CRPD, many countries have sought to make their social protection system and programmes more supportive and inclusive for persons with disabilities. However, they face significant conceptual, design and operational issues in doing so.

**This guidance seeks to address those issues based on the existing global knowledge on the issue, with a focus on low- and middle-income countries.** It has been initiated under the UN Partnership for the Rights of Persons with Disabilities (PRPD) funded global programme “Towards Inclusive Social Protection to Advance the Rights of Persons with Disabilities” led by ILO and UNICEF in close collaboration with the International Disability Alliance. The guidance draws heavily on a set of background papers developed under the project as well as exchange with staff of governments, development agencies and organizations of persons with disabilities through multiple training and webinars as well as the 2022 *Global Dialogue on Disability, Inclusion and Social Protection*.

The guidance elaborates on the key concepts relating to inclusive social protection for persons with disabilities set out in the 2019 Joint Statement, drawing on the growing practices, knowledge, and research. However, it recognizes that this is a rapidly evolving area of work, and therefore the guidance can only be considered a version “1.0” and will need to be updated by 2025 when even more practices and evidence will be available. Also, as the guidance focuses on making the overall social protection system inclusive in different contexts, it does not address in detail issues related to inclusive development of specific programs and interventions but will refer to additional resources in certain chapters.

The guidance is organized in three parts to address the broad questions in each area. The guidance is structured as follows:

- **Part 1 on the rationale and conceptual framework**
  - Part 1 explains the concept of inclusive social protection systems for persons with disabilities, and its role in supporting their participation across the life cycle. The section also presents the key challenges towards making social protection systems inclusive for persons with disabilities.
- **Part 2 on social protection instruments and inclusive design**
  - Part 2 sets out the range of instruments available to inclusive social protection systems, how they can contribute to meeting the goals of inclusion and empowerment for persons with disabilities, and how they can be mobilized and combined within a system to provide adequate and appropriate support.
- **Part 3 on enablers of disability inclusion**
  - Part 3 sets out the different preconditions that are necessary to achieve an inclusive social protection system for persons with disabilities that promotes their participation. Each precondition is then explored in dedicated sections including legal framework, data, financing, inclusiveness of delivery mechanisms and the critical importance of participation of organisations of persons with disabilities.

**Five guiding principles cut across the approach to the guidance paper:**

- **Disability = impairment + barriers:** The conceptualisation of disability as provided in the UN CRPD explains that disability can be understood as the interaction between a person’s impairment and various attitudinal, physical (i.e., built or natural environment), communication, and institutional and legal barriers. It is this interaction that hinders full and effective participation on an equal basis with others. A person’s impairment is therefore not the full picture, and the role that barriers play

in reducing someone's functioning and participation must also be considered within approaches to collecting and analysing data on disability to inform inclusive social protection systems.

- **Diversity of persons with disabilities:** Persons with disabilities are a diverse group and the experience of disability is different for all individuals. Individual experiences of disability are impacted by impairments, the level of functional difficulties, and date of onset of disability, their environment and other, often overlapping, factors such as gender, ethnicity, and age, all of which interact with the types of barriers that people face. The diversity of disability related inclusion requirements needs to be considered in the design, implementation, and evaluation of social protection.
- **Dignity, choice, and autonomy:** Some persons with disabilities may require high levels of support to live independently and be included in the community. States have the duty to ensure access to the needed supports that enable equal opportunity and to do so with equal choice and dignity as persons without disabilities.
- **Universal support:** The CRPD stipulates States' obligations to promote, protect and progressively realise all human rights for all persons with disabilities, including the right to adequate standard of living and social protection as well as living independently and being included in the community. This implies that social protection systems ensure progressively universal and sustainable access to the required support across income and age groups in terms of diversity of support needed, gender equality, geographic distribution, physical and information accessibility.
- **Consulting with people with disabilities:** Across the different stages of programme and system development and implementation, social protection practitioners should work with people with disabilities and their representative organisations (OPDs) to how best to gather information and data on the experiences of people with disabilities in a particular context, and design and evaluate appropriate policies and interventions.

#### **Box 1-1: Who are persons with disabilities?**

The Convention on the Rights of Persons with Disabilities describes disability as an evolving concept, **resulting from the interaction between persons with impairments and attitudinal, institutional, and environmental barriers** that may hinder their full and effective participation on equal basis with others.

An estimated 15 per cent of the world's population live with some form of disability, with higher prevalence among older persons, while 2–4 per cent experience significant difficulties, face greater barriers and have higher support needs.

Persons with disabilities are very diverse. They include children, working age adults and older adults of all genders with intellectual, psychosocial, sensorial, or physical impairment(s) who will face a diversity of barriers. These barriers may be related to prejudice and low expectations, discriminatory regulations, exclusion, or segregation in access to services, such as education or in the labour market, beliefs that may lead to harmful practices, lack of accessibility to the built environment, transport, information, and communication.

**Box 1-2: International normative frameworks**

The right of persons with disabilities to benefit from social protection and its importance for their inclusion has been increasingly recognized by major human rights and development frameworks.

**International Labour Standards**

*ILO conventions 102, 121 and 128* require states to adopt social security measures for persons who may acquire a disability due to employment related injury and illness. Those measures include access required medical and allied care as well as rehabilitation services, cash benefits for income replacement and support and measure to facilitate the reintegration of persons with disabilities in the labour market.

The *ILO recommendation 202* on national social protection floors stipulates that disability benefits should be included in the policies and strategies to build and extend progressively social protection systems. Social protection floors should be responsive to needs of and ensure support to persons with disabilities whether or not they have had an opportunity to contribute to social security schemes. It also states that access to at least essential health care for all, over the life cycle, should be guaranteed, including for specific care required for disability, irrespective of the origin of the disability for which such care is required.

In general, international labour standards primarily frame disability benefits as supporting income security for those unable to work, but with little account taken of disability-related extra costs.

**UN Convention on the Rights of Persons with Disabilities (CRPD)**

The CRPD sets out the obligations of States to ensure that all persons with disabilities are in a position to enjoy and exercise all their human rights on an equal basis with others. Elaborating on the provisions of the Universal Declaration of Human Rights and the International Covenant on Economic Social and Cultural Rights<sup>1</sup>, the CRPD adopts a broad understanding of social protection and emphasizes its critical role in supporting the full and effective participation of persons with disabilities.

The CRPD and related standards stipulates the following obligations of States regarding social protection:

- To ensure that persons with disabilities enjoy adequate standards of living on an equal basis with others and have equal access to all social protection schemes and programs, including pensions, public housing (art 28), health insurance (art 25), and return-to-work programs (art 27).
- To ensure that persons with disabilities have access to assistance to cover disability-related expenses as well as to affordable and quality disability-related services and devices (art 28) that required to live independently in the community (art 19).
- To support children with disabilities and their parents and to prevent institutionalization and ensure that in any case children are living in family like settings (art 7, 16, 18 and 23).
- To address the disadvantages faced by women and girls with disabilities (art 6 and 28).
- To meaningfully consult and involve persons with disabilities through their representatives' organizations in the design, implementation and monitoring of policies and programs (art 4.3).
- To ensure that international cooperation programs and interventions situations of humanitarian crisis are inclusive of and accessible to persons with disabilities (art 32 and 11).

These obligations emphasize that social protection should always contribute to the empowerment, participation and inclusion of all persons with disabilities and implies a change of perspective in the design and implementation of social protection policies systems and schemes.

**Agenda 2030**

The importance of social protection has also been highlighted across the post 2015 frameworks with explicit reference for persons with disabilities in the Addis Ababa Agenda for Action<sup>1</sup>. The Sustainable Development Goals target 1.3 explicitly commits to implementing nationally appropriate social protection systems and measures for all, including floors, and Indicator 1.3.1 specifically refers to persons with disabilities.

## 2 INCLUSIVE SOCIAL PROTECTION SYSTEMS FOR PERSONS WITH DISABILITIES

**Across the life cycle, persons with disabilities face multiple barriers that increase their vulnerabilities, exposure to risks and the impact of diverse shocks, which make it more difficult for them to achieve a decent standard of living and participation compared with people without disabilities.** These barriers and vulnerabilities may change as people transition from one phase of the lifecycle to the next or even within a lifecycle phase if situations change, like a shock or stress. These factors contribute to persons with disabilities and their families consistently having higher levels of poverty, being more likely to face catastrophic health expenditures, having lower levels of education and economic participation and living in households more exposed to economic insecurity and shocks than persons without disabilities (Mizunoya and Mitra, 2013; Mizunoya et al., 2016; WHO, 2011; UN, 2018; Mitra, 2018; Trani et al., 2015). Given that 15 per cent of the global population are estimated to experience some form of disability (Box 1-1), and at least 1 in 4 households have a member with a disability, these are issues with wide-ranging impacts (WHO, 2011 and UN Women, 2017). Alongside other required inclusive policies such as awareness raising, physical and informational accessibility, anti-discrimination, inclusive education and labour market policies, social protection plays a critical role in providing support required to facilitate inclusion and participation of persons with disabilities across the life cycle.

This section begins by describing what is meant by inclusive social protection for persons with disabilities, and the important role it plays. It then describes specific considerations for inclusive social protection for persons with disabilities in diverse circumstances, framed around the life course. The section ends with a summary of the extent to which low- and middle-income countries have achieved inclusive social protection for persons with disabilities.

### **What is an inclusive social protection system?**

*An inclusive social protection system combines in a coherent way all relevant instruments to ensure rights-based, comprehensive, adequate and sustainable social protection of all the population across the life cycle in a way that is gender responsive and takes into consideration vulnerabilities that stem from social exclusion.*

This implies developing a combination of schemes in ways that explicitly promote social inclusion, gender equality and provide additional support required by marginalized groups, such as persons with disabilities, indigenous persons, children and older persons among others.

Inclusive social protection systems also foster dialogue between stakeholders and ensure meaningful participation of representatives of a diversity of stakeholders including women and marginalized groups such as organizations of persons with disabilities. International Social Security Standards, in particular Social Protection Floors Recommendation (No. 202) and human rights standards provides valuable guidance on building such inclusive social protection systems.

### 2.1 WHAT DO WE MEAN BY INCLUSIVE SOCIAL PROTECTION FOR PERSONS WITH DISABILITIES?

**Historically, social protection policies tended to perceive disability mostly as a risk related to incapacity to earn income and by extension to care for oneself.** This perspective, while contributing to some level of income security for workers through social insurance, created an entrenched dichotomy between those who can and cannot work or care for themselves. It led to policies narrowly focused on basic income

replacement schemes and social care residential institutions rather than flexible support for inclusion (Cote, 2021a).

**Reflecting the paradigm shift promoted by the CRPD, inclusive social protection for persons with disabilities means supporting, across the life cycle, their active and meaningful participation and full inclusion in all spheres of social, political, cultural, and economic life.** It requires a holistic response. One that includes not only income support to prevent and protect individuals from poverty and the impacts of shocks and stresses but also diverse interventions that support them to overcome barriers and promote access to education, decent work and transform their role in society. Achieving this vision relies on a systems approach to provide coherent and comprehensive support to persons with disabilities across diverse sectors and stakeholders, both national and international. This vision represents a paradigm shift in thinking about the role of social protection from narrowly defined income replacement/security to supporting the full and effective participation of persons with disabilities. This conceptualization of disability inclusive social protection is strongly influenced by the CRPD and was articulated in a 2019 Joint Statement on inclusive social protection for persons with disabilities (ILO and IDA, 2019).

**A core characteristic of inclusive social protection for persons with disabilities is recognizing the importance of disability-related costs.** Persons with disabilities and their families face a diversity of direct and indirect disability related costs to overcome both their functional limitations and barriers in their environment when pursuing everyday activities. These includes higher costs for regular items such as transport or disability-specific items such as assistive devices and personal assistance as well as indirect costs such as loss of income of family members providing them with unpaid care and support (Key Concept 1). Disability-related costs have a significant age and gender dimension, not least because most unpaid care and support globally is provided by women and girls.

#### **Key concept 1: Disability-related costs (see Mont et al., 2022)**

**Disability-related costs** fall into various categories:

- **Direct costs**
  - **Additional spending on regular items:** which might include health care, transportation costs (due to inaccessibility of public transport), childcare services for children with disabilities (for example, more intensive or for a longer period of time), housing (accessible housing are often in more modern buildings or families relocating to larger cities where services are available their child with disability) among many others.
  - **Disability-specific spending:** Including assistive devices (e.g., wheelchair, braille reader), (re)habilitation and human assistance (such as personal assistance or sign language interpreters).
- **Indirect costs**
  - **Lower income** for persons with disabilities due to discrimination in accessing education and employment.
  - **Opportunity costs** as family members, often women and girls, commonly provide unpaid support and care services in absence of formal support services. This constrains opportunity to pursue education and take up work, with both immediate and lasting social and economic consequences.

Social protection systems commonly do not consider disability related costs. As a result, systems provide support narrowly, often through inadequate cash benefits, and undersupply of required in-kind benefits and services.

Few countries have carried out systematic data collection and analysis to establish the range, type, and level of disability related costs for the diversity of persons with disabilities across the life cycle. The lack of such critical information hampers the development of more responsive social protection systems (See Section 8 on data for greater discussion).

**The level and scope of disability related costs** are impacted by a range of factors including:

- The nature of impairments, level and type of functional difficulties and support needs,
- The age of onset of disability,
- Other individual characteristics including, but not limited to gender identity, sexual orientation, ethnicity, and age,
- The environment in which an individual lives, including in relation to the family, community, physical environment, the labour market, attitudes towards disability as well as the availability, quality and accessibility of public services and public infrastructure generally available,
- Place of residence, this includes living in urban or rural areas, or in fragile contexts,
- The type and level of participation that people seek.

**In order to support inclusion**, these different factors should be thoroughly assessed by social protection systems **to progressively develop and provide a range of support responsive to the diversity of persons with disabilities and their support requirements over their life course.**

While traditional disability schemes providing minimum income security can help compensate for irregular and unreliable income to help secure common necessities, they most often do not cover the diversity of disability-related costs. Reducing or compensating for these costs is essential for participation and sustainable escape from poverty of all persons with disabilities and their families at different stages of the life cycle. Additionally, by providing people with the financial means to access medical care, proper nutrition, safe housing, and access to other essential services and by ensuring safe working conditions social protection plays a key role in preventing disability from worsening or even acquiring a disability.

### **Key concept 2: Disability inclusive social protection**

As described in the 2019 Joint Statement, disability-inclusive social protection systems are those which have the following features:

- **Key feature 1: A combination of schemes purposefully designed to support socio-economic participation and inclusion:** Rather than solely focusing on providing minimum income for those deemed unable to work, inclusive social protection entails a set of complementary and adequate interventions that provide both basic income security and coverage of health and disability-related extra costs. Responsiveness to the diversity of persons with disabilities and their changing needs across the life course means moving away from a one-size fits all approach to social protection to a more flexible one. This can be achieved through a mix of cash benefits, in-kind goods and services, and access to affordable health care. It also implies a twin-track approach, involving access to mainstream social protection schemes but also developing disability specific schemes that explicitly promote social inclusion and provide required additional support. Appropriate disability and need assessment as well as case management are necessary to optimise both access to support and resource allocation.
- **Key feature 2: Ensure accessibility and non-discrimination:** Persons with disabilities should be able to access and benefit from social protection programmes on equal basis with others, which often implies removing barriers (in the physical environment, communication, information, institutional and attitudinal barriers), and addressing their diverse inclusion requirements, and active outreach to most marginalized groups. Where conditionalities (such as education, health, work) are associated with benefits support should be provided to overcome barriers or adjustment must be made.
- **Key feature 3: Respect for dignity, personal autonomy, choice, control over one's life and privacy:** Social protection programmes within the system must not directly contribute to stigmatisation/discrimination, marginalization, exclusion, and inequalities faced by children/adults with disabilities and their families. This relates to placement in social care institutions, renouncing of legal capacity and/or coercive bundling (force treatment) for

persons with disabilities to access social protection benefits or channelling support mostly through household benefit instead of individual benefits.

- **Key feature 4: Meaningful consultation with representative organisations of persons with disabilities** (OPDs) on the design, implementation and monitoring of social protection at a scheme and system level. An obligation under the CRPD (Art 4.3) engagement with OPDs and the diversity of persons with disabilities is critical to provide lived experience perspective and complement data, inform inclusive design and prioritization of investments as well as to foster ownership on reforms needed for implementation and sustained demand.

To this end, inclusive social protection systems for persons with disabilities should perform a range of functions across the life cycle. These are:



#### **INCOME SECURITY**

that enables access to common necessary goods and services



#### **COVERAGE OF DISABILITY-RELATED COSTS**

including access to the required care and support



#### **COVERAGE OF HEALTHCARE COSTS**

including disability-related medical care, rehabilitation and assistive technology



#### **IMPROVED ACCESS TO SERVICES AND ECONOMIC EMPOWERMENT**

such as childcare and education, transport, vocational training, support to employment and livelihood generation, financial inclusion, among others

**Building inclusive social protection systems for persons with disabilities requires a context relevant combination of mainstream and disability specific schemes.** The distinction between mainstream and disability specific schemes is summarised in Key concept 3. The 2019 Joint Statement defines this twin-track approach as:

1. All social protection programmes (**mainstream** and **disability-specific**) are designed, implemented, and monitored in a way that ensures the inclusion of persons with disabilities, and
2. Adequate **disability-specific programmes** are developed to provide the support required by persons with disabilities and not met adequately through other programmes.

The basic rationale for this twin track approach is that persons with disabilities require protection from the range of risks addressed by a social protection system – on an equal basis with others – but also support more directly linked to their disability. Meanwhile, some mainstream schemes may be particularly relevant for persons with disabilities such as unemployment benefit, old age pensions and affordable health care services.

### **Key concept 3: Mainstream and disability-specific schemes**

**Disability-specific** schemes are those that:

- Target solely persons with disabilities and their families,
- Seek to address disability related needs,
- Provide benefits mostly at an individual level, that is, benefits are paid directly to an individual, but also to others based on the specific circumstances as with child disability benefits or caregiver benefits.

These include cash benefits, but also in-kind benefits, community support services and concessions that are justified by disability-related needs.

**Mainstream benefits** are social protection schemes that do not fulfil the above criteria. Examples of such schemes include:

- Schemes addressing other life cycle risks and vulnerabilities such as old age, unemployment, maternity, parenthood, sickness etc), even if those would also benefit persons with disabilities. General poverty assistance schemes targeted to poor households may consider different vulnerabilities alongside wealth or income as an eligibility criteria, such as having a household member with disabilities or where specific criteria are included to prioritise household with person(s) with disability.

## 2.2 INCLUSIVE SOCIAL PROTECTION ACROSS THE LIFE CYCLE

Women, children, youth, older persons, informal workers, rural populations, persons with disabilities, LGBTIQ+ populations, indigenous people, ethnic and linguistic minorities, migrants, and forcibly displaced populations experience distinct vulnerabilities that put them at a higher risk of social and economic exclusion. Many individuals are highly vulnerable because they face compounded discrimination due to multiple identities and risk factors related to their socio-economic characteristics and/or location. It is therefore important for any inclusive system to consider the multiple and overlapping vulnerabilities individuals face at different times over the life course. For example, women and girls with disabilities commonly confront compounded vulnerability linked to age, disability, and gender discrimination. In turn, these vulnerabilities influence the nature of support required by the social protection system, and the relative importance of the functions relating to income security, disability-related costs, access to healthcare and economic empowerment.

**A life cycle and gender responsive framework is useful for exploring the specific considerations required by inclusive social protection to provide adequate support to persons with disabilities in a diverse range of circumstances.** The following sections briefly highlight prominent barriers faced at different life cycle stages (childhood, working age, and older age) and concerning gender, and key considerations for building inclusive social protection systems. For each life-cycle stage, illustrative case studies are included to highlight the potential role for social protection systems.

### 2.2.1 Childhood

**People who are born with impairments or who acquire them in childhood face particularly high levels of social exclusion which vary tremendously depending on the context.** Certain barriers are particularly notable for children with disabilities, including:

- **Stigma:** Negative beliefs pervade about what causes disability, and this is often exacerbated for children born with disability. This can lead to social isolation, such as children with disabilities being hidden away. Girls with disabilities often face compounded stigma and discrimination linked to both their gender and functional limitations.

- **Education (including early learning opportunities):** Children with disabilities are 49 per cent more likely to have never attended school than those without disabilities, and significantly less likely to have foundational numeracy and literacy skills (UNICEF, 2021). Education disparities are more pronounced among girls, the bottom quintile, and children living in rural areas (UNICEF, 2021). Despite the push to accelerate inclusion education, segregated models of education delivery persist leaving large numbers of children with disabilities isolated from the school community and quality education. This has a lifelong impact on social and economic opportunities of children with disabilities. Beyond barriers in the education system, lack of available and affordable assistive technology and rehabilitation, medical care and accessible transport significantly undermine access to education of children with disabilities.
- **Separation from family:** Discrimination, extra costs of disability, and lack of support services can push families to place their children in residential institutions. In the Europe and Central Asia region, children with disabilities are 17 times more likely to be institutionalized than children without disabilities (Jones, 2019). Such institutions are grounds for widespread human rights violations. In many countries, children with disabilities are overrepresented in orphanages. Growing up in an institution is damaging for any child, but particularly for children with disabilities because Institutional settings cannot provide the nurturing relationship, nor the attachments needed to support their development and participation in the community (Jones, 2019).
- **Health care:** Children are particularly vulnerable to gaps in access to affordable health care, and this can be a contributing factor to children acquiring a disability. There is also commonly a lack of specialised medical and (re)habilitation services in place for children with disabilities, and provision of assistive devices with such services often only available in major cities and unaffordable.
- **Transitioning to independent life:** Transitioning to adulthood involves making choices for oneself about employment, living arrangements, family formation, among others. Ideally, during the adolescent years, children with disabilities will have gained the skills and knowledge they need to live independently. However, low levels of participation in school, limited access to medical services, including sexual and reproductive health, (re)habilitation services, and stigma and discrimination on the part of employers creates barriers to transitioning to independent living, particularly for adolescent girls with disabilities.

**Child poverty and disability are inextricably linked.** Children living in poverty are more likely to become disabled, while families of children with disabilities are often pushed into or deeper into poverty owing to disability-related extra costs, family break-ups and unemployment following the onset of disability. A particularly important issue is the opportunity costs of parents and carers of children with disabilities who forego paid employment to provide care and support to children. This situation is exacerbated by covariate shocks, as has been illustrated by the COVID-19 crisis, where children with disabilities have experienced particular socio-economic marginalisation.

**Social protection can play an important role in supporting inclusion of children with disabilities.** Social protection schemes can directly address **disability-related extra costs** through provision of services and cash benefits. As part of this, they can also compensate for the opportunity costs of family members, often women and girls, who provide care and support to persons with disabilities. By addressing disability-related extra costs, social protection can reduce poverty of children with disabilities, but also facilitate access to services including education and early childhood development. However, one important consideration is how conditionalities may, in fact, create barriers to accessing social protection. This may be the case where receipt of social protection is conditional upon enrolling in a school which is inaccessible for children with disabilities, or where support is provided in an inaccessible service location (as with school feeding). Another critical consideration in building inclusive social protection are actions to move away from institutionalization of children. Provision of adequate community support services is central to this endeavour.

The case of Maria (Box 2.1.) illustrates some barriers faced by children with disabilities and the potential entry points for social protection.

**Box 2-1: Children with disabilities: The case of Maria**

**Maria** is six years old, and has had an intellectual disability from birth. She faces a number of important issues that a more inclusive social protection system could help address.

Before Maria was born, her parents were already struggling to **earn a living** with their combined income only putting them just above the national poverty line. The arrival of a child would have already put pressure on household finances, but the **disability-related extra costs** associated with Maria's disability have been particularly difficult for the family to manage. The only public support available for Maria is to put her in an institution, which her parents are unwilling to do. The national **health care** system does not provide the assistive devices that Maria requires. This means that the family must cover costs including:

- Paying for (re)**habilitation sessions, assistive devices**, and adapted learning materials so that she can attend school.
- Maria's mother has stopped working to support her (an **opportunity cost**), meaning they rely exclusively on the father's income.

The extra costs and squeezed income mean that Maria's parents are taking on ever-increasing levels of debt.

## 2.2.2 Working age

**Persons with disabilities of working age face significant barriers to independent living and economic empowerment.** Across the globe, levels of employment for persons with disabilities are consistently lower than the average, and they are more likely to be working in the informal economy where earnings tend to be lower (ILO, 2020). Women with disabilities are less likely to be in paid employment than men with disabilities and people without disabilities (ILO, 2020). Evidence points to women's with disabilities higher engagement in unpaid work than women without disabilities (UN, 2019). Lower level of earnings means persons with disabilities are more likely to live in poverty. This is particularly acute for those who acquire a disability at birth or during childhood, as they commonly miss out on invaluable learning and development. However, it is also the case for those that acquire a disability after reaching adulthood. Significant barriers exist to the economic inclusion of persons with disabilities, such as discrimination, inappropriate working environments and higher costs faced for participation in the labour market.

**Social protection systems can play a critical role in promoting independent living and economic empowerment, but this will require a shift in thinking about their role.** There is a tendency for cash benefit schemes to focus solely on providing a minimum level of income security, based on a logic of the "incapacity to work". While recognising the challenge that persons with disabilities face in earning income, this perpetuates the misconception that persons with disabilities cannot participate in the labour market and therefore will need to be dependent on others. A sole focus on minimum income replacement/security also fails to recognise disability-related costs both for those working or not working, which have crucial impact on socio-economic inclusion.

**An inclusive social protection system recognises both the significant income earning potential of most working age persons with disabilities but also the significant barriers they face in doing so. This requires provision of adequate and flexible support.** It also recognises the diversity of persons with disabilities, in that some will be in position to work full-time, others may only be able to engage in partial employment, while others with very high and complex needs may not be in position to do so for now.

An inclusive approach involves going beyond a sole focus on minimum income replacement to also address disability-related extra costs – including those related to seeking and keeping work such as transportation, support services – such as rehabilitation, personal assistants, return to work programmes and assistive

devices. This implies avoiding “get it all- lose it all” schemes<sup>2</sup>. Rather it facilitates risk taking by **ensuring coverage of disability related costs for those working and gradually phasing out income security schemes while facilitating re-uptake in case of loss of work**. In contexts with few social protection schemes, **ensuring that the sole disability benefit is compatible with work is critical to provide basic support for those seeking work**.

Economic empowerment of adults with disabilities also involves a labour market that provides an enabling environment for persons with disabilities. An important part of this equation is to **link social protection schemes to labour market policies** that directly promote economic empowerment.

The cases of Zeyneb and Andrei (Box 2-2) capture some important dynamics of disability for working age adults, and entry points for social protection.

### Box 2-2: Working age adults: the cases of Zeyneb and Andrei



**Zeyneb** has been deaf since she was 3 years old. She was able to complete high school and got an accountancy diploma. Due to discrimination, she could not find the job she was qualified for, but her salary nevertheless allows her to achieve a **basic level of income security**.

However, she still faces important **disability-related extra costs**. She spends more money on mobile data plan than average, to use video calls and she also needs to use sign language services which are very costly.

**Andrei** is 30 years old and has been blind since birth. He lost his job in the last economic crisis and has not been able find another one. Employers imply that it would cost more to recruit him compared to candidates without disabilities.



With no income, he is dependent on his family and what they can provide him to achieve a **basic income security**. Meanwhile, he also has disability-related extra costs, including:

- He needs a good smartphone with accessible features.
- He has to travel by taxi to look for work as public transportation in his city does not facilitate mobility for a blind person.
- He has to employ a personal assistant or ask for support of a family member to access health services or seek work. In most cases he asks family members which limits their own earning capacity (an opportunity cost).

Overall, while his family members support him to the extent they can, this is not sufficient to cover necessary costs, which limits his potential to search for a new job. It also puts pressure on the finances of his family members.

### 2.2.3 Older age

**Increased prevalence of disability with age significantly limits the income security of older persons.** Global estimates suggest between 38 and 46 per cent of older persons globally (aged 60 and over) live with moderate to severe disability, compared to between 15 and 16 per cent of the population on average (WHO, 2011). Older persons with disabilities include those with disabilities from birth, those acquired in childhood or working age, and those acquired at older ages. In the absence of effective pension and in-home care and support services, older persons increasingly rely on their families for support, which can

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<sup>2</sup> When most or all disability related support (cash transfer, health insurance subsidy...) is linked to the obligation of not working and/or to a poverty eligibility threshold, there is no support available for persons with disabilities seeking and finding work even though their disability related costs tend to increase (transport, assistive products...). This type of approach creates a get all support or lose all support dilemma for people seeking economic empowerment.

contribute to pushing a household into, or deeper into, poverty and can also limit the autonomy, dignity, and social participation of older persons.

**The significant disability-related extra costs faced by many older persons with disabilities are not well-recognized.** Pension systems are intended to provide income security in old age through a mix of contributory and non-contributory schemes (ILO, 2021). While around 78 per cent of people above retirement age receive a pension, significant disparities across regions, between rural and urban areas and between women and men persist (ILO, 2021). Pensions typically should be conceptualised as replacing income from employment however, adequacy of pensions, particularly non-contributory social pensions protection remains a challenge in the face of ageing populations, low contributory capacity, and limited fiscal space (ILO, 2021). Even if old-age pensions cover basic costs in old age, the benefit value does not account for the fact that many older persons have substantial disability related costs.

One area of disability-related costs with particular relevance for older persons is care and support. Older persons in low- and middle-income countries typically have to look to families – and mainly women and girls – for unpaid care and support. In addition, demographic change is resulting in sharp increases in the “older old” – typically understood as those above the age of 80 years – who are more likely to require care, but also fewer children to share this role. The number of older adults requiring support for activities of daily living is estimated to quadruple by 2050 ([The Lancet, 2021](#)). Investments in collaborative care models which bring healthcare including geriatric services, and social services such as personal support and long-term care services will be crucial as the global population ages.

#### Box 2-31: Older person with disabilities: The case of Yusef



**Yusef** is 75 years old and became a wheelchair user after an accident in his 40s. He received a disability pension until retirement age and now an old age pension which provides a **basic income security**. His old age pension is much lower than it would have been if he had been able to return to work after his accident.

He also has **disability-related extra costs**:

- As his family does not live nearby and works, he must pay for a personal assistant to get out of bed, get dressed, do domestic chores and to get around.
- He has to pay for specific transportation as buses are not accessible.
- He also pays for repair of his wheelchair as this cost is not covered by his **health insurance** scheme.

His family provides some money to cover these costs, but it is not sufficient. They are also only able to provide care and support some days as they are working full time. Eventually, these costs mean he will have to sell his home and move in with his family, which will limit his own independence.

### 2.2.4 Gender

**Women and girls are disproportionately impacted by disability.** Global estimates suggest that women are more likely to be living with disability, especially in old age, while they also face greater exclusion across a range of dimensions (WHO, 2011). Failure to address the gender dimensions of the disability gap will keep disability inclusion out of reach. Women and girls with disabilities face “double discrimination” resulting from their impairment and gender, putting them at greater risk for exclusion and violence and abuse. This double discrimination is further compounded by other characteristics such as age, belonging to ethnic, linguistic, or indigenous group, migration status, place of residence, or sexual orientation that result in discrimination and marginalization.

Women with disabilities are less likely than other adults to be employed, more likely to be out of school, have unmet health needs and are also more likely to be institutionalised. Available data reveals that compared to men without disabilities, women with disabilities are three times more likely to be unable to

read, three times more to have unmet health care needs, and two times less likely to be employed (UNDESA, 2020). Poverty is disproportionately higher among women and girls with disabilities, with gender and disability (UN Women, 2017) being multidimensional poverty determinants (UN ESCAP, 2018). The social and economic isolation women and girls with disabilities experience contributes to the increased likelihood that women and girls with disabilities will experience gender-based violence; they are three times more likely to experience gender-based violence compared to peers without disabilities (UNFPA, 2009).

Women and girls, including women and girls with disabilities, are also disproportionately affected by the nature of care and support arrangements for persons with disabilities. Where families take on the primary responsibility for care and support, it is primarily women and girls that fulfil this role, with the vast majority of unpaid carers worldwide being women (Addati and al, 2018). This contributes to reduced education and economic opportunities for women and girls, which poses an issue for women themselves including not earning pension entitlements for old age, wider households and the economy as a whole.

**Given these issues, it is critical to apply a gender lens to make social protection systems inclusive, in terms of policy development, scheme design and delivery.** This involves recognising how gender inequalities may intersect with disability, and how it can compound the exclusion of women with disabilities. Applying this gender lens implies proactively involving women with disabilities in decision making, considering women's realities in scheme design and disaggregating data by sex. Doing so can support the greater inclusivity of social protection schemes in various respects, from designing schemes in a way that better address the particular circumstances of women with disabilities, to addressing specific issues faced in accessing delivery systems. A gender lens also points to the importance of strengthening formal community care and support services to reduce the disproportionate burden of unpaid care on women and girls.

## **2.3 KEY GAPS AND CHALLENGES UNDERMINING INCLUSIVE SOCIAL PROTECTION**

While there is a broad acknowledgement that social protection has significant potential to support inclusion of persons with disabilities across the life cycle, most social protection systems in low- and middle-income countries fall short of effectively providing the required support. Latest data shows that despite their significantly higher support needs, children with disabilities have similar likelihood of living in a household receiving social protection than those without and adults with disabilities only slightly more likely.

The key gaps undermining effective support from social protection systems are summarised below and organized according to the key features of disability-inclusive social protection described in Key concept 2 above. All gaps are further exacerbated by precipitant inequalities in society, including but not limited to gender gaps, urban-rural gaps, and gaps between wealth quintiles. Greater efforts are required to generate evidence around the disability development and intra-disability gaps.

While low- and middle-income countries face challenges in developing inclusive social protection systems that are efficient and effective, fragile and humanitarian contexts have additional and significant challenges that need to be considered when developing inclusive social protection systems. In fragile contexts national institutions tend to be weaker or unstable, administrative systems are underdeveloped, if existent at all, human resources for delivery of public services is limited, and fiscal space is constrained with high reliance on short-term, international financing. Building comprehensive inclusive social protection systems in fragile contexts requires an incremental, step-wise approach that promotes disability-inclusion and increase age- and gender-responsiveness.

**Key feature 1: Combination of schemes purposefully designed to support socio-economic participation and inclusion**

- **LOW COVERAGE OF CASH DISABILITY BENEFITS:** Globally, only around a third (34 per cent) of persons with severe disabilities receive a disability benefit (ILO, 2021). However, this average is strongly influenced by higher levels of coverage in high-income countries at 86 per cent compared with 41 per cent in upper middle-income countries, 11 per cent in lower middle-income countries and 9 per cent in low-income countries (ILO, 2021). Disability has the lowest coverage among the five policy areas of the Social Protection Floor in low- and middle-income countries. Key drivers of this low coverage include the limited number of countries with non-contributory cash benefits in place (only 36 per cent of 188 countries considered in the 2021 ILO World Social Protection Report), and that those in existence are often limited to those deemed to be living in poverty.
- **FOCUS OF CASH BENEFITS ON INCAPACITY TO WORK:** While few low- and middle-income countries have recently adopted a more inclusive approach, disability related social protection benefits are often provided based on an incapacity to work requirement. As a result, existing cash benefits relate almost exclusively to basic income security primarily for those with more severe levels of disability. This ignores the significant disability-related costs faced by persons with disabilities both inside and outside the labour force. It also fails to recognise disability related costs of children and older persons with disabilities and how addressing these costs could support participation across the life cycle, including in paid employment.
- **LIMITED PROVISION OF REQUIRED GOODS AND SUPPORT SERVICES:** In low- and middle-income countries, only a small share of those who need assistive devices have access to them. Meanwhile, meaningful systems providing community support services are virtually non-existent in most low- and middle-income countries, placing the primary responsibility of care and support on families. While many countries have concessions (such as discounts, subsidies, and tax-exemptions), their design often limit their contribution to covering disability-related costs.
- **BARRIERS IN ACCESS TO HEALTH CARE:** Persons with disabilities tend to have higher needs for health care than those without but face significant barriers in terms of accessibility, affordability and the breadth of services covered, including the provision of rehabilitation and assistive devices. This contributes to elevated levels of catastrophic health expenditure and higher forgone health treatment.
- **UNACCESSIBLE AND NARROW DISABILITY ASSESSMENT:** Disability assessment is a key mechanism for identifying persons with disabilities and the support they require. However, in most countries, it is still framed by a medical model that focuses solely on medical assessment of impairments. Limited account is usually taken of actual functional limitations, the barriers persons face to participation and their support needs. In addition, setting medical assessment by doctors as an initial requirement often restrict access in many countries where medical human resources and facilities are not widely available, especially in rural areas.
- **HIGH EXCLUSION ERRORS:** For disability specific benefits, the focus on medical and/or complex disability assessments limits access to disability determination mechanisms of many people in need of support in most countries. This happens due to shortage of qualified staff as well as travel and opportunity costs for persons with disabilities and their families. For means tested benefits (both mainstream and disability specific), the lack of consideration for disability related costs in means test thresholds and formula exacerbate the inherent exclusion errors related to poverty targeting. In many contexts, the combination of poverty targeting, and disability determination related issues structurally limit access to support.

**Key feature 2: Accessibility and non-discrimination**

- **INACCESSIBILITY:** Persons with disabilities face additional barriers to accessing social protection benefits and services, which result in exclusion and/or entail high costs. Important issues relate to physical access (including distance to reach service points, and the physical environment) and information and communication.
- **DISCRIMINATION:** Discriminatory attitudes towards persons with disabilities influence the design of social protection schemes as well as the delivery of social protection benefits and services. Also,

the lack of attention to supply side inclusiveness issues in conditional cash transfer (inaccessible health care and education among others) may inadvertently discriminate persons with disabilities and their families.

***Key feature 3: Respect for dignity, personal autonomy, choice, control over one's life and privacy***

- **PERSISTENCE OF MEDICAL AND CHARITY APPROACH:** Factors such as medical and charity approaches to disability and inadequate attention to enabling participation of persons with disabilities have contributed to service models based on the idea of dependence, resulting in segregation and institutionalization of persons with disabilities, limiting their opportunities to live independently in and as part of their communities. They are also compounded by stigma and discrimination. As a result, children with disabilities are more likely than those without to be placed in segregated settings or face neglect and abuse. Also, with cash transfer being often household based, persons with disabilities are less likely to exert control over the use of social protection support.

***Key feature 4: Participation of persons with disabilities***

- **LIMITED ENGAGEMENT:** Recent studies show that while there has been an increasing effort to engage with OPDs in the development of programs and policies and many countries have adopted specific national consultations mechanisms, their effectiveness has been limited. Consultations with OPDs are still mostly focused on disability specific programs and policies and are rarely meaningful in terms of process. There are significant issues in terms of access to information as well as investment in capacity of OPDs to meaningfully participate. Diversity of persons with disabilities still need to be further recognise and foster in efforts to ensure meaningful participation, including the participation of young people and women with disabilities.

All these factors contribute to undermine impact of social protection systems leading to higher levels of poverty and social exclusion amongst persons with disabilities and their families, and greater exposure to other risks and vulnerabilities they may face throughout the life cycle. They also constitute a lost opportunity to harness the significant contributions that persons with disabilities and their family can make to the national development of social and economic life of a whole country.

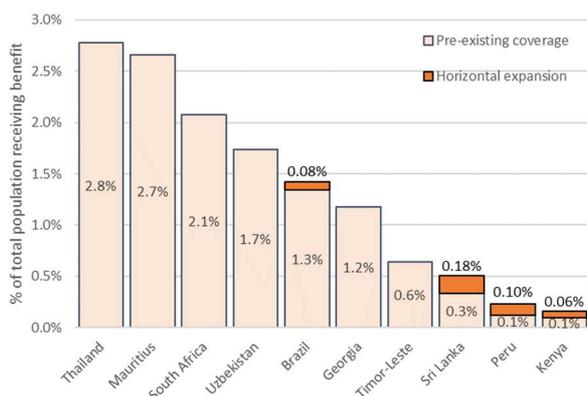
### Lessons learned from the COVID 19 crisis (Knox-Vydmanov et al., 2021)

Unfortunately, the COVID-19 crisis has only confirmed that persons with disabilities of all ages and their families are more vulnerable to shocks and social protection systems in most LMICs are not yet designed to support them effectively.

**People with disabilities have been particularly vulnerable to the impacts of the COVID-19 pandemic.** Prior to the crisis, households with persons with disabilities were more at risk of poverty, had lower savings, had on average fewer members in employment, higher informality among working people with disability, higher dependency ratios and unpaid care burdens (especially for women), and greater difficulties to access health care education which made them more likely to be severely impacted by the crisis.

**The social protection response to COVID-19 has considered persons with disability to a certain extent, but national systems were not ready for an inclusive response.** Just under half of countries that announced social protection measures (44 per cent) specifically referred to persons with disabilities, representing in total only 9 per cent of the all the measures surveyed by the ILO as of May 2021. The lack of community support services in most LMICs limited the kind of measures specifically targeting to persons with disabilities mostly to cash benefits with very few countries providing additional services.

The vertical expansion of schemes was the most common type of adjustment to disability benefits with many cases involving meaningful increases in benefit levels for a substantial duration of time (6 months or more). However, vertical expansion needs to be understood in relation to the adequacy of regular benefits. For example, value of topped-up disability benefits in Thailand remained below those provided in normal times in countries such as Brazil, Georgia, Mauritius and South Africa. Additionally, coverage of schemes was initially often very low.



Very few countries have an adequate disability registry and inclusive social protection MIS allowing that would have allowed rapid and effective horizontal expansion as identification of persons with disabilities has been an even greater challenge in the midst of COVID-19. Pre-existing significant coverage gaps therefore persisted during the crisis despite the efforts of governments and organisations of persons with disabilities who provided them critical support for identification of new beneficiaries.

In some countries, there are evidence that persons with disabilities have been reached by expansion of existing mainstream schemes and ad hoc measures. In **Indonesia**, where only 5% of persons with disabilities accessed disability specific social protection prior the crisis, the combination of diverse mainstream interventions (utilities subsidies, ad hoc cash transfer) significantly increased their access to basic support. A key factor was the mobilisation of local authorities, who often prioritised people with disabilities, used the nascent disability registry and engaged with OPDs. However, globally persons with disabilities have reported the lack of accessibility to information about schemes and to facilities providing relief, and few appeared to have been designed and implemented in inclusive ways.

An in-depth look also showed that countries with stronger social protection systems, with broad coverage through life-cycle benefits including a disability allowance, were in better position to respond than those with no schemes or narrowly poverty targeted schemes. One potential silver lining, if any, is that the crisis has mobilised considerably the disability movement to engage more with social protection. In several countries, organisations of persons with disabilities played a significant role in facilitating outreach to persons with disabilities in absence of inclusive social protection information systems and have also been provider of vital assistance to people with disabilities. At national or regional level, OPDs advocated for inclusive social protection such as the [call for action in Africa](#).

Overall the crisis confirmed what we already knew but gave a depth and an urgency to some key elements: Build disability registries and inclusive information systems as a key pillar of inclusive and shock-responsive social protection, expand disability benefits towards universal coverage, develop combination of cash, concessions and supports services to better address disability related costs, improve inclusiveness of mainstream social protection schemes and actively involve OPDs in the design, and implementation of social protection programs, including during times of crisis.

## **PART 2: BUILDING INCLUSIVE SOCIAL PROTECTION SYSTEMS FOR PERSONS WITH DISABILITIES**

### **3 COMBINING SOCIAL PROTECTION INSTRUMENTS FOR ADEQUATE SUPPORT ACROSS THE LIFE CYCLE**

Inclusive social protection systems for persons with disabilities, regardless of the country context, require combination of **cash benefits, concessions, and services** to provide basic income security, address disability-related costs and health care costs, and support access to other services. **This section provides an overview of the broad categories of instruments and types of schemes that might be combined to achieve inclusive social protection for persons with disabilities.** Key considerations for the different options are laid out in more detail in subsequent sections focusing on different instruments as well as **general design principles that can be applied to increased inclusion of persons with disabilities.**

- **Contributory and non-contributory cash benefits** play a particularly important role in supporting income security, either via disability-specific schemes, or via mainstream schemes. Specifically designed non-contributory cash transfers can also offset disability-related extra costs. Cash benefits supplement income and allow more flexibility in discretionary spending enabling households to meet their diverse needs.
- **Concessions and community services** come in the form of support services and discounts, tax credits or subsidies which contribute to reducing out-of-pocket disability-related extra costs.
- **Social health protection** helps to overcome access issues related to financial barriers and avert financial catastrophe as a result of out-of-pocket health expenses. It not only reduces out-of-pocket spending, but also addresses the risk of poverty related to ill health.
- **Disability identification, assessment and determination** mechanisms are essential for social protection systems to effectively target disability specific support, to facilitate case management and policy planning for inclusion.
- **Linkages to economic empowerment programmes and other services** are critical to support the increased participation of persons with disabilities in economic activity (including childcare, education, employment services financial inclusion programmes, protection services and programmes to reduce discriminatory norms and practise), thereby increasing income security, poverty reduction and inclusion.

The combination of programmes will vary for each country depending on the maturity of the social protection system, what goods and services are available, fiscal space, institutional capacity, among other factors. **The mix of mainstream and disability specific schemes** will also depend on the level of inclusiveness of mainstream schemes: **the less mainstream schemes cover specific needs of persons with disabilities across the life cycle, the more disability specific schemes will be needed.**

Table 3-1 sets out examples of different social protection schemes in terms of the category of social protection instruments, the functions they mostly support, and how they relate to the lifecycle. The Table also highlights, for cash benefits, which schemes are disability specific. Some key points are worth highlighting.

**Table 3-1: The main categories of social protection instruments, types of schemes and related functions across the lifecycle**

CATEGORIES OF INSTRUMENTS	EXAMPLES OF TYPES SCHEMES ACROSS THE LIFE CYCLE			MAIN FUNCTION
	CHILDHOOD	WORKING AGE	OLD AGE	
CASH BENEFITS <sup>3</sup>	Poverty assistance cash transfer, cash for work			INCOME SECURITY
	Child grant/family benefits	Unemployment, maternity, sickness, parental leave benefits	Old age pensions	
	Caregiver benefits	Disability related income replacement benefits		
	Child disability benefits	Disability costs basic allowance/top up schemes		COVERAGE OF DISABILITY-RELATED COSTS AND HEALTH CARE COSTS
	Third person support / caregiver benefits			
IN KIND BENEFITS	<b>Concessions</b> Health insurance/cost coverage including early intervention, rehabilitation, assistive technology, free or discounted public transport, subsidised utilities, tax exemptions			COVERAGE OF DISABILITY-RELATED COSTS AND HEALTH CARE COSTS
	<b>Services</b> Health care, Nutrition, Case management Community care and support, personal assistance schemes, interpreters, respite care, counselling, point to point transport, housing, assistive products maintenance			
INTERLINKAGE	Early childhood development, childcare, education	Economic inclusion/ empowerment programmes, decent work programmes, return to work programmes, women's empowerment, protection services, financial inclusion services		CONNECTION TO OTHER SERVICES

**It is important to note that many of the instruments outlined in the following sections serve a primary function they can contribute to more than one function.** For instance, parental leave programmes (contributory social insurance) and care giver benefits (non-contributory cash transfers) contribute both to income security of the households, by ensuring and providing a consistent income stream, while covering disability related costs related to care and support, albeit with potential issues with regards to choice and control for adults with disabilities. This may allow parents of children with disabilities to fulfil both their productive and caregiving roles without a financial penalty. When assistive devices and (re)habilitation are covered by health insurance schemes, they not only lower out-of-pocket health care and disability related costs, but they also contribute to income security as they may facilitate efforts of persons with disabilities to engage in economic activity.

**At an individual and family level, these schemes can interact in multiple ways.** To illustrate the way in which such schemes may interact, Box 3-1 provides some examples of how income security and disability-related costs might be addressed for the case studies introduced in the previous section. The specific considerations for benefits falling into these categories are described in the following sections. In addition

<sup>3</sup> Cash benefits in the light green boxes represent the mainstream cash benefits which play a critical role for income security that anyone, including persons with disabilities. The dark green boxes represent cash benefits that are disability specific.

to the schemes mentioned in the table, *all characters in the case studies below would benefit from affordable health insurance and/or free health care provisions.*

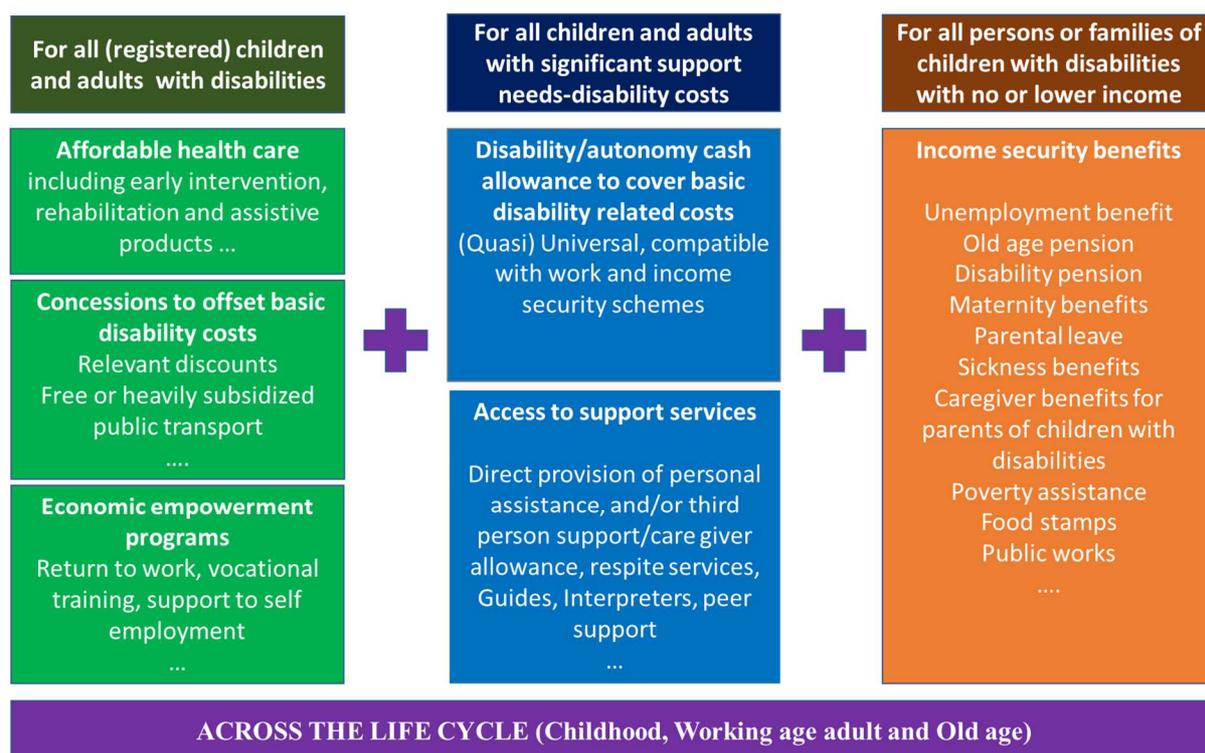
**Box 3-1: Combination of schemes across the life cycle**

Case	Income security	Disability-related extra costs
<p><b>Maria</b></p> 	<p>The income security of 6-year-old Maria's household will be influenced by mainstream schemes not specifically related to disability. These include <b>child and family benefits</b> to support the costs of raising children, <b>poverty assistance</b> seeking to address poverty and schemes protecting her parents from other risks such as, <b>maternity, sickness</b> and <b>unemployment</b> benefits.</p>	<p>A <b>child disability benefit</b> would support Maria's household to manage the extra costs of disability. This could include covering the opportunity cost of the care provided by Maria's mother.</p> <p>This would also be supported by <b>concessions</b> and provision of <b>free/subsidised services</b> including rehabilitation sessions, assistive devices, adapted learning material.</p> <p>Provision of <b>care services</b> could support her mother to enter employment again, thus boosting the family's income security.</p>
<p><b>Zeyneb</b></p> 	<p>Since Zeyneb is in work (and assuming her income is adequate) she does not require specific support to her income security. She would meanwhile benefit from <b>mainstream social protection schemes</b> ensuring income security in the case of other life cycle risks (such as <b>maternity</b> and <b>sickness</b> benefits, employment injury insurance, earning entitlements for contributory old age pensions or unemployment insurance).</p>	<p>A disability inclusion/support allowance and provision of assistive devices and services could reduce Zeyneb's extra costs related to mobile data plan and sign language services.</p>
<p><b>Andrei</b></p> 	<p>A <b>disability benefit</b> addressing income security could compensate for Andrei not being able to find paid work, providing a minimum level of income security until he finds employment.</p>	<p>A <b>disability inclusion/support allowance</b> and/or <b>provision of services and concessions</b> could reduce Andrei's costs on an accessible smartphone, transport and a personal assistant.</p> <p>In turn this could support his efforts to find work, helping to boost his income security.</p>
<p><b>Yusef</b></p> 	<p>An <b>adequate pension system</b> can ensure Yusef has a minimum level of income security in old age.</p> <p>Meanwhile, effective <b>employment injury protection</b> and <b>disability benefits/supported</b> earlier in his life may have supported him to reengage in employment, thus increasing his income in old age by maintaining his attachment to the labour market and continuity of his social security contributions.</p>	<p>A <b>disability inclusion/support allowance</b> and/or <b>concessions</b> could support Yusef to cover extra-costs such as transport and his wheelchair (that could also be provided in kind).</p> <p>A <b>caregiver benefit</b>, or <b>direct provision of support services</b> would reduce extra costs related to his personal assistant.</p>

It is important to note that **inclusive and universal support to support does not imply that all persons with disabilities will get all existing disability benefits**. All persons with disabilities must have access to affordable health care, including assistive technology and rehabilitation and benefit from meaningful concessions that help offset some basic disability related costs. All children with disabilities need adequate inclusive education, all working age persons with disabilities should be able to access economic inclusion support, and all older persons should be able to access in-home care or long-term care as needed. However, in the spirit of the progressive realisation, it is important to ensure that those most in needs receive further support first. While this has often been understood from an income point of view which is typically measured at household level, a CRPD compliant approach requires to factor the extent and type of support required to carry out activities allowing independent living and inclusion in the community. While means testing is relevant for basic income security, it is much less so when it comes to disability related costs support. Indeed, individuals or parents of children with disabilities from non-poor households can face significant extra costs that will not only severely restrict their autonomy and participation but will also exert significant downward economic pressure, undermining resilience to shock and increasing risk of poverty.

Figure 3-1 below proposes an example of distribution of social protection benefits and services according to the level of needs of different groups of persons with disabilities. To enable such a distribution, it is critical that disability assessment and determination mechanisms meaningfully take support needs into consideration.

**Figure 3-1:** Distribution of different social protection benefits based on level of needs



## 4 CONTRIBUTORY AND NON-CONTRIBUTORY CASH BENEFITS

**Contributory and non-contributory cash benefits are aimed at minimizing vulnerabilities and supporting households' income in response to poverty, shocks, or lifecycle risks.** Both are primarily aimed at replacing income – partially or fully – in response to shocks or risks. Though non-contributory cash benefits can play an important role in compensating for disability-related costs. Depending on the design they can have

different relevance for disability inclusive social protection systems, particularly in terms of coverage and adequacy of benefits.

#### Key Concept 4: Contributory vs. non-contributory schemes

- **Contributory schemes** require formal contributions by workers and/or employers to be eligible for a scheme, and these schemes are usually financed exclusively (or primarily) from these contributions. In some cases, general government revenues or earmarked taxes are sources of financing. However, most low- and middle-income countries only have small percentage of the workforce in formal employment and in a position to contribute, while the majority are working informally. Also, cash benefits provided by contributory schemes are usually earnings-related – meaning the benefit level is related to previous contributions so that workers with longer contribution periods and higher earnings receive higher benefits.
- **Non-contributory schemes** are usually financed by general government revenues. Cash benefits provided by non-contributory schemes are usually flat rate, that is, they are not dependent on previous income. Benefit levels for non-contributory schemes are often of significantly lower value than equivalent contributory schemes. Non-contributory programmes also tend to have low coverage rates, especially if programmes have narrow eligibility criteria.

In most low- and middle-income countries, cash benefits for persons with disabilities, whether contributory or non-contributory, are often focused on basic income replacement and security, and tend to not address disability-related costs. In addition, there is often only one main disability benefit, with focus on working age adults which often relates to incapacity to work. **In any case, many schemes also fall short in terms of basic income security provided, let alone coverage of disability related costs.** (Box 4-1).

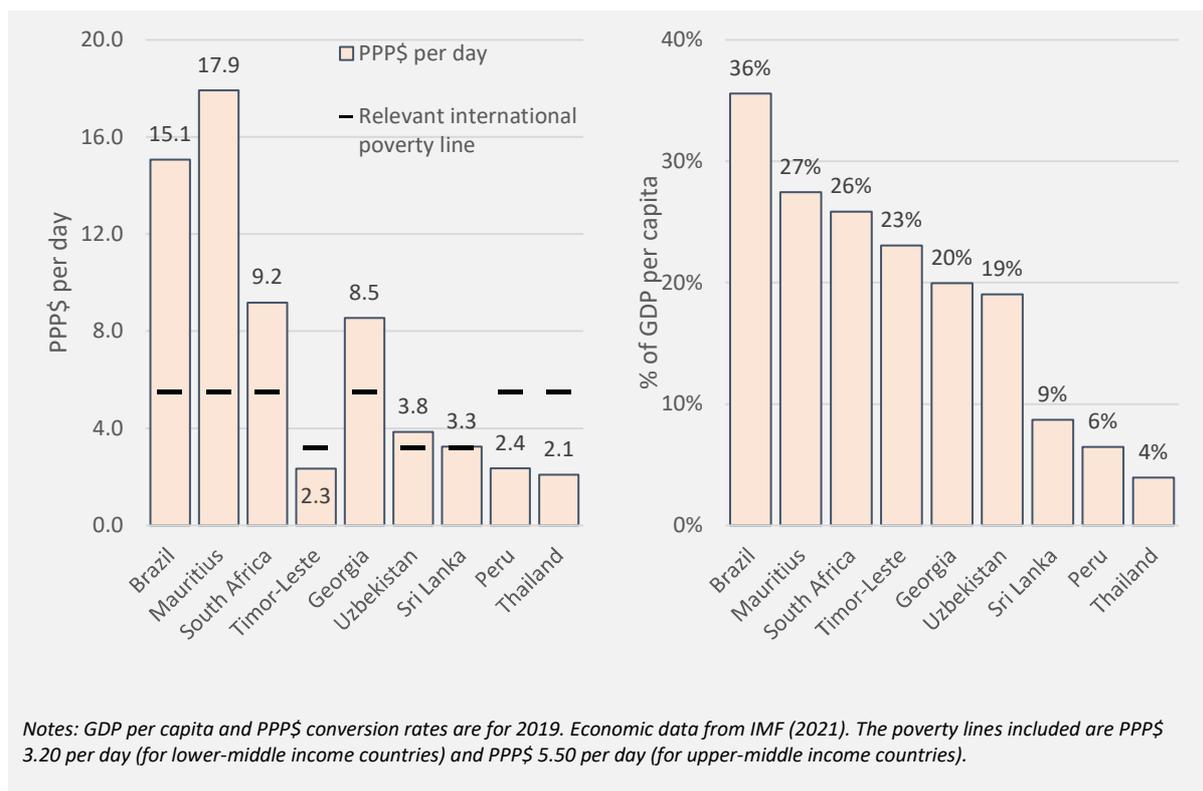
#### Box 4-1: Adequacy of disability-specific benefits addressing income security

For **contributory** schemes, adequacy is usually measured in terms of the extent to which they provide income replacement against previous earnings (measured by a replacement rate). Many countries around the world have “invalidity” benefits in place that legally comply with international standards on minimum benefits for persons losing all or part of their earned income due to acquiring a disability. Many countries also have employment injury benefits which may include provision for better and long-term disability benefits. However, even in such schemes, many workers may not have contributed to receive the full (or even any) benefit at the point they acquire a disability. Some contributory schemes – including Provident Funds – provide only lump sum benefits which have limited potential to provide reliable income security for persons with disabilities beyond a few years.

For **non-contributory** schemes related to income security, the adequacy of benefits can be measured against benchmarks of a minimum adequate income such as poverty lines (both international and national) and indicators of average earnings and wages. Figure 4-1 shows that, while benefit levels for non-contributory schemes vary significantly by country, benefits in countries such as Brazil, Mauritius, South Africa and Georgia which are among the few that can be considered to provide a minimum level of income security relative to international poverty lines.

In both cases, contributory and non-contributory schemes, benefits levels are set irrespective of people’s need and may not cover disability-related extra costs.

**Figure 4-1: Benefit levels of non-contributory disability benefits (PPP\$ per day and as a % of GDP per capita)**



## 4.1 CONTRIBUTORY CASH TRANSFER SCHEMES

**Contributory cash transfer schemes, often referred to as social insurance,** cover common lifecycle risks such as unemployment, ill health, retirement/old age, disability, and maternity. They contribute to the income security of persons with disabilities in different ways.

First, mainstream contributory schemes **address a broad set of non-disability-specific risks that affect household income security** such as unemployment, maternity or sickness benefits, old age pension. They provide support for contributing persons with disabilities.

In addition to the non-disability specific risks they cover, some of those schemes may be of particular relevance for persons with disabilities or their families:

- *Unemployment and (long term) sickness benefits* may be provided temporarily as for any other worker to persons with disabilities losing their employment or unable to work due to illness. They can also be provided for those who recently acquired an impairment before possibly transitioning to return to work and/or permanent disability benefits/pensions. This is a common logic within contributory social insurance schemes.
- *Old age pensions* play a particularly important role in ensuring income security of older persons with disabilities, considering the significant share of older persons with functional limitations who are de facto persons with disabilities even though many would not self-identify as such. According to the ILO (2021), half of the working-age population globally are legally covered by existing contributory schemes. However, there are significant variations by region and gender with implications for income security in old age. Legal coverage for men is 50 percent and 42.5 per cent for women (ILO, 2021).
- *Parental/family leave*, including maternity and paternity leave, can also provide an income security function in the short-term, where paid to parents for periods of absence from work to provide care and support to children or other relatives with disabilities. Only 43.8 per cent of the female

labour force are entitled to maternity benefits through social insurance and paternity benefits are only provided in 39 countries according to ILO (ILO, 2021).

Disability benefits which **directly address income insecurity stemming from loss of earning capacity related to disability**.

- *Disability benefits* (commonly called disability pensions or invalidity pensions) within contributory social insurance schemes are understood to provide a form of income replacement for workers deemed unable to work (conditioned to a work disability assessment). Such schemes usually require that individuals receiving benefits are not employed. In many respects, disability pensions provided for working age adults have the same function as old age pensions and, in many countries, recipients of disability pensions transition automatically to old age pensions when reaching the statutory retirement age. As of 2020, 33.5 per cent of the global working age population (those 15 years and older) is legally covered by mandatory contributory benefit with vast regional disparities: 13 per cent in South Asia to 54.3 per cent in Eastern Europe (ILO, 2021).
- *Employment injury schemes* have also a role to play for persons acquiring a significant impairment after occupational injury or disease. According to the ILO's World Social Protection Report 2020-22, 52 per cent of all workers globally are legally covered by an employment injury scheme, in case of an occupational accident or disease while effective coverage stands at 35.4 per cent (ILO, 2021). Conversely, this means that almost two-thirds of all workers are not covered for any form of income loss or medical treatment when they suffer a work-related accident or disease. The gap between legal and effective coverage suggests an enforcement problem and is also a result of high levels of informality.

**Due to progressive shift in disability policies towards inclusion but also because of increasing costs of such schemes**, higher income countries have moved towards more flexible disability related income replacement schemes and return-to-work programmes to (re)create or maintain attachment to the labour market of individuals with disability (OECD, 2022).

As mentioned previously, one of **the main limitations of contributory benefits is their limited coverage in low- and middle-income countries**. This is often related to the limited *legal* coverage of such schemes. Some countries only have disability cash benefits in place for public sector workers (such as civil servants and the military). Even schemes covering private sector workers may exclude those in certain categories of work not covered by national labour laws (such as the self-employed, agricultural workers, and domestic workers; these are sectors in which high proportions of women and migrants work). Meanwhile, the shape of the labour market – in particular high levels of informal employment in low- and middle-income countries – is also associated with low *effective* coverage of contributory schemes, with significant challenges for ensuring access for women and migrant workers. Another issue of particular note is that the requirement to have made contributions for a sustained period means that coverage mainly relates to those who will have an acquired a disability later in their working life rather than people born with or acquiring disability early in life. Women are more likely to have their careers and contributions interrupted due to care taking responsibilities for family members. These interruptions can lower the value of the pension benefits to which they are entitled. This is significant due to the higher proportion of women who live well into old age and are at an increased likelihood of acquiring a disability. Further, migrant workers may not be eligible for contributory schemes due length of employment or residency in a country.

## 4.2 NON-CONTRIBUTORY CASH TRANSFER SCHEMES

In the last two decades there has been significant expansion of non-contributory schemes in low- and middle-income countries, mostly with the aim of supporting vulnerable households that are unable to obtain a minimum standard of living due to labour constrained capacity (e.g., households with children, single parent/carer households, persons with disabilities or older persons), underemployment, or covariate

shocks. These benefits target households, depending on the composition of members and number of dependent household members. While a growing number of countries provide social pensions for older adults, fewer countries provide social pensions for persons with disabilities; just over a third of countries (36 per cent) have non-contributory disability benefit in place. An even smaller number of countries provided non-contributory cash transfers to specifically compensate for extra costs of disability. The most relevant non-contributory schemes for persons with disabilities are described below and illustrated in Figure 4-2.

- **Household benefits**
  - **Poverty assistance cash transfers:** For this guidance, poverty assistance refers to schemes that seek to provide support to households living in poverty. Examples of such schemes include conditional cash transfers (which are provided to poor households, e.g., with children linked to compliance with school attendance and/or health care activities) and unconditional schemes targeted at poor labour constrained households.
    - These schemes vary in terms of the proportion of the population they seek to cover (majority are targeted to the bottom quintile or decile) and the extent to which they explicitly address disability. This ranges from no specific attention to disability in targeting criteria to including disability as one of targeting criteria (this can be used to establish inability to work or for determining the number of “dependent” household members) or as a priority group for support.
    - The value of those benefits is usually low and is aiming more at consumption enhancement rather than true income security. Some countries seek to factor in the specific hardships faced by household with persons with disabilities and the greater challenges encountered by persons with disabilities in generating income to a certain extent by adopting higher means test threshold and/or providing higher value of benefits as in Indonesia and Zambia. However, adaptations made to programmes are usually done without understanding the full costs of disability, thus do not adequately account for disability related costs.
    - Benefits targeted at the household level rather than at the individual limit the control that persons with disabilities, who are not the head of household, may have on the use of the benefit.
  - **Child and family cash benefits** play an essential role in ensuring income security for families. 114 countries have some forms of statutory child or family benefit but only 40 countries have universal or quasi universal schemes. The coverage in terms of age and duration varies.
- **Old age and disability social pension schemes:** In many respects, social pensions perform a similar role to contributory pensions, though with lower adequacy of benefits, and are a crucial source of income for those outside the formal sector. This is especially true for women, given the challenges associated with contributory pensions discussed above. There are more countries providing social pensions for older adults than for working age adults with disabilities. The effectiveness of these schemes is constrained by a number of factors:
  - Disability pensions are often provided to persons assessed with a certain level of incapacity to work and are either means tested and/or incompatible with paid work.
    - Eligibility is usually limited to those deemed unable to work. This stems from a long-standing rationale for disability-related social protection as providing compensation for lack of income-earning capacity. This creates a dilemma for people with disabilities having to either prove their inability to work or working but losing their disability entitlements.
    - Disability assessment and determination processes that are complex and/or inaccessible and unaffordable.
    - Means testing creates additional barriers for persons with disabilities. They may be impacted not only by the significant exclusion errors inherent in all forms of

- poverty targeting, but also by the fact that means-testing methodologies – including proxy means testing which has become the primary targeting methodology in low- and middle-income countries – rarely take adequate account of additional disability-related costs (Banks et al., 2022; Kidd et al., 2019).
- In low- and middle-income countries these are often the sole disability benefit, which may undermine support for inclusion as the system does not address disability related costs of people seeking work, children, and older persons with disabilities. Like for contributory schemes, in many countries, recipients of disability social pensions must transition to old age pensions when reaching a given age.
  - Given that a significant share of older persons experiences some functional limitations and disability, old age pensions are particularly relevant for income security of persons with disabilities.
  - A common issue is that recipients of old age pensions often cannot get disability related cash transfers, leaving them without support to address disability-related costs.
- **Cash benefits designed to specifically cover disability related costs (compatible with work and with income security/replacement benefits).** In high income countries, there is a growing trend towards combining benefits strictly addressing work income replacement and those aimed at covering disability related costs. The former are means tested while the latter will have higher thresholds or no means test at all. If a person benefiting from both starts working, they may lose the first one, but keep the second one. Older persons may also benefit from old age pensions as well as benefits that address their disability related needs (even if they are more often labelled in relation to loss of autonomy). In low- and middle- income countries, except for a few countries providing child disability benefits, there are rarely cash benefits focused on addressing specifically disability related costs. Where cash benefits for disability related costs do exist they are generally designed to cover support and care, such as caregiver/third person support allowances, or cash benefits covering a general set of extra costs, such as:
    - **Disability allowance to address disability related costs** provided to adults in addition to different existing schemes addressing income security/replacement. They are typically universal, or affluence tested (means test excluding high earners) and compatible with paid work.
    - **Child disability benefits** are disability allowances provided to cover the additional costs for a child with disabilities. They should be compatible with other child and family benefits and income security schemes.
    - **Third person support benefits:** these are paid to a person with disability to cover the costs of human assistance by a third person in ways that promote choice and control. They could use these funds to purchase the services of a support assistant who could undertake tasks on their behalf. Examples of countries with such benefits in low- and middle-income countries are South Africa and Mauritius (See Box 4-2).
    - **Caregiver benefits** are paid to people, often women, who give up work – either partially or completely – to provide care and support for family members, either children with disabilities or adults with significant disability related needs. In effect, family members are providing a care service that would otherwise be paid for and they should be compensated for their labour. While caregiver benefits address some disability-related extra costs of a person with disability, they also address the income security of the individual providing care. Caregiver benefits are relatively rare in low- and middle-income countries. Examples include Cook Islands<sup>4</sup> (or Vietnam offers a benefit to carers of persons with severe disabilities (Banks et al., 2018)). While such schemes are mostly non-controversial for parents of children with disabilities, there are potentially issues in

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<sup>4</sup> <https://www.intaff.gov.ck/caregivers-allowance/>

relation to choice and control over benefits aimed at care givers of working age and older persons with disabilities.

- **“Hybrid” disability cash transfers.** Those are universal individual disability benefits, whose actual function depends on the individual circumstances, in countries where there is only one non-contributory disability cash transfer.
  - They are provided regardless of a person’s income from work. When the person earns an income, the benefit covers basic disability related costs. But if the person does not earn an income, it acts as basic income replacement. Examples of countries with schemes that provided disability extra costs benefits compatible with work include Fiji, Mauritius, Nepal, Vietnam, Thailand, and Georgia.
  - When those benefits are progressively made compatible not only with work but also with the different existing benefits that address income security across the life cycle such as family allowance, child grant, old age pension and poverty assistance, they become disability support allowances.
  - While initially not ideal because they do not adequately support people who are not in position to earn income, they provide more flexibility than schemes conditioned by incapacity to work, and they support evolution towards a truly inclusive system. For instance, in Fiji or Georgia the disability allowance is compatible to a certain extent with work as well as with poverty assistance and child benefits but not yet with old age pension.

**Box 4-2: Mauritius: a system of multi-tiered social protection cash transfer benefits for persons with disabilities**

Mauritius stands out as a country which – when compared with most low- and middle-income countries<sup>5</sup> – has put in place a relatively comprehensive and multi-tiered set of social protection interventions. These tiers include:

**INCOME SECURITY**

A flat-rate non-contributory universal **Basic Invalidity Pension (BIP)** is available for all persons with a disability under 60 years old, if the individual is assessed to have an assessed disability of at least 60 per cent. The benefit is compatible with work and with some means tested social assistance benefits. As discussed later in this paper, the adequacy of this benefit is high by international standards. All persons aged 60 and over are eligible for the country’s universal non-contributory **Basic Retirement Pension (BRP)**, which has the same benefit level as the BIP for most recipients.<sup>6</sup>

A **child allowance** is also available for carers who are recipients of the Basic Invalid's Pension. The child should be under the age of 15 (or 20 if in full-time education).

**Contributory invalidity and retirement pensions** also exist through the country’s social insurance scheme, with benefits paid in addition to the universal BIP and BRP.

A **carer’s allowance for parents for children with disabilities** with additional allowance if the child has high support needs.

Mauritius also has a **Social Aid** poverty-targeted social assistance programme. This includes several eligibility criteria relating to disability. It includes additional for beneficiaries of the Basic Pensions (e.g. BIP and BRP) who live alone, have to pay rent and have no other source of income.

**DISABILITY EXTRA COSTS**

<sup>5</sup> While Mauritius recently graduated to high income country status, it provides a relevant reference point for low- and middle- income countries.

<sup>6</sup> Recipients of both schemes receive MUR9,000 per month, apart from BRP recipients aged 90 and over that receive higher monthly benefits.

**For recipients in employment, the flat rate BIP covers disability-related costs** to different degrees depending on the support needs of the recipient.

A **Carer's Allowance** exists for adult recipients of both the BIP and BRP who are deemed to require "constant care and attention of another person."

Within the contributory system there also exists a **Constant Attendant Allowance** for an employee who has developed a disability and who requires constant attendance of another person.

Additionally, BIP recipient can benefit from concessions such as buses fare, health care and assistive devices.

*Source: Mauritius case study developed under the project ILO-UNPRPD COVID-19 response*

### 4.3 KEY DESIGN ELEMENTS TO SUPPORT INCLUSION

**Extending contributory and non-contributory cash transfers in low- and middle-countries to better reach and support persons with disabilities can be achieved in different ways.** Cash transfer programmes are essential for meeting the specific needs of persons with disabilities. They not only fulfil an income security function by providing regular and predictable transfers that enable persons with disabilities to purchase basic common necessities, but they can also address partially, but in a flexible manner, disability related costs.

Programme effectiveness can be constrained by low levels of coverage and inadequate benefit levels. Progressively moving towards higher coverage generally entails mobilizing and combining different types of schemes with different financing arrangements to ensure that everyone, particularly the most vulnerable are reached and appropriately supported.

Cash transfer programmes will need to shift away from a 'one-size fits all' approach grounded in a conceptualization of disability that equates with an incapacity to work and treats people with disabilities like other dependent household members. By recognizing differences among persons with disabilities, social protection systems can employ a more flexible approach providing the right support to fit the varying needs.

- It is important to **carry out studies to identify the structure and level of disability related costs** faced by a diversity of persons with disabilities across age group, gender and in different settings (rural/urban).
- Universal coverage and adequate benefits for income security and disability related costs can be achieved by **introducing a broader package of schemes**, both contributory and non-contributory cash transfers that address vulnerabilities across the lifecycle including disability benefits, child benefits, maternity benefits, sick leave, old age pensions, employment injury benefits, and unemployment insurance. Such programmes impact the income security of households that – if left unaddressed – will particularly affect persons with disabilities. Governments should ensure that disability and old age pension benefits are in place and are progressively scaling up coverage as a priority mechanism for addressing income insecurity among persons with disabilities.
- Contributory schemes should reduce coverage gaps by **extending the coverage beyond public sector workers to include self-employed workers, those in the private sector and those outside formal employment** (for instance for accident and employment injury schemes). This is of particular importance for reducing gender gaps as women with disabilities are less likely to be covered by contributory schemes given their lower participation in formal labour.
  - Income security calls for regular and predictable transfers, as such contributory programmes should move **away from one-time lump sum arrangements to those providing periodic benefits**, including for workers with relatively short contribution histories.

- Interruptions in paid employment leave women who take career breaks to care for family members with disabilities with lower benefits in retirement as benefit levels are typically tied to length of full-time work. Innovations to accommodate for breaks in contributions such as pension credits or contribution catch-up programmes should be explored.
- Expand the comprehensiveness of contributory schemes to include the provision of maternity protection<sup>7</sup>, paternity leave, and family sick leave to enable working age adults, especially women, balance their work-family responsibilities.
- Given the limited reach of contributory disability benefits, countries should complement efforts to facilitate formalization with **non-contributory disability-specific benefits** addressing income security. Non-contributory benefits are particularly important for people with disabilities who are not of working age.
- Non-contributory programmes should be designed to **limit exclusion errors** by moving away from a narrow poverty-targeting of disability benefits, towards higher-coverage schemes. This may include affluence testing and benefit testing. An alternative to poverty-targeting in the short term may be focusing schemes on those with more severe disabilities.
- Where household poverty targeted schemes<sup>8</sup> are in place, **certain design features can be introduced so that schemes better address income security of persons with disabilities**. This includes:
  - adjusting eligibility criteria to higher thresholds for persons with disabilities to account for their greater consumption needs,
  - increasing benefit levels for household with persons with disabilities as their capacities to generate additional income is reduced and to compensate for higher expenditures,
  - excluding benefits that address disability related costs benefits when assessing household income status,
  - providing top-ups to incentivize increased investments in education and health services for boys and girls with disabilities, for example by designing soft conditionalities such as labelling and messaging to encourage school enrolment and attendance of girls with disabilities,
  - for working adults and older persons with disabilities, make them individual rather than household benefits.
- To cover basic disability-related costs, countries should seek to **introduce (quasi) universal disability-specific cash benefit which are compatible with work and with other benefits** providing income security. This can be phased in starting with children with disabilities and/or people with higher support needs.
- **In countries where no mainstream non-contributory income security schemes** exist (e.g., household poverty assistance, old age social pension), a starting point can be to introduce hybrid disability benefits which are provided to persons with disabilities regardless of their employment status.
- Poverty targeting can be applied not only to poverty assistance schemes, but also to categorical schemes, as child benefits or old age pensions that target households below a poverty threshold. These poverty thresholds generally do not account for disability related costs. While shifting to universal benefits is more aligned with the rights-based approach it may not be politically or fiscally feasible. **Affluence testing** (excluding the richer households/individuals rather than targeting the poorest) **provide an alternative to traditional poverty targeting** mechanisms and roll out can start with children and people with high support needs.

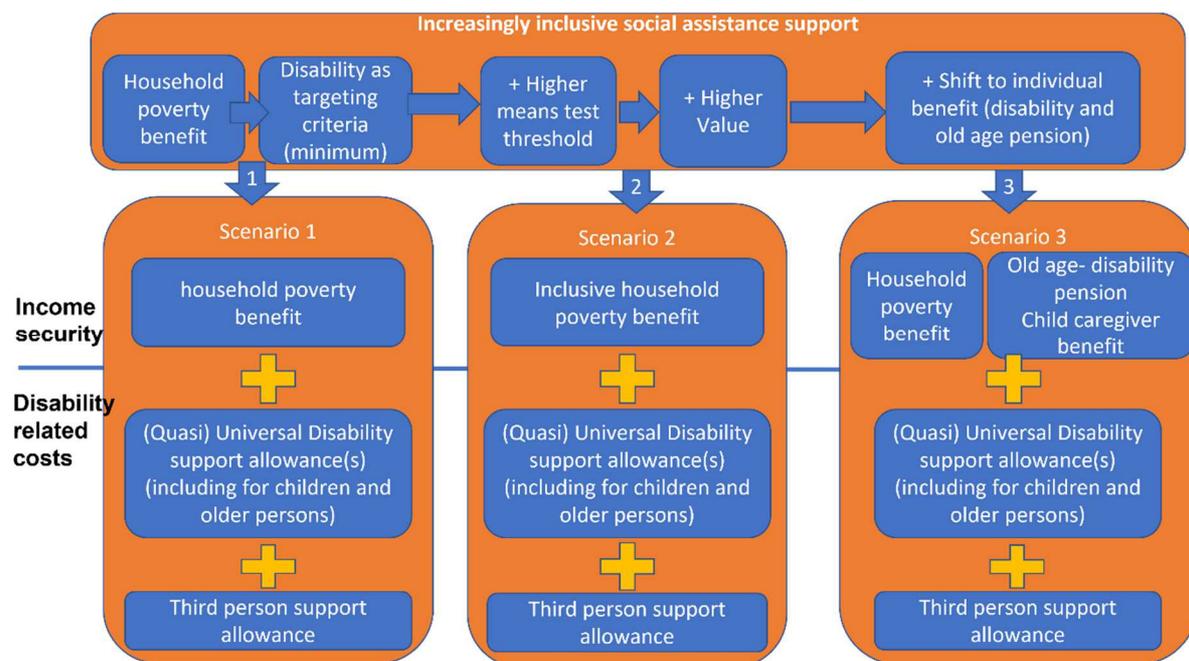
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<sup>7</sup> Maternity protection includes five components: maternity leave, maternity income protection, medical benefits, health protection at work, employment protection and non-discrimination, breastfeeding arrangements at work.

<sup>8</sup> Poverty targeted schemes can not only be poverty assistance schemes, but also categorical schemes that include means-testing, such as child benefits or old age pensions that target households below a poverty threshold.

Figure 4-2 shows in context where the main social assistance program is multipurpose household poverty benefit the different possible evolution towards greater inclusive design of such flagship program (disability as targeting criteria, higher eligibility thresholds and benefit values, shift to individual income security benefits) and the different scenarios progressively leading to a more rights based comprehensive cash transfer support to persons with disabilities. In all the scenarios, there is a (quasi) universal disability allowance for all ages aiming at covering disability related costs as well as progressively an additional third person support allowance.

**Figure 4-2: Scenarios for countries with household non-contributory cash benefits as starting point**



**Box 4-3. Syria: An Integrated Social Protection Programme for Children with Disabilities in humanitarian context**

UNICEF launched the Integrated Social Protection Programme for Children with Disabilities in partnership with the Ministry of Social affairs and Labour (MoSAL) to improve the well-being and social inclusion of children with disabilities affected by the conflict in Syria. The programme provides integrated support to address the needs of children with disabilities through the combination of regular, unconditional cash transfers accompanied by case management services. It is the largest social protection intervention for children with disabilities in Syria. Since the launching of the programme in 2016, over 35,000 children with severe disabilities, as well as over 180,000 people in families of children with disabilities, have benefited from the programme across seven governorates.

Through an integrated approach, the programme enhances the resilience of families and strengthens the continuum of humanitarian and early recovery interventions. Families of children with disabilities receive a regular, quarterly transfer of USD120 (equivalent to USD\$ 40/month). While the cash transfer helps families meet the basic needs of children with disabilities and their families, the case management component helps to empower families to better respond to the needs of children with disabilities by referring children with disabilities to social services, including health, education, livelihoods and protection services. A trained case manager is assigned to each child throughout the period to identify needs and refer them to appropriate services. On average, one case manager is responsible for 30 children.

Due to the conflict, the national registry and identification process of children with disabilities have been significantly affected. To address this situation, eligible children are identified through a network of national NGOs, community and religious leaders, community platforms and outreach activities/field assessments. To enrol in the programme, children must provide a recent medical report attesting to her/his disability or a national disability card. Children without medical documentation are referred to a doctor who can conduct the assessment and provide certification that the child meets at least one of 12 criteria for disability according to the national classification of disability.

One of the key objectives of the Integrated Social Protection Programme is to support families to obtain the national disability card for their children. The disability card issued by the Department of Social Affairs and Labour (DOSAL) in coordination with the Department of Health (DOH). The card facilitates access to social services and government benefits and concessions, such as reduced public transportation costs.

Source: UNICEF (2022) Key Highlights Post-Distribution Monitoring Survey Integrated Social Protection Programme for Children with Disabilities. Damascus: UNICEF

#### **Box 4-4. Uganda: Designing social protection responses with disability, age and gender lens**

The Kampala Capital City Authority (KCCA), in partnership with UNICEF, developed the Girls Empowering Girls programme aimed at safely transitioning adolescent girls into adulthood with greater autonomy and protection through increasing their socio-economic prospects. The programme provides adolescent girls with cash transfers combined with services, mentoring and training to empower them to achieve their goals. The programme pays special attention to groups of girls with compounded vulnerabilities, including adolescent girls with disabilities.

The Girls Empowering Girls pilot programme takes an integrated approach combining cash transfers, mentoring, and referral to services. The programme reaches 3,000 girls – 2 per cent of which are adolescent girls with disabilities. Programme participants receive an unconditional cash transfer of UGX40,000 per month (~USD 130 per school year) delivered three times during the school year. Girls enrolled in secondary school receive an additional UGX20,000 per month. In recognition of the additional costs associated with disabilities the programme provides a top-up of UGX 20,000 for adolescent girls with disabilities. To be eligible for the disability top-up, girls must provide a medical document certifying the disability. Certificates can be obtained free of charge from a KCCA run verification centre within the city. The programme supports the girls to obtain the certification by making appointments on behalf of the girls and providing transportation to the centre. Girls with disabilities can self-identify during the registration process or can be referred for an assessment by a mentor during the course of the programme.

In addition to the cash the girls receive support through a peer-mentoring programming. Each peer mentor is assigned five mentees through monthly one-on-one and groups sessions to equip the girls with foundation, 21st century and life-skills. The mentoring sessions provide personalized support for girls with disabilities. For instance, some girls may not be able to participate in groups sessions and so mentoring is provided through one-on-one sessions. The programme also provides sign language interpretation to enable greater inclusion and communication. Girls with disabilities are provided referral to general health, education and livelihoods services but also disability-specific services, such as assistive devices.

Source: Interview with staff from UNICEF Uganda and KCAA

#### Box 4-5: Pathways towards comprehensive disability support via cash benefits

The discussion above on cash benefits relating to income security and disability-related extra costs describes a broad menu of schemes that can be put in place to address income security and disability-related extra costs. However, most low- and middle-income countries will only be able to gradually extend the coverage and adequacy of such schemes, and the extent to which they address different costs will vary. The following Table describes typical country groups, and potential policy options towards more inclusive cash benefits arrangements. It should be noted that these pathways are only illustrative, and countries may take distinct routes. It should also be noted that this only applies to cash benefits, with an emphasis on those provided by non-contributory schemes.

NATIONAL CONTEXT	EXAMPLES OF COUNTRIES	POLICY PATHWAYS
<p><b>Group 1:</b> Countries that have no specific account of disability within existing cash benefit design</p>	<p>Philippines, Ghana, Angola</p>	<ul style="list-style-type: none"> <li>• Adjust poverty assistance schemes (where they exist), such as increasing means-testing thresholds and topping up benefits</li> <li>• Progressively introduce disability-specific benefits, potentially initially limited to persons with severe disability, children and young adults and older persons in absence of old age social pension (affluence-tested)</li> <li>• Ensure inclusion of disability information in social registry and initiate a universal disability information management system</li> </ul>
<p><b>Group 2:</b> Countries with disability-specific cash benefits or significant adjustment to poverty assistance, but with design that severely limits inclusion (e.g., poverty-targeted/incompatibility with work)</p>	<p>India, Bangladesh, Indonesia, Kenya, Zambia, Timor Leste</p>	<ul style="list-style-type: none"> <li>• Increase coverage of disability-specific benefits (e.g., move towards universal or affluence-tested schemes)</li> <li>• Make disability support compatible with work and progressively with other benefits to address disability-related extra costs (e.g., in the introduction of “hybrid” disability benefits)</li> <li>• Address issues of access including disability assessment and certification</li> </ul>
<p><b>Group 3:</b> Countries with inclusive design of disability-specific benefits (not means tested, compatible with work and possibly other benefits), but shortfalls in terms of coverage and adequacy</p>	<p>Thailand (low benefit levels), Nepal (low coverage linked to implementation), Fiji (adequacy and compatibility with old age pension)</p>	<ul style="list-style-type: none"> <li>• Seek to progressively increase benefit levels</li> <li>• Increase compatibility with other benefits such as poverty assistance benefits, old age pension and others</li> <li>• Address issues of access including disability assessment and certification</li> </ul>
<p><b>Group 4:</b> Countries with disability-specific benefits with high coverage and adequacy, but incompatible with work</p>	<p>South Africa, Brazil</p>	<ul style="list-style-type: none"> <li>• Provide support compatible with work and other benefits through combination of schemes addressing both income security and extra costs (e.g., remove means test, introduction of disability/inclusion support benefit for people in formal/informal employment and meaningful caregiver/third-person support benefits)</li> <li>• Address issues of access including disability assessment and certification</li> </ul>

## 5 CONCESSIONS AND SUPPORT SERVICES

Concessions, community care, and other support services can help to offset the additional costs associated

### Key Concept 5: Concessions and community services addressing disability-related extra costs include:

- **Concessions**, including discounts on free/subsidised transportation, utility bills, and tax credits
- **Community services** for care and support, including personal assistance, respite care, interpreters, circle of support and peer support, point to point transportation, supported housing...

with disability which are a critical driver of poverty and lower standards of living among this group. Concessions support access to services through reduction or exemption of fees. Concessions can play a key role, not only to cover disability-related costs but also to promote participation in society. Community services lighten the caretaking responsibilities of family members, and support inclusion, and participation in the community for persons with disabilities.

### 5.1 CONCESSIONS

**Concessions and discounts can help to relieve some of the additional financial strain experienced by persons with disabilities.** They can compensate for the lower purchasing power experienced by persons with disabilities by reducing the price of everyday goods and services and offset some disability-related extra costs. Many countries, such as Nepal, India, Vietnam, Philippines, Georgia, Kenya, and South Africa, offer different forms of concessions to persons with disabilities as part of their social protection systems. **Concessions are not an alternative to cash transfers but a complement.** In many countries where cash transfers are not adequate to cover both basic household needs and disability specific needs, concessions can provide extra support.

**Concessions can be a cost-effective way to support the majority of persons with disabilities who may not be eligible for other schemes,** like non-contributory cash benefits, but still face disability related costs. Many people with disabilities who do not qualify for mainstream or disability cash benefits, because they are above the means test threshold, or because they are not assessed as having severe enough disability, are still at risk of falling into, or deeper into, poverty.

**The types of concessions broadly used are tax exemption, discounts, fee waivers and subsidies.** Not all concessions have the same impact for persons with disabilities and some are more effective at alleviating financial burdens than others. One of the main criticisms of concessions is that they generally benefit those with income from formal employment and/or those with higher disposable incomes; in other words, those who are better off. Persons with disabilities in rural areas may face difficulty taking advantage of concessions as many agricultural workers are own-account workers and many rural businesses (e.g., small shops) or services (e.g., transport) are informal and concession may imply some tax refund mechanism from government for businesses that are registered. Some concessions such on public transport may not benefit all persons with disabilities due to unavailability in some regions, or inaccessibility for some groups of persons with disabilities. In countries with highly restrictive social norms, women and girls with disabilities may be unable to move around freely to access the different business and services to which concessions are tied. It is important when designing concessions to understand which measures would be more effective for the diversity of persons with disabilities, depending on their employment status, functional limitations, or place of residence.

- Some countries offer exemptions or reduced rate of income **taxation** for households with persons with disabilities, thereby increasing the level of disposable income to cover disability-related costs. For instance, Georgia has instituted a greater threshold for non-taxable income, while India and

the Philippines allow for a lumpsum tax deduction for individuals with disabilities or families with dependent members with disabilities. South Africa offers a tax credit on certain disability related expenses, such as medical costs or costs of assistive devices. The former examples are more progressive as they provide relief on first dollar earned therefore benefiting also lower income household while the latter imply capacity to pay upfront and then deduct those expenditures from taxable income. Income tax concession only reach a fraction of persons with disabilities as they are more likely to be working in the informal sector or not working at all. However, together with tax incentives for employers they can facilitate entry in formal economy.

- Sales tax exemptions and import duty exemption on disability specific items, such as assistive devices or adapted vehicles and auto insurance, can help reduce prices of disability specific goods but will still be useful mostly for individuals/households with initial capacity to pay.
- Many countries have adopted a wide range of **discounts and fee waivers** for persons with disabilities including:
  - o *Healthcare*: These are extremely important given that persons with disabilities have on average a higher need for health care services. Concessions related to healthcare are covered in Section 7 on social health protection.
  - o *Transportation*: One of the most common concessions is highly subsidized or free public transportation to persons with disabilities and their personal attendants (India, Fiji, Nepal, Vietnam, UK, USA). These have been identified as a very important benefits as it allows for greater freedom of movement and ability to participate more fully in social and economic spheres. They are often tailored at local level. However, to be most useful, public transportation must be available, accessible and perceived as safe especially for women and girls, which is not always the case. Expanding public transportation network and making accessible is outside of the remit of the social protection sphere.
  - o *Utility*: In countries with extreme weather, such as heat or cold, utility subsidies for persons with disabilities can be very important as persons with disabilities may use more electricity for heating, cooling, and lighting as they tend to spend more time at home. This will be even more relevant due to climate change. Again, this presupposes adequate electricity and water grids, including in remote areas.
  - o *Education, training and livelihoods*: Removing financial barriers to education and training through scholarships and tuition fee waivers for children and adolescents with disabilities is important to ensure they can acquire productive and social skills. For adults with disabilities accessible training and livelihoods supported is essential for (re)entering work. In some countries, like Vietnam, financial institutions offer concessional loans for self-employed persons with disabilities to cover production and business activities.
  - o *Arts and Leisure*: Discounts or free admission to cultural facilities such as museums or concert halls, sports events, and parks are widespread. These can be important for facilitating participation in cultural and social life, but facilities must be accessible for most persons with disabilities to benefit.

A common element for those discounts is to ensure that they are progressive. Some country will offer 20 per cent discount to persons with disabilities on some services, which implies that one will still have to pay the remaining 80 per cent. These types of schemes are likely to benefit the better off rather than people at the lower end of the income spectrum. Concessions must be meaningful for most persons with disabilities to be effective and therefore preferably target the first dollar spent or earned.

Few countries have developed consistent strategies when designing and implementing concessions which have been more often adopted by successive governments without evidence-based assessments of the potential impact for the diversity of persons with disabilities. In countries with weak administrative capacities and delivery systems, concession may be fast and relatively easy to implement.

## 5.2 COMMUNITY CARE AND SUPPORT SERVICES

**Community care and support services take many forms.** These include human assistance and assistive technology to support communication, decision-making, personal assistance, point to point transportation, mobility, housing, and support for other life activities. They respond to individual support requirements which vary according to the circumstances and characteristics of each individual, including age, sex, gender, type and degree of impairment, participation sought as well as barriers and facilitators in their environment. A person with disabilities may require support in one or more areas of life. Table describes, in a non-exhaustive way, key domains of community support, examples of community support services and products and different populations of disabilities they may relate to. While the table includes both services and products, this sub-section only relates to services. Within this guidance, community support products are covered under the discussion of assistive devices within Section 6 on health care costs.

**Table 5-1: Key domains of community support**

Formal or informal interventions - Services or products			
Domains	Description	Examples	Mostly used by
<b>Communication</b> CRPD, arts. 19, 21	Support to overcome barriers that limit the ability to communicate and be understood.	e.g., sign language interpretation, tactile interpretation, braille, assistive technology and software, easy-to-read and plain language, speech therapy, captioning, augmentative and alternative communication, among others.	Deaf and hard of hearing persons, blind and persons with low vision, deafblind persons, persons with speech impairments, persons with intellectual disabilities.
<b>Decision-making</b> CRPD, arts. 12, 19	Support to make decisions and exercise legal capacity. This includes assistance to: (a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision.	e.g., support agreements, peer support, self-advocacy support, advance directives, crisis support, financial management assistance, among others.	Persons with intellectual disabilities; persons with psychosocial disabilities; persons with high support needs; older persons with cognitive disabilities.
<b>Mobility</b> CRPD, arts. 9, 19, 20	Support for personal mobility and access to affordable and available quality mobility assistance. This includes training in mobility skills to persons with disabilities and staff working with them. They help overcome lack of or limited accessibility of existing public transport	e.g., mobility aids, assistive technologies and devices (prostheses, orthotics, wheelchairs), assistance animals, point-to-point transport, among others.	Persons with mobility impairments, blind persons and persons with low vision, persons with intellectual disabilities, persons with psychosocial disabilities.
<b>Assistance with daily life</b> CRPD, arts. 12, 19	Support to assist persons with disabilities in a one-to-one relationship to perform daily life activities like getting up, bathing, dressing, grooming, going out, cooking, cleaning, guiding, shopping, or laundry.	e.g., full or part time professional personal assistance, paid friends or family members, informal personal assistance, household cleaner, equipment for independence, among others.	Persons with disabilities with high support needs, across the life cycle.

<b>Housing and accommodation</b> CRPD, arts. 19, 28	Support with housing and living arrangements, including home modifications.	e.g., housing information and assistance, home support, supported living services, respite services, among others.	Persons with disabilities with high support needs, across the life cycle.
<b>Family support</b> CRPD, art. 8, 16, 19, 23, 28 UNCRC art. 18, 23	Training and support to families providing informal support for persons with disabilities.	e.g., awareness-raising, peer support groups, surrounding support services (childcare), early childhood support, respite care, among others.	Families of all persons with disabilities, especially of children with disabilities

**Combined with cash transfers, this set of services becomes a community support system which helps persons with disabilities to live independently in the community with equal choices to others.** For many persons with disabilities, access to such support is a precondition for participating in society and living with dignity (UN HRC, 2016). Without community support services, many persons with disabilities would not communicate, get out of bed, bathe, eat, leave the house, go to school or work, or participate in community activities and public life. In addition, support services enable many persons with disabilities who would otherwise be considered unable to work to engage in employment. Community support services also help overcome remaining barriers in the environment and make health, education, justice, and other mainstream services inclusive. Further, access to formal support services provides employment prospects for family members who provide support (OHCHR, 2020).

**Formal community support services are particularly important for inclusion.** *Formal* community support services are those directly provided or funded by governments or the private sector. As opposed to *informal* community support which refers to those provided directly by people in the community – including family members – without state or private support, such as unpaid assistance and peer-support. The absence of formal community-support services, which is the case in most low- and middle-income countries, results in one (or more) of the following outcomes all of which are problematic for inclusion.

- **Persons with disabilities and their families purchase support services:** These costs put pressure on household incomes and can be a driver of poverty. Some costs – such as personal assistance – are usually well beyond what most households can afford, unless they have access to a third-person support benefit.
- **Persons with disabilities forego support services:** As discussed above, an absence of these services can threaten survival and creates significant barriers to living independently in the community with equal choices to others. Persons with disabilities can end up stuck at home for extended periods of time with very detrimental effect on their health.
- **Persons with disabilities rely on family and community members to provide support services:** This may constitute a substantial opportunity cost for other household members, which can contribute to household poverty. Unpaid support can lead to long-term social and economic disadvantages, including forgone education and employment opportunities, added household expenses, burnout, family breakdown and even violence (UNECE, 2019 and Gérard and Zech, 2021). This has **significant gender implications, as this unpaid support is most often provided by girls and women** who bear the brunt of foregone opportunities.
- In the absence of formal community care and support services, **persons with disabilities are at higher risks of neglect, abandonment and institutionalisation.**

Different challenges limit access to community support in low- and middle-income countries.

**On the demand side, there is a lack of awareness at all levels on the need for and importance of support services.** Human assistance is often considered a family duty with state intervention limited to persons without family support. Due to the systemic and structural discrimination experienced, persons with

disabilities and their families do not often advocate for community support services. There is also **invisibility of disability-related support requirements due to lack of data** and incomplete information on the diverse needs for support services.

**On the supply side, there is limited capacity to provide quality support services due to low investments and shortages in service providers and trained workforce** (i.e., professional sign language interpreters, trained personal assistants, etc.). Where services exist, they are typically fragmented, unsustainable, and of low quality. This is particularly challenging in rural areas where shortages in service providers are even starker.

**In most low- and middle-income countries, formal community support systems are therefore severely underdeveloped, with existing support services limited to residential settings.** This increases the likelihood that persons with disabilities will be institutionalised, with significant implications for their choice and autonomy. Some countries, in particular those most affected by demographic ageing such as China, have seen an increase in institutionalisation with rapid growth of formal residential long-term care services for older persons, many of them older persons with disabilities (Knapp et al, 2021; Shi and Hu, 2019). This process is driven by many factors, including population ageing, social stigma, scarce specialist resources, urbanisation and breaking up of traditional family structure, and lack of community alternatives (Knapp et al, 2019). Some of these new institutional settings are run by NGOs and private organisations, which often operate unregulated and unmonitored. In former socialist Central and Eastern Europe countries, which historically have had high institutionalisation rates, deinstitutionalisation reform has progressed, but with uneven and re-institutionalising results (Mladenov and Petri, 2020). In many of these countries, community support services outside residential settings, such as personal assistance, are scarce (Cojocariu and Kokić, 2020).

#### **Box 5-1: Guiding principles for the provision of community support**

The Committee on the Rights of Persons with Disabilities – the body of independent experts which monitors implementation of the CRPD – has provided in its General Comment No 5 (2017) a set of guiding principles for the provision of community support:

- Respect for the inherent dignity and autonomy of persons with disabilities.
- Be available, universally accessible, affordable, acceptable, and adaptable for all persons with disabilities within the community.
- Be individualised according to their requirements and personal preferences
- Be flexible to adapt to the needs of the service user and not the other way round.
- Enable choice and control over the way support is provided.
- Enhance community inclusion and combat segregation or isolation.
- Have a holistic approach to provide services within all domains of life, including employment, education, and political and cultural participation.

The CRPD does not prescribe any specific system for the provision of community support. It acknowledges that countries may respond differently to designing community support systems and delivering support services based on their political systems, economic development, cultural traditions, and social norms. Some guiding principles are outlined in Box 5-1. One of key issues that many countries are facing is **how to ensure access of children and adults with disabilities to more and better support without increasing gender inequality in relation to the care economy.**

Depending on the contexts, development, management and financing of community support systems will be covered to different extent by the national social protection system. For instance, in some, those services are mostly under responsibilities of local authorities. However, **extension of formal care and support system is interlinked to different elements of the social protection system in various ways:**

- **Disability and needs assessments** and certification mechanisms are central for designing community support systems, including for the identification of support needs (discussed in detail in Section 8).
- **Means testing criteria** will have a significant implications for coverage of care and support services, as discussed in Section 4 on cash benefits.
- **Care and support services can be linked directly to cash benefits (“cash plus” programming)** which would likely significantly enhance the impact of cash transfers on the autonomy and participation of persons with disabilities and can create streams of public funding for the development of community support services.
- **Public employment programs can be used to finance the development of community care and supports services** when financing childcare to support workers but also by recognising and remunerating community care and support related labour as work.

### 5.3 DESIGN ELEMENTS FOR INCLUSION

Extending concessions and community support services in low- and middle-countries can come in many forms.

- Carry out disability costs analysis and participatory studies to identify structure and level of additional costs faced by the diversity persons with disabilities across age group and in different settings (rural/urban) to inform policies, planning and design.
- Work to **put in place more meaningful concessions** that have a proven impact in offsetting disability-related extra costs.
- **Expand the range of publicly funded community support services**, with increasing geographical coverage, and greater breadth in the range of services provided. In some countries this can be tied to the process of deinstitutionalisation, with governments redeploying staff and budgets towards greater levels of care and support provided in the community.
- **Strengthening the legal and policy framework and building awareness for community support services.** Given the limited recognition of the role of community support services, a central agenda is to build awareness and understand of its importance. This involves reflecting human rights obligations in national legislation, developing policy frameworks for community support, and building awareness to change attitudes. This should all be supported by comprehensive data on support requirements.
- **Mobilisation of community resources, including through public-private non-profit partnerships.** Community structures, including organisations of persons with disabilities and community-based organisations and volunteers, are likely to be central in the transition to community-based support systems in low- and middle-income countries. These could potentially be leveraged and strengthened, including through sustainable government funding, to deliver community support for persons with disabilities. Families should also be supported through information, training, respite, and funding to assist their family members with disabilities. This could involve supporting non-profit organisations through an adequate regulatory and financing framework to provide disability support. This includes organisations of persons with disabilities, non-governmental organisations, and community-based inclusive development (CBID) and community-based rehabilitation (CBR) initiatives.
- **Workforce development.** There is a shortage of service providers and trained workforce (i.e., sign language interpreters, personal assistants, etc.) throughout low- and middle-income countries (Musengi et al, 2013; Encalada et al, 2021). This requires the development of human resources, especially in areas where specialisation is necessary. It also involves the training of informal caregivers and other supporters.

- **Mobilisation of public employment programmes, including guaranteed employment programmes and public works, could contribute to the provision of care and support.** Public works programmes have the capacity to respond to community needs while boosting employment earnings and skills. Some countries have included employment opportunities to deliver care and support services within their public employment programmes. The types of programmes will not only close the gap in workforce numbers but can be transformative for those providing care, notably women, as these programmes recognize care labour and remunerate it. When designing such programmes considerations around gender equality, including decent wages, flexible hours, proximity of work to home, need to be taken into account. Importantly, public employment programmes related to care services must be accompanied by adequate training and monitoring of works to avoid abuse or poor quality of care.

**Box 5.2: Lessons learned from South Africa on Public Employment Programmes in the Care Economy (ILO, 2021)**

The COVID-19 pandemic, along with the ensuing economic crisis, has amplified unemployment within the care economy, causing significant consequences for care workers, predominantly women. The pandemic has underscored inherent flaws in many healthcare systems, escalating gender disparities in paid and unpaid care work, and the repercussions of failing to address the rising global demand for care.

South Africa's care economy exhibits three main features: 1) Both public and private entities deliver care services in formal and informal sectors, with a substantial portion delivered through non-profit and non-governmental organisations, 2) Women are the majority of the paid and unpaid care workforce, and 3) Where paid, women's services are often undervalued and undercompensated.

Public Employment Programs (PEPs), owing to their emphasis on labour intensity and higher employment per unit of government expenditure, are pivotal in addressing these challenges. The most notable PEPs within the care economy are found in the Expanded Public Works Programme's (EPWP) Social Sector and Community Works Programme components. The Social Sector aims to engage the unemployed in productive work through social service delivery, thereby providing them an income, skills, and education to establish their businesses or secure employment with the Home Community Based Care (HCBC) and Early Childhood Development (ECD) as primary initiatives.

The South African experience illustrates that PEPs have aided in the progressive achievement of decent work by acknowledging and compensating care-related labour. However, in scenarios of persistent unemployment, market failure to generate sustainable work opportunities, and fiscal constraints limiting the state's ability to assimilate PEP workers, these programs often result in slow or no progression beyond the initial step.

This experience further prompts questions about PEPs' effectiveness in delivering direct care services. The government has several options, including acknowledging these services as long-term and continuous. Regardless of the policy decisions made to address these challenges, a fundamental redesign of the PEPs funding framework is essential to improve wage levels in the care economy and structurally transition workers into more decent forms of employment.

## 6 COVERING HEALTH CARE RELATED COSTS

### 6.1 UHC AND PERSONS WITH DISABILITIES

**The promise of Universal Health Care (UHC) is of special importance for persons with disabilities.** UHC is defined as ensuring that all persons 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. The achievement of UHC is covered in the 2030 Agenda for Sustainable Development Target 3.8 of Goal 3: Good Health and Well-being (UN, 2015). ILO Social Security (Minimum Standards) Convention No. 102 and Social Protection Floors Recommendation, in line with the Universal Declaration of Human Rights, define medical care, including maternity care as a core social protection guarantee that governments have to provide to the population throughout the life cycle. Article 25 of the Convention of the Rights of Persons with Disabilities reaffirms the rights of persons with disabilities to access healthcare without discrimination and outlines the obligations for states to ensure access to both mainstream and disability specific health care.

Social protection can play a contributing role in the achievement of UHC for persons with disabilities by addressing the cost of health care and reducing out-of-pocket expenditures but many of the barriers to health services are outside the scope of the social protection sector and are the purview of the health sector. For instance, lack of accessible healthcare facilities and equipment, inaccessible communication and outreach, lack of specialized services especially away from urban centres, negative attitudes, discrimination and lack of training and knowledge among staff about the specific concerns and inclusion requirement of persons with disabilities are among the barriers persons with disabilities face when accessing healthcare. These barriers need to be addressed by the health sector.

Social health protection is of particular importance for persons with disabilities due to the following:

- **Greater need for healthcare:** Persons with disabilities need to access to the same general health services as others in the population, and often even more so as they are more likely to have underlying health conditions. Research has found persons with disabilities are almost three times as likely to have a serious health problem; for children this can be up to five times as likely (Kuper and Heydt, 2019). Furthermore, people with disabilities have a greater need for specialist services related to their impairment and health conditions. There are a range of different pathways linking disability and poor health, including:
  - Persons with disabilities are often more disadvantaged and marginalised in society, and are on average older, therefore more likely to face ill health,
  - Health conditions can increase the likelihood of an impairment (such as diabetes and diabetic retinopathy and vision impairment)
  - Different impairments can also cause or contribute to secondary health conditions such as bed sores arising from physical impairment or increased risk of respiratory diseases among persons with downs syndrome.
- **Greater barriers to access health care:** Persons with disabilities will face magnified barriers to access health care compared to population without disabilities due to inaccessibility of transport, facilities, services, information and communication. They may face discrimination and prejudice from health care staff which can be compounded for women and girls with disabilities, including when seeking sexual and reproductive health care. Finally, the lack of knowledge and specialised health care responsive to their specific needs can limit the quality of the care they receive which may require them to travel, for those who can afford it, to the country capital or even abroad.
- **Greater cost to access healthcare:** Those higher needs for persons with disabilities and their families are associated with greater:
  - **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, accommodation and personal assistance or interpretation required when accessing healthcare, which increase with often long waiting times and repetitive visits (UNICEF, 2015);
  - **INDIRECT COSTS:** such as loss of income or time persons with disabilities face while seeking care, or for other family members who provide personal assistance or caregiving support.

As a result, persons 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.

**There are various ways in which the social protection system can reduce financial barriers, thereby contributing to improved access to health care for persons with disabilities.** These are categorized here into two main areas: financial coverage and adequacy of benefits.

## 6.2 INCREASING FINANCIAL COVERAGE

**The role of the social protection systems in efforts to increase social health protection coverage will vary according to how financial coverage is arranged.** The aim is to reduce the reliance on out-of-pocket expenditures which can create financial hardship. Countries vary in the extent to which they use different approaches (described in Box 6-1) to achieve financial coverage. Some low- and middle-income countries – such as Brazil, Georgia, the Maldives, Sri Lanka and Thailand – have been able to provide relatively affordable health care to the population via direct provision of health care using tax-financed universal schemes. Other countries, such as Indonesia, Kenya, Philippines, Viet Nam and many Latin American have put greater weight on contributory social health insurance schemes to provide financial protection. In many cases, taxes and social contributions are mixed within the same system. These two pillars of social health protection financing may be complemented by voluntary schemes, but these have generally made a limited contribution to achieving UHC.

### Box 6-1: Approaches to financial coverage of health care

Financial coverage of direct medical costs can be delivered through the following social protection schemes:

**DIRECT PROVISION OF HEALTH CARE:** automatic coverage for all citizens/residents, or certain groups (e.g., persons living in poverty). Schemes are non-contributory and financing is derived from government budgets (tax financed).

**SOCIAL HEALTH INSURANCE SCHEMES:** mandatory enrolment for all citizens/residents or certain groups (e.g., formal sector workers and their families). Schemes are fully or partially contributory (e.g., employees and/or employers pay earnings-related contributions). In some cases, governments will cover or subsidise contributions for certain groups (e.g., persons living in poverty, persons with disabilities, children).

**VOLUNTARY HEALTH INSURANCE:** may include government, cooperative or commercial schemes in which individuals opt in and pay regular contributions. Governments may directly or indirectly subsidise some voluntary schemes (e.g., tax credits). Voluntary schemes alone are unlikely to achieve UHC due to affordability issues, adverse selection, and possible exclusion of persons with pre-existing conditions among other issues.

**WORKERS COMPENSATION HEALTH INSURANCE SCHEMES:** The insurance covers medical expenses directly resulting from industrial accidents or illnesses and may be mandated to be purchased by the employer (or self-insured).

**There is a strong rationale that persons with disabilities should be prioritised in efforts to extend health population coverage.** In many countries, the move towards UHC is happening progressively, with new or adapted schemes being gradually expanded to different population groups over time. Progressive extension sometimes means progressively providing a more comprehensive benefits package (discussed in more detail in the next section). There is a strong case that persons with disabilities should be prioritised in this process. Not only do persons with disabilities have higher health needs on average, but higher levels of poverty and more limited access to the labour market constitute a barrier to coverage under social insurance schemes.

Key approaches to this prioritisation include:

- **Prioritisation in extension of health insurance schemes:** There are numerous examples of persons with disabilities being prioritised in efforts to extend subsidized social health insurance. A common approach in extension of social health insurance is to combine a fully contributory component for those in formal employment, a partially contributory component for those in the informal economy and a fully subsidized component for those on low incomes or with high levels of vulnerability. Box 6-2 provides examples of countries which have included persons with disabilities within the fully subsidised component. Given the significant vulnerabilities faced by persons with disability, there is a strong case for removing the requirement that they meet a means test, even if the scheme is means-tested for other population groups. The logic of this approach is less obvious where countries opt to extend coverage via a universal tax-financed approach but – if this were being expanded progressively – persons with disabilities should be defined as a priority group.

#### Box 6-2: Prioritising persons with disabilities in social health insurance schemes

- In the **Philippines**, all registered persons with disabilities are covered by the national health insurance programme of PhilHealth (PhilHealth, 2019), with additional benefit packages designed for children and adults with disabilities.
  - In **Vietnam**, eligible persons with disabilities receive a full waiver on contributions to the compulsory social health insurance programme (usually individual contribution is 1.5% of salary) (Banks et al, 2018). Persons with disabilities also receive subsidies on co-payments, reducing out-of-pocket payments on eligible medical expenses to 5%.
  - In **Ghana**, the National Health Insurance Scheme waives some individual contributions for persons with disabilities who register with the Social Welfare Department (Howard, 2019), or receive the poverty-targeted cash transfer (Livelihood Empowerment Against Poverty, LEAP scheme) which includes vulnerable populations, including persons with a disability who cannot work.
- 
- **Co-payments:** Where co-payments exist, there is a strong case for these to be reduced, capped or eliminated for persons with disabilities. It is common within different kinds of social health protection schemes for members to be expected to make co-payments covering a certain portion of the treatment or medicine (for example, 20 per cent). These costs can be particularly burdensome for persons with disabilities given that they tend to use health services more than those without disabilities and the services they use are often more expensive than average (implying a higher co-payment. Higher costs may lead to persons with disabilities to forego treatment. For example, in China, the likelihood of accessing inpatient mental health services amongst people with mental health conditions was linked to the type of plan; people with plans that offered higher reimbursement rates were more likely to utilise needed mental health services.<sup>49</sup> Reducing levels of co-payments or eliminating them could be applied to all health services or focused on those that are particularly relevant to persons with disabilities.
- 
- **Addressing direct non-medical costs and indirect costs.** As noted above, health care costs not only include direct medical costs, but also direct non-medical costs and indirect costs. These also need to be covered through the social protection system since otherwise, there is a high risk that people forego needed care.
    - **Direct non-medical costs** include transportation, accommodation and personal assistance or interpretation required when accessing healthcare. These can be addressed through a range of measures including concessions (e.g., to cover transport), community support services (in the case of personal assistance and interpretation) and cash benefits (such as disability/inclusion support allowances).
    - **Indirect costs** (such as loss of income or time persons with disabilities and/or family members face while seeking care) can be addressed through income security to individuals (see Section 4) including disability pensions and sickness benefits as well as

those addressing opportunity costs (carers benefits, child disability benefits, paid parental leave).

### 6.3 BENEFIT ADEQUACY (EXPANDING SERVICES COVERED)

**Expanding services covered by financial protection schemes is critical for persons with disabilities.** While initiatives to increase population covered by social health protection are widespread, it is common for these schemes to only cover a limited package of services, which often exclude those that can be particularly relevant for persons with disabilities. For example:

- **Assistive devices:** Health insurance schemes in Ghana and Viet Nam only cover a limited range of rehabilitation services and mental health services and provide no coverage for assistive devices. Similarly, people with disabilities in Iran report that their health insurance does not cover many disability-specific health services and assistive devices, or that they had to pay prohibitively large co-payments for them.<sup>75</sup> See Box 6- and 6-4 on assistive devices.
- **Rehabilitation:** In Peru, people with disabilities enrolled in Seguro Integral de Salud (the more limited tax-financed programme for the vulnerable) were much less likely to access rehabilitation (9 per cent) compared to people with disabilities enrolled in the more extensive coverage commercial health insurance (27 per cent) or Social Security (social health insurance for people in salaried positions) (21 per cent).

#### Box 6-3: Expanding access to assistive devices

- **Kenya:** People with disabilities can apply for assistive devices through the National Development Fund for Persons with Disabilities run by the National Council of Persons with Disabilities. 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 be registered with the National Council as a person with disability to apply. 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.
- **Maldives:** People with disabilities 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 example of countries with social protection programmes to provide free or subsidised assistive devices include **Lebanon, Palestine, Yemen, Tajikistan** and **Lesotho**, although the scope and coverage of these programmes is not clear.

### 6.4 DESIGN ELEMENTS FOR INCLUSION

- **Achieving universal health coverage for persons with disabilities will require mobilizing and combining different contributory and non-contributory health schemes and considering concessions or subsidies.** While countries may offer contributory health insurance schemes, either

public or private, persons with disabilities who are less attached to the formal labour market and have less financial capacity are more likely to be left uncovered. Prioritise persons with disabilities in approaches to extending financial protection including, where relevant, subsidised social health insurance for persons with disabilities. There is a strong case to provide such coverage to all persons with disabilities, without use of means-testing.

- **Reduce, cap or eliminate co-payments for persons with disabilities**, reflecting higher healthcare usage and the cost of specialised treatments.
- **Ensure that guaranteed benefit packages include disability related services, including assistive devices and rehabilitation services.** Put emphasis on extending benefit coverage to include services relevant to persons with disabilities, including assistive devices and rehabilitation. It is also important that gender-related services, such as sexual and reproductive health, are included and benefit women with disabilities. Gradually seek to combine a more comprehensive package of assistive technology under UHC, combined with dedicated social protection mechanisms to cover rare and expensive devices for persons with disabilities.
- **Improving awareness and outreach, simplifying application processes and communications, and addressing physical access** for different schemes (See Section 10).
- **Persons with disabilities should be actively engaged in the development, implementation and monitoring of social health protection systems** (See Section 9). This is both an obligation under the UNCRPD, as well as a key strategy to ensure that social health protection schemes are more responsive to the needs and concerns of persons with disabilities.

#### Box 6-4: Assistive technologies and social protection<sup>9</sup>

Evidence shows that assistive technologies make a significant difference in supporting greater autonomy and socio-economic participation over the life cycle. However, assistive devices constitute a disability-related extra cost that many persons with disabilities cannot afford, especially those with high support needs. This leads persons with disabilities to miss out on education, work opportunities and higher income that assistive technologies would have allowed. Alternatively, people might opt for low quality devices which could be detrimental to their health and functioning or, even if they can originally afford adequate assistive technologies, do not have the resources to maintain them in good condition.

In many countries, social protection systems are a gateway to accessing assistive devices either through social health insurance, direct provision via tax-financed healthcare systems, subsidies or cash transfers – or a mix of these mechanisms. However, only a minority of persons with disabilities in low- and middle-income countries have access to relevant assistive technologies. Low coverage of provision of assistive technologies is influenced by a number of factors:

- The low coverage of health care systems and other relevant social protection mechanisms.
- Even where included under health care schemes, few assistive devices are covered, the most expensive ones are excluded and there may be co-payments that people cannot afford.
- Mechanisms are often ad hoc and require a lengthy application process.
- Access to assistive technologies through social protection is often conditioned by requirement for official disability status and/or a means test or poverty targeting requirement. On their own each requirement limits access and may exclude people in needs of support, which is magnified when those requirements are combined.
- Issues relating to accessible delivery, including lack of awareness, information, availability and human resources.

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<sup>9</sup> For more details see Cote A. Social protection and access to assistive technology in low- and middle-income countries. *Assistive Technology*. 2021 Dec 1;33(sup1):102-108. doi: 10.1080/10400435.2021.1994052.

One important factor linked to limited access to assistive technology is the lack of coordination between health care systems and the parts of government with specific mandates related to disability (e.g., Ministries of Social Affairs/Welfare). Channelling assistive technology via Ministries of Social Affairs facilitates more tailored support but can also perpetuate the perception that assistive technologies are a disability-specific issue, despite the growing evidence and recognition of their relevance for diverse segments of the population across the life cycle. On the other hand, there may be a reluctance from social health insurance bodies to take on the sole responsibility for covering the cost of assistive technology. An emerging model for extending provision of assistive technologies involves a combination of the following components:

1. Developing a national list of priority assistive products based on WHO global priority list,
2. Increasing inclusion of most common assistive technology product in UHC package accessible to wider diversity of persons irrespective of disability status,
3. Ensure coverage of more expensive or rare AT products required by fewer persons with disabilities with high support needs by schemes or institutions responsible for issues related to disability (e.g., Ministries of Social Affairs).

Such approach could distribute the budgetary costs of access to assistive technologies across ministries and level of governments and facilitate the required progressive increase of resource allocation to ensure universal access.

## **7 DISABILITY IDENTIFICATION, ASSESSMENT AND CERTIFICATION<sup>10</sup>**

In line with the principles of universal design and the human centered approach, one could envision a universal and inclusive social protection system which provides tailored support to the diverse members of society based on an assessment of their vulnerabilities and needs at different stages of life without attributing specific labels such as poor, old or persons with disabilities. For instance, social support needs of an older man with disabilities would be assessed and addressed alongside those of an unemployed single mother, who may or may not have a disability, through an inclusive needs' assessment carried out by a social worker/case manager. A tailored support package combining inclusive and flexible cash and in-kind schemes would be provided based on the discrete needs.

While there is a real merit in this vision, no country has developed such universal and inclusive social protection system probably due to the historical legacy of policies, technical challenges, financing issues and political economy of resource allocations and social protection reforms.

Sections 4 through 7 on contributory and non-contributory cash transfers, concessions and health coverage discussed different schemes, measures and programmes that countries put in place to reach the objective of ensuring income security, coverage of disability-related and access to health and other needed services for people with disabilities. The majority of these measures are targeted to people with disabilities and their specific needs, which implies a capacity within the government to determine disability status and needs.

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<sup>10</sup> This section is based on a upcoming working paper produced jointly by UNICEF and UNESCAP on disability assessment and determination systems in low- and middle-income countries.

The CRPD does not prescribe either adopting disability assessment and determination mechanisms or attributing a “disability status” to support inclusion of persons with disabilities. Indeed, many CRPD provisions that are geared towards mainstreaming and making all infrastructure, services, and facilities accessible and inclusive of persons with disabilities. Where equal access to services is guaranteed based on non-discrimination and provision of reasonable accommodation, systems would not require identifying persons with disabilities to ensure inclusivity. However, many provisions related either to specific measures to accelerate de facto equality (article 5.d) or provision of individualized support such as on legal capacity (art. 12), support services to live in the community (art. 19), health (art 24), employment (art. 27), on education (art. 24) and with regards to individualized support, social protection (art. 28) may imply that States develop capacities and mechanisms to identify who requires disability-related support, what kind of support they need, and ultimately who is entitled to get such support.

In all countries that have fairly mature social protection systems, while access to mainstream social protection schemes such as poverty assistance, old age pension, health insurance, public housing might not require identification of persons with disabilities (assuming that they are made accessible), providing disability specific support (cash transfer for income replacement and/or disability related costs, costly assistive devices, personal assistance, among others) require such identification to ensure that programmes reach those for whom they are designed.

In low- and middle-income countries, which are building their social protection systems, there is in addition the importance of prioritization of persons with disabilities in the design of and access to social protection schemes in view of their specific vulnerabilities regarding their ability to secure decent income, avoid catastrophic health expenditures and tackle the diversity of disability related costs. This is in line with the commitment of the 2030 Agenda for Sustainable Development to leave no one behind and the principle of progressive universalism.

## 7.1 DIFFERENT TYPES OF DISABILITY IDENTIFICATION FOR SOCIAL PROTECTION PURPOSE

**From a social protection standpoint, the purpose of disability assessment and determination mechanisms is three-fold:**

- Identify children, working age adults and older persons (and their basic support needs) who may require and want disability related social protection support to live independently and to be included in the community
- Enable targeting, prioritization and access to a diversity of available programmes and schemes providing required support (including via case management)
- Design, plan and cost the development of required services and schemes to respond to unmet support needs (which require additional data and evidence)

An important caveat is that **disability assessment and determination mechanisms cannot be used to estimate how many people experience disability within the total population**. Indeed, many people who may be experiencing functional limitation and disability related participation restriction may not self-identify as persons with disabilities in the first place and would not seek disability status. However, Disability registry can provide data contributing to such endeavor, but they will only provide information about people who access the system. Census and nationally representative population surveys are required to know how many people experience disability among the total population.

Social protection systems and schemes have different entry points for identifying persons with disabilities depending on the type of purpose and intervention they seek:

- **Identification of households which are likely to have member(s) with disabilities:** this can be done for monitoring purpose such as measuring the share of households involved in particular

programmes who are likely to have members with disabilities or identifying the difference in structure, standards of living and needs between households with and without persons with disabilities for inclusive design and delivery purpose. It can be also done in the context of humanitarian crisis or need for rapid expansion as during Covid 19 response, seeking information for a more inclusive social protection response.

- In these circumstances, identification is increasingly based on inclusion of disability questions such as WGSS or equivalent in social protection surveys as for census and main households' surveys (Barca and al, 2020). While cost effective, this approach is limited by the bluntness of instruments initially designed for statistical purpose at population level to generate estimates in terms of prevalence and inequalities of access and outcomes but not for individual identification.
  - They can however be used to identify people that might be referred for an individual disability assessment. This can also be useful to adjust for disability the eligibility criteria or benefit value of mainstream poverty targeted household assistance programmes. There would probably be more exclusion than inclusion errors, considering the inherent limitations of WGSS or equivalent and the survey approach (response by head of household subject to more error than individual response, under-identification of children with disabilities and some specific groups...), but this would still contribute to make the targeting and the support more inclusive to a certain extent.
- **Granting disability status and/or eligibility to disability specific schemes:** Granting disability specific support to an individual requires reliable disability identification to justify the specific allocation of resources in most contexts including in communities where poverty and vulnerability are widespread with few social protection schemes available, especially for working age adults.
- The disability determination can be carried out to establish eligibility to a specific scheme (Fiji and initially in Cambodia), to provide a disability status/card which grants direct access to a diversity of support measures (Nepal or Thailand) and can also be used as a proof for schemes in which disability is one of the eligibility criteria. The greater the benefit or set of benefits related directly or indirectly to the disability status, the more scrutiny there will be on who is considered officially as a person with disabilities.
  - In this case, countries systematically use individual assessment which take vastly different forms ranging from a medical assessment in district hospitals to home visit by a social worker, lengthy processes involving multiple medical and social assessments with different levels of complexity and costs both for persons with disabilities and for public authorities.

**As recommended by the CRPD committee, countries should avoid multiple disability assessment processes for accessing different benefits.** However, this remains commonplace in low- and middle-income countries, where disability assessment is regularly undertaken at a scheme level. There may be multiple assessment processes relating to cash transfers, contributory social insurance and other services. The need to undertake disability assessments for multiple schemes provides further barriers to accessing social protection benefits, in terms of time and cost. It can also be considered administratively inefficient that multiple agencies undertake disability assessments independently. This **implies developing a common disability assessment and determination mechanism leading to the delivery of a disability related status** and often documentation (e.g., disability or equal opportunity card, status, certificate) which will be used to grant eligibility directly or in combination with other eligibility criteria to diverse benefits.

Whether in high or low- and middle-income countries recent studies have highlighted how persons with disabilities often find disability determination processes difficult and how disability determination procedures can limit significantly access to existing benefits especially in LMICs (Waddington and al, 2018, Banks and al, 2018; Kidd and al, 2019). Even when accessible, disability determination mechanisms tend to focus on assessing medical conditions and impairments, rarely collecting information on the diverse support that people need (Ibid), depriving central and local government from useful data to prioritize resource allocation and plan the development of required schemes and services.

This section will elaborate on the different components of disability assessment and determination mechanisms, the challenge countries face to develop CRPD compliant and politically viable mechanisms and the importance of information systems.

## 7.2 UNBUNDLING DISABILITY ASSESSMENT, DISABILITY DETERMINATION/CERTIFICATION AND ELIGIBILITY DETERMINATION

Disability assessments cover a wide range of issues: access, multiplicity, costs, complexity and/or length of procedures, exclusion of certain groups de jure or de facto, fraud, lack of availability or training of qualified assessors, information or the criteria taken into consideration to grant disability status, the mode of calculation of a disability score, the inconsistency of procedures across the country, outcome in terms of eligibility to benefits and/or the lack of information system among many others. This diversity of different challenges often clustered under disability assessment issues make it difficult to address them and develop relevant guidance.

**Figure 7.1 Unbundling functions**



Faced with multiple requests for technical assistance across those many issues, experts from ILO, WHO, OHCHR, IDA and the Special Rapporteur on the Rights of Persons with Disabilities initiated a joint reflection on the matter in 2016, and agreed, among other elements, about the importance to distinguish disability assessment, disability determination or certification, and eligibility determination which are often bundled:

- **Disability screening and early identification** include diverse procedures and mechanism to identify children, youth, adults who are likely to have functional limitations and to experience disability or households likely to have members with disabilities. Those are usually fairly light processes and tools which make take place in during health check-up, in schools or as part of social protection enrolment or registration survey. The succinct nature of the screening does not allow for certainty of the type and extend of disability experienced but can inform referral to individual assessment or services to allow for the accurate treatment and prioritisation in targeting.
- **Disability (and needs) assessment** is the process and output of collecting information about the situation of an individual seeking disability related support. In different countries and mechanisms, it may include collecting information about medical conditions, impairment, cause of the impairment, level and type of functional difficulties, level and type of met and unmet support needs, barriers, level of participation or restriction of participation, family situation. Information collected during disability assessments can be useful, not only for disability determination but also for referral, case management, and policy planning. Additional specific needs assessment may be required for applicants requiring assistive devices, home adaptation, rehabilitation.

- **Disability determination or certification** is the actual decision about whether a person is considered officially a person with disabilities. The decision is made based on the information collected during the assessment in accordance with officially defined criteria and thresholds in the frame of a specific programme or legislation. In some countries, official disability status can have different levels according to a set of criteria related to severity of disability or support needs (for example in Nepal, Vietnam, Georgia, Uzbekistan).
- **Eligibility determination** is the decision to grant access to one or more existing benefits or services, disability specific or else. In addition to disability status, eligibility determination may be based on other criteria such as age, income, location, among others.

Countries may seem to merge some of those three functions when:

- the mechanism has been established solely for eligibility determination to a single disability benefit
- obtention of the disability status or disability card is automatically associated with eligibility to a set of benefits including tax exemption, discounts, or even cash transfer
- the medical certificate confirming existence and extent of qualifying impairment automatically leads to obtention of the disability status

However, often changes can be made in one of the functions without automatically impacting the way the others are designed or carried out:

- In a country with different levels of official disability (mild, moderate, severe for instance) linked to a score calculated after the disability assessment, a decision to change the threshold for severe disability from 70% to 75% of assessed disability would require change in the disability determination regulation but does not necessarily require any change in the disability assessment tool or procedure.
- A change in the way the disability assessment produces the said disability score may not influence the criteria set officially in disability determination regulation for defining disability/support need level.
- A decision to extend or remove eligibility to a cash transfer to persons categorised as having moderate disability, for instance, may not require any changes in ways disability assessment or determination is done.

It is important to distinguish those three functions first because it allows more rooms for clarification of debates and identification of the specific issues to be tackled.

### **7.3 WHICH INFORMATION IS REQUIRED TO ASSESS AND DETERMINE/CERTIFY DISABILITY?**

The CRPD implies a shift of paradigm for disability assessment, moving from answering “What is wrong with the person? or “What the person can or cannot do due to the impairment?” to “What is required for the person to be in position to live independently and be included in their community?”.

Therefore, the assessment should consider not only the impairment and/or functional limitation but the barriers to be removed and support required to achieve equal participation as stated repeatedly by the CRPD committee (Waddington, 2020).

However, as mentioned, it is critical for many governments to verify that people seeking disability support have an impairment. This has a significant impact on disability assessments and explains, in part, the persistent reliance on medical assessments. Governments often perceived medical assessments as transparent, predictable and reliable of medical assessment, thus suitable for preventing fraud and providing a supposedly objective reference. While sought for their objectivity, some studies have shown that they actually are also not exempt from discretion (Kelly, 2016) nor corruption.

A review of the evolution of disability assessments in Europe (Waddington and Priestley, 2021) confirms this tension. When programmes are focused on providing in-kind benefits such as personal assistance, related assessments tend to be more focused on the actual needs of the applicants, as opposed to assessments for income maintenance cash benefits which tend to focus on medical diagnoses and functional limitations.

Considering the purpose of disability assessment from a social protection standpoint the key information required would include:

- Is there evidence of long-term impairment?
- What are the functional limitations that may alter, prevent or restrict autonomy in daily living and community participation?
- What are the barriers that may alter, prevent or restrict community participation?
- What is the level and type of supporting goods and services that the person requires to compensate for their functional limitation(s) and overcome the barriers limiting autonomy in daily living and community participation?
- What is the level and type of supporting goods and services required that the person is currently using/receiving?
- What is the overall level of restriction of participation of the person?

This scope of information complies with the recommendations of the CRPD committee and is necessary not only to decide whether a person receives the disability status and at which level but also to enable case management, policy planning and monitoring. One challenge is that in most low- and middle-income countries, collecting the diversity of information should be done through relatively simple means and in absence of specialized staff or multidisciplinary teams that are not available at local level.

Another important element is that **while all the information gathered during the assessment can inform access to social protection support, it does not imply that all the information gathered should necessarily be factored in individual disability determination.**

While basing disability determination solely on impairment is outdated and in opposition with the CRPD, mainly considering the level of participation would lead to significant issues. Participation of persons with disabilities results from the interaction between multiple personal and environmental factors. The more factors are considered in disability determination, the less transparent the certification process becomes. Opaque procedures come with an increasing risk of complaints from applicants who do not understand the possible diversity of outcomes for people with similar impairment(s) and functional limitation(s).

Another critical element is that today most of the human assistance used by persons with disabilities across the life cycle is mostly unpaid care and support provided by family members or friends, often women and girls. When assessing participation, this unpaid care and support as well as all other inputs made by individuals and their families to overcome barriers may become invisible and the outcome may not reflect the actual support required by the person to achieve the assessed participation which is a critical information for social protection.

Finally, barriers in the environment and the level of support available can vary dramatically due to circumstances. For instance, if the person changes residence location, or if the household composition changes, or a disaster occurs, the level and type of barriers as well as support available and received may change.

While the disability assessment should collect information both on the different elements of the disability interaction as well as on the outcome of the interaction, there is a case, especially in contexts with limited institutional capacities across the country, for disability determination criteria to focus on the individual elements of the interaction (impairment, functional limitations and basic support requirement to carry out

activity of daily living<sup>11</sup>). This will allow greater consistency, and reliability and facilitate portability of the benefits attached to the status across the country and avoid unnecessary recertification.

**Assessing the basic support needs of the individual during the disability assessment does not replace in-depth needs assessment for specific support:** for instance, a disability assessment can highlight the need for assistive technology but specific needs assessment by dedicated professionals will required to decide which specific products is required.

**Figure 7.2 Disability assessment and information for different purposes**



<sup>11</sup> Arguably, assessing human assistance and support needs to carry out (instrumental) daily living activities often factor elements of the immediate environment of the person as it would be very demanding to carry out individual assessment in a supposedly neutral environment (Bickenbach 2021, Cuenot, 2021).

### **Box 7.1 Disability assessment in childhood.**

While often the debates with regard to disability assessment and social protection tend to focus on working age adults due to the incapacity to work elements, it is important to highlight that assessment of disability requires different approach and instruments between children and adults.

In early childhood significant change and development occurs when the child is rapidly acquiring large and small motor skills; language development; social behaviours; intellectual abilities and cognitive reasoning and communication skills. There are milestones in child development which must be taken into consideration if one wants to identify children that would have functional difficulties or developmental delays which will be different for children of 6 months, three, seven or fourteen years old. Similarly, assessment of environmental barriers and support will need to be age appropriate.

By contrast, when a person reach adulthood, there is no expectation of dramatic change in functioning or daily living skills except in relation to trauma, illness or ageing. While disability assessment must be sensitive to diversity of environment, in any given context, there are set of common expectations for all adults with regards to functioning and activities of daily living.

Tools that are develop for adults to not take into consideration all the changes and milestones that occur in childhood and hence there is a need to develop specific age-appropriate tools for children.

While early detection and intervention in early childhood are critical, there are questions with regards to the relevance of disability determination at this age. Timely and prompt interventions and access adequate rehabilitation and support are essential to limit and even resolve developmental delays or functional limitation. The uncertainty related to functioning and development delays makes it complicated to certify disability in early age. In some contexts, it can also have detrimental effects such as restricting their rights to inclusive education of children labelled as having disability. Some countries such as Portugal, are seeking to have a child centred approach providing support based on needs assessed. However, provision of additional disability related cash support will still often require disability certification of some sort. A solution could be the delivery of temporary disability certificate by paediatrician/health care professionals for 2-3 years to allow immediate access to needed support.

## **7.4 THE CHALLENGING EQUATION OF DEVELOPING/REFORMING DISABILITY ASSESSMENT AND DETERMINATION MECHANISMS.**

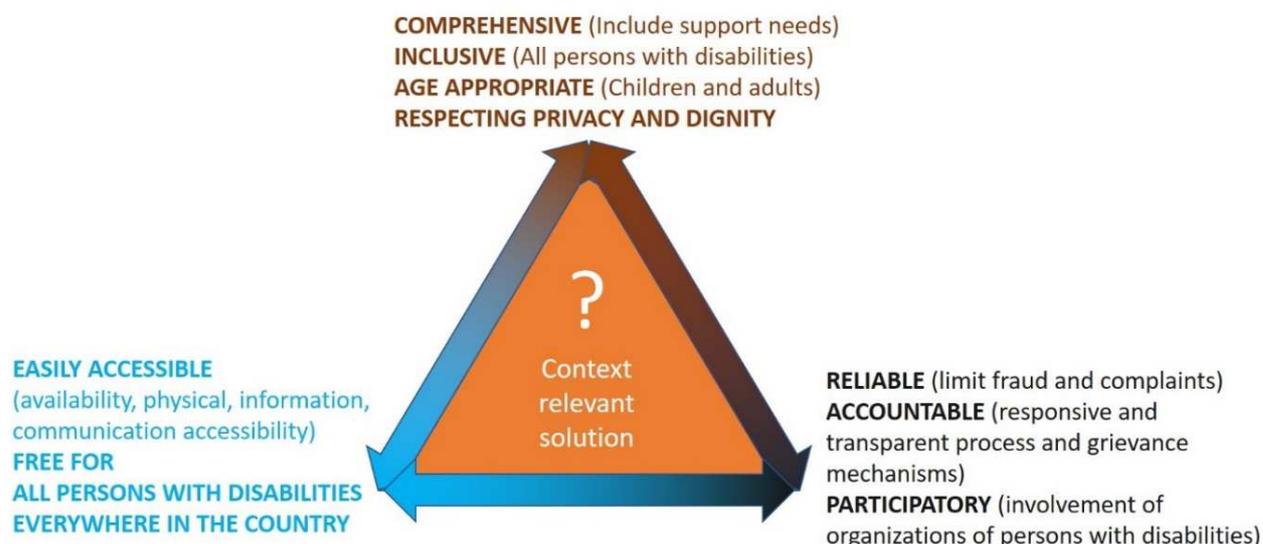
Developing or reforming disability assessment and determination mechanisms is challenging. Governments, persons with disabilities and their representative organizations have overlapping and different issues at stake. Persons with disabilities and their families need procedures that are clear, simple, accessible and predictable, while governments want mechanisms that are low cost, that will minimize inclusion errors and fraud, provide legal certainty and contribute to optimum allocation of available, usually limited resources. Often persons with disabilities and their organizations will perceive reforms of disability assessment and determination as a risk leading to curtailing or limiting their access to benefits and services (Chiriacescu and al, 2015).

The CRPD committee has also made consistent recommendations to low, middle- and high-income countries to make their disability determination process consistent with the human rights model of disability. This implies, at minimum, universal access, a focus on support requirements and barriers rather than solely on impairments, as well as meaningful participation of persons with disabilities and their representative organisations (OPDs).

Governments as well as OPDs engaged in reforming or developing disability assessment and determination mechanisms are seeking ways to fulfil those requirements in very different contexts. Many high-income countries have sophisticated multidisciplinary mechanisms which still might fall short of CRPD standards (Waddington, 2018) and some face critical levels of legal claims or political controversy (Hauben, 2012;

Bickenbach and al, 2015). On the other hand, many low and middle-income countries which are increasing their investment in social protection face significant challenges to develop disability assessment and determination mechanisms due to limited human resources and administrative capacities (Kidd and al, 2019).

**Figure 7.3 The difficult equation of CRPD compliant disability assessment and determination mechanisms**



Stakeholders are therefore seeking to solve a somewhat complex equation with three main elements in tension: **accessibility, comprehensiveness and reliability**.

- **Accessibility:** The assessment and determination procedure must be available and accessible to all, including people facing physical or communication difficulties. It must be free and available everywhere in the country. As many people with disabilities often face difficult environmental challenges, it is particularly important that the assessment application procedure is easy and not complicated. The procedure should be as transparent as possible; from the application to the assessment to the receipt of status and possible grievance, information and process should be delivered in the most accessible way possible (see Section 10). The process should be designed to impose the minimum burden possible on applicants, for instance, in terms of documentation required, or number of appointments and/or interviews.
- **Comprehensive:** The assessment process must be inclusive for all persons with disabilities, regardless of the type of impairment they may have. It must include assessment of individuals' functional limitations in relation to the specific environment they live in, e.g., support needs, barriers and participation. It must also be age-appropriate, as functional and participation expectations, functional limitations, support needs, and barriers change over the course of a person's life. It must be gender-sensitive and respect people's dignity and privacy.
- **Reliability:** Evaluation procedures must be transparent and understandable. This is important to ensure that they are applied consistently and to build trust and minimize confusion among those assessed. To this end, there is a need for standardized and regulated processes and sufficiently trained staff to ensure consistency of the process. Also, a grievance mechanism must exist, and the system must respond to complaints. Reliability also means that steps must be taken to minimize fraud and promote trust among departments to accept all evaluation results. It also means transparency and participation with organizations of persons with disabilities included in its design and monitoring.

In many contexts, **there are strong tensions between those 3 requirements**. Having more comprehensive assessment may lead to tools too complex for staff at local level or to requirement for multidisciplinary teams that are not available at the local level. This could lead to lack of access in rural and remote areas if assessment is done in bigger urban centers. Putting strong emphasis on fraud with assessment done only

by a certain number of accredited medical doctors or facilities many people in remote areas would be excluded.

There are many different parameters to consider in the attempt to balance this equation, such as:

- **Reform or initial development of disability assessment and determination mechanisms**
  - o When developing a first system, it is important to have broad consultation not only with OPDs but with the ministries and entities that will be stakeholders in the development, roll out and sue of the mechanism. When reforming the system, it is critical to consider political economy issues with regards to agreement between ministries or among groups of persons with disabilities (who fear that they may lose access to benefits and who think that they may gain access) for instance. Reassessing people that already have the status can be very unpopular and lead to significant levels of administrative complaints and litigation. To avoid such situations, some countries apply the new mechanism and/or criteria to new applicants but keep people that gained access under the previous system, except in case where the key issue for reform lies in the suspicion of widespread fraud.
- **Level and type of benefits linked to the disability status or certificate**
  - o The more benefits are conditioned by the disability status, the greater the demand will be for assessments so careful consideration should be given to the package of benefits that are linked to disability status. For instance, in context with very limited resources initially granting access to free health care, including rehabilitation and assistive technology (AT) to a status holder may be relevant in the logic of progressive universalism. However, this can be reconsidered as the health care system develop to ensure broader access and avoid the pressure on disability determination mechanism by people who mostly need health care or AT. With time, the package of benefits linked to the disability status will evolve with generic support such assistive technology progressively made available without disability status while newly developed services such as personal assistants are included in the disability status related package.
- **Institutional capacities of relevant administration and public services at local level**
  - o Countries should first assess the availability of relevant human resources at community level across the country, outreach of health, education and social work-related services, existence of effective national information systems in social protection and/or in health.
  - o Development of tools and procedure should preferably be tailored from the beginning to enable the human resources and available local level capacities to carry out assessment rather than developing tools first and then seeking to develop the human resources and capacities to carry out those assessments.
- **Level of trust of central government towards its frontline workers or local authorities**, and the level and perception of corruption in health services and public administration
  - o To ensure universal access, central governments will most likely need to entrust local level human resources and entities to carry out assessment, data verification and initial decision on disability determination. The less trust there is, the more challenging it will be, as there will be a temptation to centralize the process. This can result in limiting the number of professional accredited and location where assessment can be carried out.
- **Level of digitization of administrative procedures** (e-government), familiarity of citizens with digital services and level of internet connectivity across the country
  - o Recent country experiences have shown that digitalization can be a game changer in allowing local health, social or community workers to carry out assessments and enabling good quality checks and verification procedures while providing stronger oversight and data analysis capacity at national level.
- **Level of coordination between ministries and between central and local authorities**
  - o The investment in CRPD compliant, effective disability assessment and determination mechanisms is justified if the system is used by different entities to provide support to persons with disabilities and their families as well as facilitate case management at local level. This requires good coordination and executive agreement between authorities so

that all entities involve trust the mechanisms and can anticipate the increase of demand that the system will generate on their services.

- **Level of cooperation and engagement between OPDs and authorities**
  - o OPDs are critical to the successful development/reform of disability assessment, determination mechanisms and strengthening the capacities of frontline worker and local authorities. Their involvement is critical to ensure ownership over the reform, mitigate risk of opposition and public/legal challenges and facilitate outreach and communication with persons with disabilities and their families.

While there is no specific international guidance at this stage, in recent years, several countries have sought to solve this challenging equation by adopting different approaches often linked to pre-existing systems. Two main trends can be observed with different focuses:

- **Focus on comprehensiveness:** Partially in response to the recommendations of the CRPD committee to adopt social or human right models of disability, many countries such as Argentina, Armenia, Brazil with pre-existing systems based on medical assessment have invested in development of more elaborated assessments based on multi-disciplinary teams/commissions with tools developed based on to the International Classification of Functioning (ICF). While addressing the issue of comprehensiveness, they often face the issue of availability of human resources able to administer the assessment across the national territory limiting progress towards universal and easy access to the mechanisms.
- **Focus on accessibility:** Some countries with low coverage or no prior mechanism adopted a two-level approach that moves away from medical assessment as a first entry point to significantly increase access and coverage. They have developed simple assessment tools with a focus on functional limitations and support needs (e.g., instrumental activity of daily living) carried out at community level either by a local committee or community health or social worker such as in Vietnam, Fiji or Cambodia. Referral to medical assessment occurs when community workers are not in the position to carry out the assessment, often in relation to so-called *invisible disabilities*. Progress in digitization allows community workers to carry out more comprehensive computer-assisted disability assessments than it would have been possible with paper-based system, such as in Cambodia.

To solve the equation of CRPD compliant disability assessment and determination mechanisms, there is no one-size fits all approach and governments should develop processes, mechanisms and tools that:

- Are tailored to be used and managed effectively by the most relevant staff available at local level across the country so that all persons with disabilities are in position to access the mechanisms,
- Are easily accessible, understandable and manageable by all persons with disabilities and parents of children with disabilities, considering social norms around gender and disability.
- Can capture to the best extent possible evidence of impairment and/or type and level of functional limitations, support requirements, barriers, and level of participation
- Have effective and adapted quality control, fraud prevention and safeguard mechanisms which do not complexify and make the process cumbersome while ensuring consistent outcomes.

One of the main recommendations based on most recent reforms is to start by exploring the issue of access to the system and building up from there. Key questions that can help:

- What are the human resources that can be mobilized at local level to carry out disability assessment?
- What are the mechanisms (new or already existing) that we can use to have quality control and fraud prevention while maximizing access to all persons with disabilities and optimizing comprehensiveness?
- What are the tools that we can use to build a country relevant instrument for disability assessment in line with CRPD which can be easily use at local level?

Below are detailed some of the key elements of the reform/development of mechanisms in Armenia, Cambodia and Fiji and how they sought to balance different requirements.

Table 7.1 Experience of Armenia, Cambodia and Fiji

Country	Armenia	Cambodia	Fiji
<b>Initial rationale</b>	Reduction of fraud, compliance with CRPD and harmonisation with ICF (social model)	Extension of cash transfer for poor persons with disabilities and developing disability registry. Initial disability assessment was too medical to be used at local level	Eligibility determination for the new disability allowance
<b>Constraints</b>	Limiting impact on people who may not be granted disability status in the new system	Low institutional capacity at local level with low level of access to medical professional in many remote communities	Strong geographical constraints with remote areas and islands
<b>Focus of reform</b>	Developing an assessment tool and determination criteria based on ICF and compliant with CRPD	Developing a digitised assessment tool and process easily usable by community worker but connected to district and national level	Ensuring access to the assessment for all those potentially eligible to the disability allowance
<b>Accessibility</b>	Aim for national coverage in social service centres (roll out is ongoing)	Strong improvement of access with 1.4% of the total population officially registered as persons with disabilities as of February 2023 after 2 years initial roll-out	Based on outreach in community or at home, including staff in charge of ID documents, for remote areas, successful initial roll out >1% of the overall population in 3 years
<b>Comprehensiveness</b>	Distinct tools for children and for adults. Multidisciplinary team with tools assessing impairment, activity limitation as well as environmental and personal factors based on the ICF	Distinct tools for children and for adults. The tool includes functional limitations and a few questions about need for support and assistive devices	No distinction between children and adults. Simple tool assessing the level of assistance required to carry out basic activities of daily living. Focused on persons with higher support needs, with possible bias towards persons with physical and sensory difficulties. Few questions on support, assistive devices, medicine and disability costs.
<b>Reliability</b>	The process includes different mechanisms to prevent fraud such as random assignment of cases to assessors and cross checking between assessors which strengthens reliability but may increase costs.	Local workers carry out the assessment, recommendations for determination are automatically calculated by the app. Data verification is made at provincial level and preliminary list is published on community board (which may raise privacy issues). Once validated, the application and recommendations for determination are sent to national level for last check and for printing of the card. Possibility of referral for confirmation assessment with medical professionals	Assessments are carried out by the social worker in charge of eligibility determination for other social protection programmes who benefit in strong trust from the system. There is a certain level of discretion for the social worker due to the limited details provided by the assessment tool. Village chiefs and OPDs may be consulted for reference and verification. OPDs involved closely in the design and implementation. Possibility of referral for confirmation assessment with medical professionals.
<b>Registry</b>	Currently contributing to disability registry with the development of an integrated information system in process	Development of a Disability National Information System with the aim of interoperability with other registries	Simple database of beneficiaries but no disability management information system so far

## 7.5 THE IMPORTANCE OF DISABILITY REGISTRIES AND INCLUSIVE INFORMATION SYSTEMS

Until recently, in most countries, information collected during disability assessment was mostly used for determining disability status but was not actually use for effective case management or policy planning. There are different reasons for this, such as focus on medical assessment with little to no information on support requirements and paper-based procedures making aggregation and use of data very resource intensive. The development of management information systems in health, education and social protection have opened new possibilities.

**An increasing number of countries have adopted a disability card or status that is associated with a national disability registry (e.g., Kenya, India, Senegal, Thailand, Cambodia, Georgia).** These registries often sit within a dedicated institution and act an official proof of disability across the government, for ministries and services. With the development of more comprehensive assessments and digitisation, disability registries are evolving towards Disability Management Information System. Disability registries/management information systems have several advantages depending on the type of information they include:

- When linked to single window/assessment mechanisms, they can **reduce the administrative burdens** on persons with disabilities and their families, eliminating the need for repeated disability assessments for different schemes and **reduce the administrative cost of schemes** for government.
- They **facilitate case management and access to a diversity of social protection benefits**, including cash benefits and in-kind provision of goods and services (such as health care, assistive devices, support and concessions). If assessments include information on skills and occupation, they can be used to facilitate job placement. If data on locally available services are available, they can facilitate effective referrals. **Connection and interoperability with social protection information systems** is being explored by several countries to increase case management capabilities.
- They make social protection systems more shock responsive by **supporting horizontal and vertical expansion** of existing disability benefits, and mainstream schemes, and help create new ones during times of crisis, such as those that were created in response to the COVID-19 pandemic. For example, benefits only provided to some persons with disabilities in normal times could be extended to all persons on a disability registry in times of crisis.
- Aggregated data can be used at local and national level to **prioritise, plan and cost extension or development of services and schemes** based on the needs of people that have been assessed whether or not they received the disability status. It can help change the package of benefits linked to disability status with more generic support such as assistive technology progressively made available without disability status while new services such as personal assistants are included in the disability status related package.

As mentioned, several low- and middle-income countries have invested in developing such registries and information management systems:

- **Cambodia** recently developed a Disability Management Information System (DMIS) enabling local community workers to carry out disability assessment and managed to cover more than 1.4% of the total population in less than 2 years (see box 3). The DMIS has already been used to improve targeting of cash transfers, prioritise persons with disabilities registered for the COVID-19 vaccine and will be used to inform the development and access to new cash and care schemes.
- **Senegal** has for several years managed a registry for its equal opportunity card delivered to persons with disabilities. While the coverage and consolidation of the system is still limited, in response to COVID-19, the government used data from the equal opportunity card registry and the unified social registry to ensure that registered persons with disabilities would have access to COVID-19 related relief.

- **India** is engaged in a vast reform building a National Database and is in the process of issuing a Unique Disability Identity Card to each person with disabilities. The card is both physical and electronic. The aim of the reform is to encourage transparency, efficiency and facilitate access to schemes and benefits provided by the Government through its various Ministries and their Departments at all levels of government – from village level, block level, district level, state level and national level. The delivery of the card is based on an initial assessment which is primarily medical with limited information on individual support requirements, the potential use for case management and policy planning is low.
- In 2022, the National Council of Persons with Disabilities in **Rwanda** (see box 3) with the support of GIZ is piloting a national disability management information system based on simple but broad individual disability assessment that would capture support needs related to health and rehabilitation, assistive devices, human assistance, education and livelihood as well as available services at local level.
- In 2022, local NOGs, who work for people with disabilities and are members of FETAPH, permanently register into platform all persons with disabilities by means of a digitized tool in **Togo**. A total of approximately 3,500 persons with disabilities were already registered, which is only the beginning as the goal is to cover all persons with disabilities in Togo.

Digitisation also allow faster and more accurate analysis of data (including geotagging) which will support design and planning of interventions in a more effective manner to meet the needs in a defined environment.

It is important to note efforts of other countries to **make their social protection management information system or social registry more inclusive** by integrating disability related questions in their routine social registry survey (Dominican Republic) and/or carrying out specific additional survey (Sierra Leone). These efforts can support reforming existing benefits to have a more inclusive design and enable prioritisation of households likely to have persons with disabilities during crisis response.

While disability registries and management information systems (MIS) have great potential to improve the support provided to persons with disabilities across the life cycle, **specific attention should be paid to ensure data privacy and protection**, particularly given the broad scope of individual information they may collect. Only the minimum necessary information should be accessed by the different professionals using the system and/or shared in case of connection with social protection MIS.

In any case, it is important to use administrative data stemming from disability registry in combination with national statistical data sets. Complementing administrative data with survey data provides a broader picture of inequalities and issues faced by persons with functional limitation who may or may not self-identify as persons with disabilities, and who may not access or seek to access disability related support through disability assessment and determination mechanisms.

### Box 7.3: Towards Disability Management Information Systems to support inclusive and shock responsive social protection – Rwanda and Cambodia

**Rwanda:** The initial disability determination mechanisms, formalized in Law 01/2007 and Ministerial Order N° 20/18 of 2009, employed a medical model assessment based on the 1973 Belgian invalidity barème. The system classified disabilities into five impairment groups and five severity levels based on impairment percentages. The National Council for Persons with Disability (NCPD) initiated a broad national disability identification campaign in 2015-2016 with mobile teams of medical professionals assessed an estimated 300,000 people.

However, the medical-focused assessments faced difficulties, including poor accessibility due to lack of medical staff and limited data for case management and policy planning. Learning from this experience and with the support of GIZ, the NCPD developed in close consultation with OPDs a National Disability Management Information System (DMIS) – a digital tool aimed at identifying persons with disabilities, managing high-support needs cases, and creating a disability service directory for referrals.

The DMIS relies on a comprehensive assessment carried out by local assessors using a 300-questions computer-assisted questionnaire building on the Washington group extended set and the child functioning module, as well as questions related to barriers, support needs (Human assistance and AT) for daily living activities and for access to education and work. Currently, the DMIS has been piloted in select districts with the goal of wide-scale disability identification.

The DMIS also aims to enable case management for persons with high unmet support needs, using an Individual Support Plan (ISP) developed with a case manager. The information system, once fully implemented, will provide interactive dashboards with detailed demographic and disability-related data accessible by all stakeholders, although access restrictions will be in place to ensure privacy regulations are upheld.

The DMIS will be integrated with the national Integrated Social Protection Management Information System for more inclusive targeting and monitoring of access to social protection programs and services.

**Cambodia:** In 2011, the Cambodian Government introduced a cash transfer program targeting poverty-stricken people with disabilities. The Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY) developed identification tools that used existing mechanisms to register poor individuals with disabilities. However, the initial pilot in 2015-2016 revealed issues with the tools due to their overreliance on medical definitions of disability and unclear instructions for community workers. A first change was the development of a series of age-appropriate questionnaires focusing on a person's level of functioning to be used by community workers. Challenges were still experienced in data handling between administrative levels, leading to significant delays in decision-making for persons with disabilities.

Consequently, in 2018, MoSVY, initiated the development with UNICEF support and in close consultation with OPDs of a digitized system featuring an app-assisted disability assessment for smartphones to improve data flow and expedite decision-making. This system allows for annual or on-demand registration and simplifies the process for families, starting and finishing at the village level with verification and oversight at provincial level and final approval and ID card issuance national level.

Despite COVID-19-related challenges, the tool was successfully rolled out in eight provinces in 2020, resulting in the registration of over 250,000 persons with disabilities and was already used to increase access to cash transfer and to prioritize persons with disabilities for COVID 19 vaccination. It will facilitate the development and access to new cash transfer as well as care and support schemes.

## **8. INTERLINKAGES (TO BE DEVELOPED)**

- This section will be developed in second semester 2023 and will explore rationale and promising policies and practices of interlinkages between social protection and nutrition, education, work and employment.

## PART 3: ENABLERS OF INCLUSIVE SOCIAL PROTECTION

### 9. DATA FOR DISABILITY INCLUSIVE SOCIAL PROTECTION

High-quality data is important for the design, monitoring, and evaluation of social protection policies and programmes. Unfortunately, although many countries collect a great deal of data towards these ends, they rarely collect data that supports disability-inclusive social protection. This lack of data inhibits the design and adjustment of schemes that would effectively support persons with disabilities across the lifecycle and prevents monitoring the level of inclusivity and the impact of the overall social protection system on persons with disabilities.

This section briefly summarizes the types of data required for disability-inclusive social protection and provides recommendations for collecting them.

In discussing disability related data, it is essential to choose the preferred methods and sources for data collection in line with the purpose of the data collection. These purposes can include:

- Measuring the prevalence of disability and demographic patterns of prevalence, including disaggregation by age and gender to devise the potential scope for disability-inclusive policies in general and social protection in particular,
- Measuring the extent of inequalities by disaggregating gender, age, and socio-economic indicators by disability status,
- Identifying general barriers in the environment that might drive exclusion on a population level,
- Assessing the diversity, scope and intensity of the met and unmet support needs of men, women, girls and boys with disabilities and the disability related costs they face,
- Designing, monitoring and evaluating social protection programmes for the inclusion of people with disabilities including those facing multiple discrimination based on gender, age and other personal characteristics.,
- Costing and financing the development of inclusive social protection programmes.

This section describes ways in which way the collection of disability data relevant to social protection systems can be strengthened. Specific attention is paid to national surveys, social protection administrative data among other relevant methods and approaches. These data sources combined can contribute to inclusive design and comprehensive monitoring and evaluation of the social protection system.

As for all social protection schemes, ensuring confidentiality of private information is of key importance when collecting, processing, analysing, storing, or sharing data. In addition to the key socio-demographic information shared, people accessing disabilities benefits and services often share sensitive medical and other personal data which may require additional attention to ensure confidentiality.

#### 9.1 NATIONAL CENSUS AND SURVEYS

**Including questions related to disability within national population census and surveys supports the development and implementation of disability-inclusive social protection systems in many respects.** This includes population censuses, household income and expenditure surveys (HIES), labour force surveys (LFS), living standards measurement surveys (LSMS), Multiple Indicator Clusters Survey (MICS) and Demographic and Health Surveys (DHS). These can be complemented by specific surveys focused on disability such as the Model Disability Survey (MDS).

- They allow an estimation of the **prevalence** of disability, which is key for planning and budgeting for social protection interventions.

- Different approaches and criteria may be used to estimate the share of the population who would benefit from inclusive services and environment or the smaller population of people with higher support needs also requiring disability specific social protection.
- The disability disaggregation of the main indicators related to income, consumption and expenditure, labour force participation, health and education, among others captured by the census and surveys provides an **overview of the inequality in outcomes and access** faced by persons with disabilities. Further disaggregation by age, sex, location can indicate **compounded inequalities and discrimination**.
  - This is essential to both generate evidence and rationale for investment in, as well as monitoring progress and impact of social protection programmes.
- Estimating the economic impact of **disability related extra expenditures** by comparing standard of living achieved by households with and without persons with disabilities.
- When relevant questions or modules on social protection exist within surveys it can support monitoring of the **coverage and effectiveness of social protection systems** for persons with disabilities, disaggregated by gender and age. This can help answer more specific questions related to who is excluded from social protection and the extent to which social protection addresses poverty, extra costs and support needs.

**There are several ways in which social protection practitioners can support the enhancement of national surveys.** While social protection practitioners may not be directly involved in the design of national surveys, they often have opportunities to influence their design, including in formal consultations. Adjustments to national surveys inevitably require an assessment of the trade-offs in terms of greater comprehensiveness, and potential increased costs and time taken to undertake surveys. Nevertheless, in many case the refinement of surveys requires the improvement of existing questions, or small additions.

Key priorities include:

**USING INTERNATIONALLY COMPARABLE QUESTIONS ON DISABILITY STATUS:** This enables both estimation of disability prevalence and analysis of other domains disaggregated by disability status. Various internationally comparable question sets, and modules exist relating to disability (See Box 9-1). Key recommendations for national surveys are:

- All national surveys should include, as a minimum, the **Washington Group Short Set of Disability Questions**.
- Surveys with a focus on children should include the **Child Functioning Module (CFM)**.
- Surveys with a specific focus on disability should seek to include more in-depth questions on disability status such as the Washington Group Extended Set of Disability Questions or the Model Disability Survey. These may be adapted based on the purpose of individual surveys.

#### **Box 9-1: Internationally comparable questions, modules and surveys relating to disability**

The Washington Group on Disability Statistics established by the UN Statistical Commission has designed and tested a variety of question sets to identify persons with disabilities. These focus on daily functions.

- **The Washington Group Short Set of Disability Questions (WGSS):** This asks about the level of difficulty a person has performing six different daily functions (seeing; hearing; walking or climbing steps; remembering or concentrating; self-care; and communicating or being understood). The WGSS are designed to be added into the core demographic section of national surveys (including censuses and nationally representative household surveys). This tool has emerged as the preferred methodology for estimating disability prevalence and helping to generate disaggregating data by disability status. The WGSS has only been validated for persons over the age of 5 years and is recommended by UN statistical commission and the World Bank for basic disability disaggregation of census and mainstream national surveys.

- **The Washington Group Extended Set of Disability Questions (WGES):** This adds additional questions in the domains in the WGSS as well as additional questions on psychosocial issues and upper body mobility, and some questions on functioning with assistive devices. The goal was to identify more people with disabilities and obtain a deeper understanding of the degree and range of their functional difficulties.
- **The Washington Group Short Set Enhanced.** Because the length of the WGES is sometimes seen as prohibitive, the Washington Group put out the Short Set Enhanced that asks the same six questions as the WGSS and adds the four questions asking about the frequency and level of anxiety and depression a person experiences from the WGES, as well as an optional two questions on upper body mobility.

**The Child Functioning Module (CFM):** Developed by the Washington Group and UNICEF to address the two issues inherent in the WGSS and WGES: they are not valid for children under the age of 5 years and tend to miss a significant number of children with developmental or psychosocial disabilities. The CFM module asks questions about a broader range of functional domains including those particular to children such as playing and learning. It has two separate question sets, one for children aged 2-4 and one for children aged 5-17, due to the significant differences in child development at those ages.

**The Model Disability Survey: (MDS):** Developed by the World Health Organization, this survey asks multiple questions related to the functional domains covered by the WGSS, as well as for additional domains including hand and arm use, pain, breathing, affect (anxiety and depression), interpersonal relationships. An advantage of the MDS is that it provides much more detail on human functioning as well as elements on barriers and support needs including assistive technology and human assistance. It does not, however, in its standard form, address several elements relevant to social protection such as disability status or access to specific benefits which require tailoring of the survey questionnaire. Other disadvantages are the length of the survey and the complexity of the method for identifying who has a disability. However, WHO has also created a brief version of the MDS. While the brief module is still too long for censuses, it could be used in a module on disability in a household survey.

## COLLECTING DATA ON DISABILITY RELATED BARRIERS AND SUPPORT NEEDS

- **Barriers** that exist in different sectors and of different types (attitudinal, physical, information and communication). Understanding diversity of structural barriers also contributes to a better assessment of the extent to which social protection can impact inclusion. For instance, if the education system is fundamentally discriminatory, cash support to household will have little impact on access to education of children with disabilities without strong supply side measures.
- **Support needs** including the activities for which support is needed, the type and intensity of met and unmet support needs, and who is currently providing human assistance. Assessing the diversity, scope and intensity met and unmet support needs and disability related costs at population level is critical for the design, costing and resourcing of social protection programmes and to build an effective combination of benefits. It is also critical to assess how the way existing support is provided affects both persons with disabilities and households, especially family members providing unpaid support who are often women and girls.
- **Assistive products and technology** are a specific form of support with critical importance. They include the type of assistive products and technology that people currently use or may need to perform daily activities. They can contribute to lessen needs for human assistance, help overcome barriers and increase autonomy in a cost-effective manner.
- **Disability related costs** for persons with disabilities and their families across the lifecycle can be estimated, in part, by collecting data on barriers, met and unmet need for support and assistive technology.

**ENHANCING QUESTIONS OR MODULES ON SOCIAL PROTECTION:** While national surveys usually include questions relating to social protection, they are often out of date or not developed with the input of those working in the social protection sector. Their design may create specific limitations on disability inclusive social protection. Key ways to strengthen social protection questions and modules are the following:

- **Questions are asked about receipt of all relevant social protection benefits.** This means having questions that relate to the diversity of social protection benefits, including disability benefits, rather than general ones that aggregate multiple benefits or under a broad overarching term. For example, asking about receipt of “pensions” does not distinguish between those provided for disability, or for old age and survivors. Similarly, some questionnaires ask about receipt of any benefit from a given institution.
- **Questions are asked at the individual rather than the household level.** It is common for surveys to ask if anyone in a household receives a given benefit. However, this limits the ability to identify whether a specific person with disability received a given benefit.
- **Questions are asked about benefit levels.** This can help to understand the adequacy of benefits (particularly where multiple benefits are combined) and its contribution to household income.
- **Questions are asked about accessibility of social protection.** This is particularly relevant for understanding the issues discussed in the Section 10 on accessible delivery. Examples of relevant questions related to accessibility can be found in Box 9-2. Some of these questions may go beyond what is possible in a routine national survey, and might be a better the focus of less routine surveys or programme monitoring.

There is an inevitable trade-off between the comprehensiveness of any given survey module and questions of cost, and the time taken by survey respondents. In this context, it may not be possible to include all of the questions above, particularly those relating to accessibility, which could be included as part of more focused surveys.

**Box 9-2: Key questions relating to accessibility of social protection**

- Do people know of the existence of social protection programmes?<sup>12</sup>
- Do people know how to apply for benefits?
- Are registration and payment methods accessible – both physically (e.g., accessible offices) and informationally (e.g., sign language interpretation and Braille)?
- Does the person with a disability have access to the benefits in question, or is another person designated as the recipient, either officially or de facto?
- Are disbursement methods accessible (physical distribution sites, electronic distribution)?
- Do recipients receive the full benefit amount they are eligible for?
- Are payments made on time?

**ENHANCING OTHER MODULES:** Other modules of national surveys can be strengthened to ask questions which shed light on the situation of persons with disabilities. These include:

- **Health:** Including questions on incidence of illness and injuries, and health seeking behaviour, foregone treatment and consultation.
- **Expenditure:** Including questions about expenditure on items relevant to persons with disabilities (with necessary detail) such as specialised transport, assistive devices and care services.

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<sup>12</sup> For example, in a special survey done in two states of India, the World Bank found that over 60 percent of people with disabilities were not even aware that there was a cash benefit for which they could be eligible. For more details, see O’Keefe, P. (2007). People with disabilities in India: From commitments to outcomes. *Human Development Unit, South East Asia Region, The World Bank*, 157, 295583-1220435937125.

- **Employment:** These modules can draw on a disability module developed for Labour Force Surveys by the Washington Group and the ILO that can identify some environmental barriers and facilitators when it comes to employment.<sup>13</sup>

**ENSURING A SYSTEMATIC MINIMUM LEVEL OF ANALYSIS AND DISAGGREGATION:** While refinement of survey questionnaires can improve the potential of survey data, there is a danger that disability-focused analysis is limited to specific research activities undertaken using such data. To address this, it is important that survey reports include a minimum level of disaggregation by disability status for most domains, including social protection. Whenever possible disability data should be disaggregated and analysed by gender and age to gain a better understanding of the different experiences and needs of men and women, boys and girls, cross the lifecycle.

**UNDERTAKING SPECIFIC SURVEYS ON DISABILITY:** Such surveys create the opportunity to go into greater depth on issues that cannot be effectively captured by other national surveys which serve a more general purpose. Comparatively fewer countries have implemented such surveys, such as Philippines, Chile, Georgia, Thailand<sup>14</sup>, Uganda and Viet Nam<sup>15</sup> among others. Such surveys tend to be undertaken less frequently than other national surveys (for example, Thailand seeks to undertake the survey every 5 years), and often on an ad hoc basis. The design of such surveys can draw on a range of resources including the question sets and modules described in Box 9-1, and the design of similar surveys in other countries. Opportunities may also be provided by surveys focused on other population groups such as older persons and children.

## 9.2 SOCIAL PROTECTION ADMINISTRATIVE DATA

**Social protection administrative data is a key tool for assessing the extent to which a social protection is disability inclusive.** The kind of administrative data collected by schemes varies in the following way:

- In **all cases**, social protection administrative data will include information on the number of individuals or households receiving a social protection benefit. It should also provide basic information on the profile of individuals and households, including age, sex and disability status (of individual recipients and the household head).
- Schemes involving **more complex targeting criteria** (such as poverty-targeted social assistance schemes) may include much more detailed information about the household or an individual, including their income, assets and household/family composition.
- **Contributory schemes** will also include information about the number and profile of contributors (including age, sex, wages, etc.) as well as disability status for specific schemes.
- **Scheme targeting specifically persons with disabilities** may collect more detailed administrative disability data, especially those providing community support services.
- **Disability assessment and determination mechanisms** can collect and aggregate much richer information on situation and support needs of persons with disabilities especially within disability management information system (See Section 7).

**Administrative data is a key source for evaluating issues of coverage, exclusion and accessibility.** Administrative data on numbers of beneficiaries can be compared with demographic data (for example, the total number of persons with disabilities in the population) to provide an estimate of coverage of a social protection scheme. Such data analysis can also be used to identify issues related to accessibility, for

<sup>13</sup> For more information see the [Washington Group-ILO Labour Force Survey Disability Module](#)

<sup>14</sup> For more information on Thailand's 2017 Disability Survey, see

<sup>15</sup> For more information on Viet Nam's 2016 National Survey on People with Disabilities see [Launch of Key Findings of Viet Nam's first large-scale National Survey on People with Disabilities \(2016\) \(unicef.org\)](#)

example, if coverage is unusually low in a particular group, such as people within a particular geographical location, with certain demographic characteristics, or based on disability status. This would require further follow-up analysis to understand why these issues of accessibility exist. Ideally, administrative and survey data should be used together.

**Administrative data can also be an important source of disability related data, at least for the population related to the social protection system.** Considering the limitation of the national census and surveys in relation to disability and in absence of regular national disability survey, inclusive social registry and disability registries can provide comprehensive data on situation and needs of persons with disabilities and their households.

The following actions can be taken to strengthen the role of administrative data:

**COLLECTING DATA ON DISABILITY:** As with national survey data, this is essential if administrative data is to be used for analysis of inclusivity. The way in which data on disability is integrated depends on the type of scheme in question.

- For **disability-specific schemes**, confirming disability status will be an integral part of the eligibility determination, either via a specific assessment, or by considering an official disability status (card, certificate, registry) outside the scheme (See Section on Disability Assessment). However, it is important to include questions related to functional limitations questions (such as the WGSS) and support needs to serve as a cross-reference to survey data and support better design especially when administrative determination of disability is based solely on type of impairment and medical diagnosis.
- While disability status may not be required to determine eligibility for **mainstream cash transfer schemes** (such as poverty targeted social assistance or old age pensions), it is essential that questions on disability, in addition to questions on age and gender, should be included (such as the WGSS) to assess the inclusivity of such schemes and to inform more inclusive targeting and design.

#### **COLLECTING DATA ON SUPPORT NEEDS:**

- Schemes providing community support services (whether via health services, social welfare or social protection) should collect data on support needs to ensure they are delivering the appropriate support.
- Schemes not directly providing support services (e.g., cash benefits, or disability registries) should collect this data to support referral to support services or whenever possible seek interoperability with disability management information systems.

	<b>Census</b>	<b>Surveys</b>	<b>Administrative Data</b>
<b>Main characteristics</b>	Large sample but size limited information. Also sampling frames often exclude institutionalized and homeless populations.	Extensive socio-economic indicators but smaller sample size limiting in-depth disaggregation by type of disability, especially for groups with low prevalence, such as persons with deaf blindness. (Statistical matching with census data can help if disability data harmonization allows). Also sampling frames often exclude institutionalized and homeless populations.	Limited to population enrolled in specific services and systems.  Though some data can be extrapolated with census /survey data if disability data harmonization allows.
<b>Prevalence</b>	Number of observations allows for more accurate estimates, but limited space on form does not allow for good estimates of child disability, or certain group that may be of particular interest.	Allows for inclusion of questions capturing better child disability and diversity of disability experience such as psychosocial disability.	Not appropriate for estimates of prevalence in the population but can be used for identifying the share of the service users/ recipients likely to experience disability.
<b>Inequalities, Standards of living and Poverty</b>	Depending on the scope of indicators included.  Usually limited to a small group of assets used as a proxy for wealth.  Sample size allow for in depth disaggregation by type of functional limitations, sex, location and age for adults	HIES, LSMS, LFS, DHS, and MICS (and special surveys) have additional information needed for assessing diverse horizontal and vertical inequalities related to outcome and access and computing multidimensional poverty.  Sample size can limit disaggregation by type of disability and geographical area but enabling statistical matching with census can help.	Disaggregation of social registry and other administrative data can provide a differentiated profile of households that are accessing the related services/ benefits, including persons with disabilities, health outcomes, among others.
<b>Barriers and support needs</b>	Does not contain information on barriers and support needs per se but identification of significant inequalities can inform further data collection.	Evidence of significant inequalities of outcomes and access can inform further data collection. Multidimensional poverty can inform needs for cash transfer. While it would be possible to get a broad sense of barriers and needs by adding some questions to a DHS or HIES survey, a more in-depth picture would require a	Disability management information system that based on a comprehensive assessment can provide wealth of information on barriers and support needs of persons assessed.

		specific module (e.g., ILO disability module for LFS, UNICEF inclusive education module for HIES) or, ideally, a disability survey (e.g., MDS) would be needed.	Provide information on uptake and use of services provided.  Inclusive education module for EMIS.
<b>Access and impact of social protection systems</b>	Does not typically include questions on social protection.  Including a question, in addition to WGSS, on whether household members have an official disability status can provide valuable information on access to disability determination mechanisms and access/impact of disability related support	An HIES, for example, usually collects information on government benefits received, and can have enough information on income and other characteristics to make estimates of access and impact, explore who should be covered by social protection programmes and simulate how much coverage and adequacy would change if programme parameters were altered or if new programmes were introduced.  It is important to include social protection module in any disability survey.	Full information on number of recipients and benefit disbursements, and less response error than surveys. However, no information on people who are not receiving benefits who should be, or who would start receiving benefits if programme parameters were changed.
<b>Disability related costs</b>	Not enough indicators and datapoints in census.	HIES with disability disaggregation can inform average estimates of current household disability related extra expenditures. For the costs of goods and services required for participation, disability specific survey and/or qualitative data are required.	Technically, some information can be collected during a comprehensive disability assessment.

### 9.3 OTHER METHODS AND APPROACHES

Data from national surveys and administrative data can be complemented by a wide range of other approaches to data collection and analysis. While such initiatives may be undertaken less frequently, they can provide more sophisticated analysis on key questions relevant to inclusive social protection systems for persons with disabilities.

Relevant examples of such approaches include:

- **Qualitative research** can play an important role in understanding the dynamics of people's lives and how various attitudinal, institutional and structural barriers interact with their life situation to create exclusion. This is of particular importance for awareness raising aimed to combat discrimination, change attitudes or rallying backing for support measures. Quantitative data can highlight where barriers are and the scope and scale of those barriers, but qualitative data can be particularly useful in understanding how to best design policies to break down those barriers (Palmer et al, 2015). Where possible qualitative research should be disaggregated by gender and age to identify different needs and barriers across the lifecycle. This can be used to explore a broad range of questions related to social protection, including:
  - The **situation of persons with disabilities**. This includes questions of income security, barriers to participation, support needs and disability related costs. This can be used to design or reform social protection measures.
  - The **impact of existing social protection measures**. This can complement quantitative approaches such as impact evaluations and help to explore questions that are not best suited to quantitative methods.
  - Issues of **accessibility of social protection**. For example, qualitative research can be used to understand drivers of exclusion and issues of access highlighted by administrative and survey data.
- **Impact evaluations** using experimental or quasi-experimental methods can be undertaken to measure the impact of social protection schemes for persons with disabilities. These usually require specific baseline and follow-up surveys, although in some cases they can be performed using national surveys. Impact evaluations on mainstream programmes are much more common than those on disability-specific programmes. While there has been increasing focus on analysing data to show differences in program outcomes between men and women, most impact evaluations remain disability blind. A key pre-requisite for impact evaluations of mainstream programmes is that they include questions on disability status (such as the WGSS) and ensure an adequate sample size<sup>16</sup>.
- **Knowledge, Attitudes, and Practices (KAP)** surveys provide a useful approach to understand attitudes towards persons with disabilities, which may hinder the development of social protection systems. Common attitudes towards persons with disabilities include discriminatory beliefs, such as the assumption that people with disabilities are not capable or deserving of inclusion, but also the well-intentioned but misplaced belief that people with disabilities need to be protected and sheltered. These attitudes in turn can be internalized by people with disabilities, furthering their exclusion. KAP questionnaires should be designed to capture information about what people know, believe and experience about disability, but also how the knowledge, attitudes and practices around disability may vary depending on gender, age and other personal characteristics.
- **The Goods and Services (GS) and Goods and Services Required (GSR) methods for assessing disability-related extra costs** collect data on the actual purchases made by households due to disability and usually require extended, personalized interviews and focus groups, as well as price

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<sup>16</sup> See The Washington Group (2019) [Basic Guide to Sampling for Disability Surveys](#) for further discussion

surveys to estimate the cost of unpurchased items (Republic of South Africa, 2016; Disability Resource Centre, 2010).

### **Box 9-3: Methods to measure disability-related costs**

There are two main approaches that can be used to estimate extra costs of living with a disability:

**The Standard of Living (SOL) method:** This approach uses differences in asset levels between families with and without members with disability, but which have similar characteristics (income, household size, rural/urban, etc.) to estimate the extra costs incurred because of disability.<sup>17</sup> All the data necessary to determine extra costs using the SOL methodology is available in current household surveys, as long as disability identification questions are included in these instruments. The caveat with this method is that it can only give an indication of the current expenditures related to disability and thus its impact on household's overall standard of living. It provides no indication of how that money is spent nor how it contributes to participation nor how much money would be needed to ensure equal participation.

**The Goods and Services (GS) and Goods and Services Required (GSR) methods:** These methods collect data on the type of extra costs incurred. GS collects information on the actual purchases made by households because of a disability; the GSR method estimates the projected costs of purchasing all the things that would be required to equalize the ability of people with disabilities to participate in society to the same extent as their peers without disability. These data are too extensive to be included in a typical survey module. Studies that have attempted these measures have used more extended, personalized interviews and focus groups, as well as price surveys to estimate the cost of unpurchased items (Republic of South Africa, 2016; Disability Resource Centre, 2010).

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<sup>17</sup> A more complete explanation of the SOL method, its advantages and shortcomings are discussed in a different background paper. That paper also includes the range of estimates that different researchers have produced as to the extra costs of disability.

## 10 MEANINGFUL PARTICIPATION OF PERSONS WITH DISABILITIES

To inform the inclusive design, monitoring and evaluation of social protection policies and programmes, it is critical to consult meaningfully with persons with disabilities through their representatives' organisations (i.e., organizations of persons with disabilities or OPDs). Such consultations are an obligation under CRPD (Art 4.3). This has been translated in guidance and disability strategy of multilateral (e.g., UN, WB, ADB, EU) and bilateral development agencies (e.g., FCDO, GIZ, DFAT, USAID). Beyond the participation principle there are at least three strong rationales for investing in meaningful engagement with OPDs.

- **Complementing data and inform on situation of persons with disabilities:** The required data on persons with disabilities to build inclusive social protection system is often scarce and might not always reflect the range situations faced by the diversity of children and men and women with disabilities across the countries. The unique perspective of persons with disabilities lived experience and the knowledge and experience of OPDs can provide context and meaning to the data and fill in data gaps. They can provide a first-hand perspective on the barriers they face, the type of support that would be the most useful and about the issues of most marginalised groups which are rarely captured by national data.
- **Support inclusive design and delivery:** Knowledge on disability inclusion is still severely limited within social protection teams both in national governments and international agencies. OPDs have the expertise to help raise awareness of staff, inform accessible and inclusive design, contribute to inclusive outreach, among other areas of design and delivery.
- **Building ownership:** Building inclusive social protection systems is a long-term endeavour that requires sustained political will, focus, and investments, often across successive governments whose priorities might shift as would donors'. It also requires deciding how to phase investments, type of schemes and targeting. Meaningful engagement of OPDs will develop their capacity and the ownership required for effective and sustained advocacy efforts as well as to ensure that there is a strong commitment to the reforms.

In addition to the necessary attention to accessibility of venues, information, and communication, successful and meaningful engagement with OPDs requires attention to the perception of social protection within the disability movement, the diversity of persons with disabilities and their capacity and resources to engage.

### 10.1 “WE WANT JOBS, NOT CHARITY”: THE GREAT MISUNDERSTANDING ABOUT SOCIAL PROTECTION WITHIN THE DISABILITY MOVEMENT.

Along with the emergence of the global disability rights movement in the 1980s, there has been significant misunderstanding and unease within movement about social protection. It is often perceived as a demonstration of the persistence of the charity and medical models, which has limited engagement of OPDs in framing the development of social protection systems. **It is critical to be aware of this issue to better engage and understand the diversity of perspectives** that can emerge through consultations.

Indeed, as many governments adopted schemes for labour constrained households, which include “poor people with severe disabilities who can't work or care for themselves” as a target population disability rights activists striving to raise awareness on the contributions of persons with disabilities, their skills and inclusion often perceived social protection as a persistent and demeaning expression of charity rather than a rights-based support to inclusion.

As a result, in many low- and middle-income countries where social protection systems were minimal, leaders of many organizations of persons with disabilities would focus on advocacy for accessibility, employment and livelihood programmes with the motto “we want jobs, not charity”. This is also reflected

in the debates on whether disability ID cards, which are set up to facilitate targeting and access to different benefits, actually reinforce stigma rather than contribute to empowerment and positive awareness.

However, the implementation of the CRPD at national level combined with the Leave No One Behind Agenda and the broader mobilisation for universal social protection, contributes to changing this perception. The austerity policies following the 2008 financial crisis generated strong mobilization of OPDs across Europe, where [more than two third of persons self-reporting activity limitation would be at risk of poverty without social protection benefits](#). With the emergence of social protection systems in lower- and middle-income countries, OPDs are increasingly engaged on their own terms. In Senegal, for instance, OPDs are advocating for an equal opportunity card rather than a disability card. The co-facilitation by the International Disability Alliance and the ILO of the process leading to the 2019 Joint Statement on inclusive social protection systems also initiated a broader momentum within the disability movement.

The growing awareness of the nature and impact of [disability related extra costs](#), including for adults with disabilities seeking work, children with disabilities or older persons, and the responsibility of government to address them also contributes to a shift in OPDs' perception about the role of social protection towards levelling the playing field and enabling social participation "on an equal basis with others". This provides an approach to advocate for social protection based on a human rights model as an alternative to charitable appeals based on "incapacity" or "dependency". Furthermore, addressing "disability extra costs" goes beyond appeals based on poverty as it applies to all persons with disabilities regardless of their economic status.

The extensive shutdowns of the economy in response to the COVID-19 pandemic demonstrated, even more than in the aftermath of the 2008 financial crisis, the critical importance of having strong social protection systems to support their overall population, not only those in poverty. The [social protection response to COVID 19 crisis](#) showed to OPDs that countries with (quasi) universal disability allowances and registries were better positioned to provide additional support to persons with disabilities swiftly. In many countries that lacked such mechanisms, OPDs played a significant role in facilitating outreach and quick identification of persons with disabilities. More broadly, OPDs have significantly increased their engagement in social protection reform and debates globally in the wake of crisis (see the [report on south Asia](#) and [call for action in Africa](#)).

It is essential that social protection professionals embrace a human rights based and inclusion focused approach to contribute to this growing engagement of OPDs and shift in understanding of the potential of social protection in supporting participation and empowerment of persons with disabilities.

## 10.2 DESIGN FOR INCLUSION

It is important to engage with OPDs in the design and implementation of social protection policies or programmes regardless of whether they are specifically about people with disabilities or more general. Of course, such engagement will be more in depth for disability specific programmes especially in relation to the diversity of persons with disabilities.

While the disability movement and organisations of persons with disabilities have developed and grown across regions, and many country parties to the CRPD have developed formal national consultation mechanisms, recent studies (see IDA, 2020, BtG, 2019) have shown that there is still a long way to go to ensure meaningful engagement and participation. Review of OPDs engagement with social protection processes in the midst of COVID-19 crisis shows that there is a diversity of barriers and bottlenecks that can be addressed.

- **Taking into account diversity of persons with disabilities**

The diversity of barriers that persons with disabilities face in accessing education, employment, and community participation is also reflected in participation in public life, trade unions and civil society.

Persons with disabilities who have higher support needs will face higher barriers to access information and be consulted. Those who in certain context face stronger stigma will face additional hurdles to engage in public debate and voice their concerns.

While other movements such as farmers or women's groups might not be inclusive of persons with disabilities in general, the disability movement might not always be representative of the diversity of all groups of persons with disabilities.

It is important to acknowledge and factor this difference in when engaging with civil society by:

- Ensuring accessibility of venues, information and communication and provide reasonable accommodation for the diversity of persons with disabilities.
- Ensuring that information and consultation reach most marginalized groups of persons with disabilities, women with disabilities, or parents of children with disabilities who may not be adequately represented within national federation of OPDs,
- If possible, engage in local consultations especially in remote areas as persons with disabilities in those contexts might have limited connection with national platforms.

- **Identification of relevant consultation and engagement mechanisms**

Depending on the intent of engagement (needs assessment, national policy or legal reforms, programme design or monitoring) there are different ways to engage effectively with OPDs.

At the programme level, OPDs can be involved in ad hoc advisory or steering committees. Whenever possible a twin track approach should be used to ensure and facilitate participation of OPDs in the general consultation mechanisms with other civil society stakeholders. Specific consultations with OPDs should also be undertaken to foster their diversity and level the playing field in terms of access to information.

For policy or national reforms, a growing number of countries have adopted national disability coordination mechanisms with OPDs, in line with Articles 4.3 and 33 of the CRPD, which can be used for consultation and engagement. Often, these bodies include representatives from national federations of OPDs and relevant ministries. They are often hosted or supported by the entity which acts as government disability focal point, often Ministries of Social Affairs, but can be hosted in higher levels of government or act autonomously. However, recent studies show that across many countries those mechanisms are not yet perceived as effective consultation mechanisms by OPDs. This can be explained by different factors linked to the issues of representativeness and membership, the lack of resources, limited mandate, and the mechanism's lack of convening power and influence on policy making and resource allocation across ministries, among others. It is nevertheless important to use those mechanisms whenever possible to increase their relevance and capacity.

- **Invest in mutual capacity building and space for meaningful consultation**

Social protection is an emerging field of advocacy and engagement in many regions for civil society in general and OPDs in particular. It is important to acknowledge that among OPDs there may be limited understanding of and exposure to social protection policies, systems, instruments and schemes. Conversely, there may be a limit in understanding of disability rights and inclusion among social protection professionals. Therefore, there is a need to invest in mutual capacity development so that OPDs can meaningfully participate in spaces that are inclusive.

**Text box 10.1 Lebanon: capacity building and twin track consultation process of OPDs for national social protection strategy as well as design of pilot disability allowance**

The COVID-19 pandemic and the Beirut port explosion add to a very complex context in Lebanon, as the country grapples with a very severe financial, economic and political crisis. Building a national social protection system has been at the core of the demand for a new social contract since the popular uprising

in September 2019. ILO and UNICEF have therefore supported the development of national social protection strategy, process which was supported in part by the joint SDG fund social protection program.

From the beginning, the involvement of the disability movement in the developing a national social protection strategy has been at the core of national dialogue process. The engagement strategy has been twofold. On the one hand, mainstreaming disability in national social protection dialogue, by ensuring participation of OPDs in the broader national policy dialogue and programme design conversations. On the other hand – and in preparation for the above - to convene a dedicated platform for internal discussion with and amongst OPDs to identify common points of concern and advocacy and develop a common understanding of the relevance of social protection for the disability inclusion agenda.

Initiated with a face-to-face workshop just before the start of the pandemic, a collective of OPDs representing the diversity of the movement has regularly and virtually met to exchange with and produced few joint products, such as a brief on the COVID-19 Response with some specific recommendations for Persons with Disabilities; or a position paper for inclusion and empowerment of persons with disabilities through Rights-Based and Comprehensive Social Protection System to guide their joint advocacy and clarify their demands for the national strategy.

They contributed at all stage of the process which led to the finalisation of the national social protection strategy in 2022 which reflect many of their demands.

In parallel, thanks to a fund from European Union, OPDs have co-designed all the elements through a year-long participatory process of the pilot disability allowance which has been launched in April 2023<sup>18</sup>.

The whole process has been a mutual learning for OPDs and UNICEF and ILO staff involved sharing insights on both social protection systems and scheme design as well as disability inclusion, lived experience of persons with disabilities and work of OPDs to support them in those difficult times.

Several pivotal aspects emerged from this process:

- Unified Voice: The disability movement gains strength from unity in its interaction with government, development agencies and mainstream civil society. As any social movement, OPDs are diverse and with sometimes divergent views and stakes. Overcoming fragmentation enhances representation and visibility but necessitates time, regular interaction, common tasks and advocacy objectives and sometimes a neutral, trusted convener.
- Inclusive Social Protection: Each social protection system pillar benefits from a disability inclusion perspective. This includes advocating for inclusive healthcare access, essential service continuity, labor inclusion opportunities, social assistance access, and disability-sensitive insurance schemes.
- Redefining Income Support: Overcoming the perception that income support perpetuates dependency and disempowerment among PwDs is crucial. Rights-based social assistance is an enabler of full participation in social and economic life, marking a significant shift in perception for the Lebanese OPD collective.

## 11 ACCESSIBILITY ACROSS THE DELIVERY CHAIN

**A lack of accessibility in the delivery of social protection benefits can constitute a significant barrier to the inclusion of persons with disabilities.** Even where the configuration of social protection systems and design of specific schemes can be considered inclusive, issues of access can significantly undermine

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<sup>18</sup> <https://www.unicef.org/lebanon/press-releases/ministry-social-affairs-introduces-social-protection-programme-people-disabilities>

coverage. Many issues of accessible delivery affect a diverse array of recipients of social protection benefits, but they are amplified for persons with disabilities.

This section outlines key approaches for improving the accessibility of social protection schemes, with a focus on actions which can be taken by social protection implementing agencies. The section is oriented to the delivery of cash benefits, but many of the lessons can be extended to other forms of support.

## 11.1 TRAINING

**Adequate diversity and disability training of staff is critical to address attitudinal barriers resulting from discriminatory practices and attitudes, and to ensure staff understand the minimum standards and administrative processes discussed below.** Key approaches include:

- **Extending disability awareness training** to all staff in national and international agencies, departments or ministries responsible for social protection policy making and programme implementation to strengthen skills in developing and implementing inclusive delivery mechanisms. This should include disability rights and inclusion. In some cases, training on disability awareness could be provided alongside other training related to inclusion, such as gender equality training.
- Develop **more tailored training** related to specific roles and responsibilities within the delivery chain (e.g., customer service practices for those directly interacting with persons with disabilities on a regular basis).
- **Training should be carried out in partnership with OPDs.**

## 11.2 MINIMUM STANDARDS

**A key means of encapsulating disability inclusive adaptations to the design and implementation of social protection schemes is developing a set of minimum standards with which schemes should comply.** Minimum standards can relate to all areas of scheme implementation, and across the delivery chain. They can relate specifically to the accessibility of the built environment and information (e.g., web portal, cards, app, electronic terminal, e-kiosk); the maximum distance that recipients should travel to apply for a scheme or collect their benefit; the format of communications materials; the provision of reasonable accommodations (e.g., sign language interpreters); the possibility for individual adaptation such as home visit for registration or benefit delivery; and standards of conduct for outreach and administrative staff.

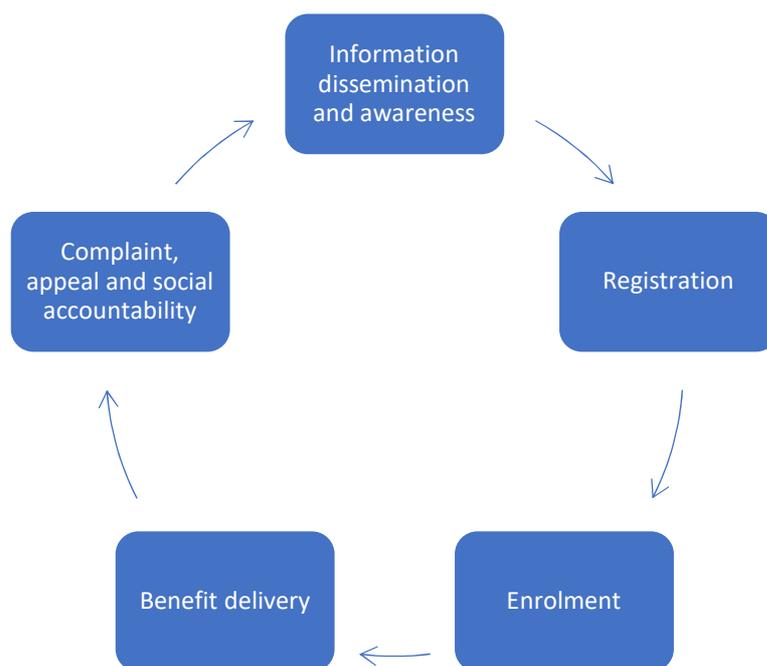
Key considerations in the development of minimum standards are:

- They should be **developed in collaboration with people with disabilities**, involving their representative organisations. External experts may also be contracted to advise the process.
- They should be **published in disability accessible formats** and be easily available.
- They should be **incorporated into any contracts, service agreements and standard operating procedures** with third parties (public or private), with regular reporting and penalties for non-compliance.
- They should be rooted in the scheme design, but also **refer to human rights standards** and other relevant national legislation.
- Implementing agencies should **collect data and publish annual, public reports** on performance against the minimum standards.

## 11.3 DELIVERY CHAIN

**Making social protection schemes accessible and inclusive, requires consideration of implementation across the delivery chain.** The key steps in the social protection delivery chain are captured in Figure 11-1.

**Figure 11-1: The social protection delivery chain**



**An important consideration that cuts across the delivery chain is physical access.** Two important aspects of physical access are, first, the long distances that persons with disabilities often need to travel to access social protection schemes. And, second, the physical environment of offices or locations used for registration, enrolment, benefit delivery and complaints/grievance. These issues are particularly acute for registration – where poor physical access may prevent people from benefitting from a scheme at all – and payment – given that this is a process undertaken regularly. Box 11-1 outlines key considerations for improving physical access in social protection delivery.

While this section focuses on delivery of cash benefits, physical distance and environment are key for delivery of health care and other services.

#### **Box 11-1: Improving the physical access in social protection delivery**

##### **Addressing physical distance**

- ✓ Maximum distances that applicants should travel to service points are defined in minimum standards.
- ✓ Strategies are developed and implemented to **minimise the distance individuals must travel**, including:
  - **Adequate physical infrastructure** (such as registration centres, social welfare offices) to reduce the length of travel. This could include supporting the development of accessible one-stop shops for government service delivery.
  - **Systems of outreach** such as mobile and community-based registration/payment centres.
- ✓ **Support is provided for persons with disabilities to travel** to service centres. This may be delivered by OPDs and other civil society organisations.
- ✓ **On-line and written systems** are developed for processes across the delivery chain to reduce the extent to which people with disabilities need to travel.
- ✓ **The option is available for processes to be undertaken at homes** for persons with disabilities who face particular difficulties in traveling.

##### **Creating an accessible physical environment**

- ☑ Minimum standards for the physical environment are developed and monitored.
- ☑ Buildings are accessible for individuals with a range of disabilities, including:
  - Wheelchair access and doors that are easy to open
  - Relevant services (registration, payment, etc.) are located on the ground floor or with lift access.
- ☑ If registration is undertaken outdoors:
  - The ground is smooth or temporary 'walkways' are available to put down.
  - There is adequate shade and shelter from the rain.
- ☑ There are accessible toilet facilities for persons with disabilities.
- ☑ Drinking water is available and easily accessible.
- ☑ There is adequate seating for recipients, alternates and carers.
- ☑ Waiting and queuing times are as short as possible. Where long queues develop, people with disabilities should be given seats to use and offered priority in the queue. Ticket systems can also reduce queuing times.
- ☑ Inclusive childcare facilities are available for all children where there are significant wait times, with special arrangements made for children with disabilities as they may require additional care.

**INFORMATION DISSEMINATION AND AWARENESS:** Poor quality communications are major cause of people with disabilities not accessing social protection schemes or engaging with them effectively. Effective communication is critical both to raise awareness of the existence of schemes for prospective applicants, and to engage with applicants and recipients across the delivery chain. Key approaches to enhance the information dissemination and awareness can be found in Box 11-2.

#### Check list 11-2: Information dissemination and awareness

- ☑ There is **necessary expertise** to make communications accessible and develop an outreach strategy (this may include in-house and/or external expertise (including input from OPDs))
- ☑ Communication materials are available in a **wide variety of formats** accessible to persons experiencing different kinds of disability. For example:
  - All written publications should be available in large print and braille; audio and easy-to-read versions produced where appropriate,
  - Any videos should include sub-titles and sign language interpretation.
- ☑ **Dissemination of information** should consider the barriers faced by persons with disabilities, keeping in mind that barriers will vary based on age gender and other characteristics and make use of multiple communication strategies and channels to overcome these barriers, for example:
  - Communication products, including those using pictograms or easy to read formats, should be placed in locations frequented by people with disabilities,
  - Information should be communicated verbally using face-to-face dissemination or radio,
  - Websites should be accessible, including e-readers, for people with disabilities,
  - Programmes should work with OPDs, older persons organisations', women's organizations, parents' organizations and NGOs as channels to transmit messages to their members and clientele.
- ☑ **Communication channels to applicants and recipients are adapted** to the individual needs of persons with disabilities:
  - The preferred means of communicating with a recipient is recorded and that form is always used,
  - Home visits are used to transmit messages where required,
  - Sign-language interpreters are available communicating with deaf people,
  - If schemes use bulk SMS messages, alternative communication strategies must be planned for and used.

**REGISTRATION:** Many of the causes of exclusion occur during the registration processes for social protection schemes. The registration mechanism comprises programme administrators collecting relevant

personal data relating to applicants, verifying its accuracy and assessing compliance with the eligibility criteria set for each specific scheme. Registration can be undertaken on an on-demand basis and/or using census or survey-based approaches which involves visits to communities and households. Depending on the scheme design, the personal data collected can relate to residency/citizenship status and socio-economic characteristics. In some cases, supporting documentation is required, such as national IDs or birth certificates. Persons with disabilities, especially those with intersecting identities, are less likely to have registered at birth and excluded from the national ID system (World Bank, 2020). For many disability-specific schemes, the registration also requires a disability assessment, although in some cases this assessment is undertaken independently (for example, in registering for a disability card). In this respect, this stage of the delivery chain can be strongly linked to questions of disability assessment discussed in Section 7). Key approaches to making registration more accessible include the following.

- Streamlining and simplifying registration processes, such as:
  - Assessing whether all steps in the process are necessary,
  - Taking on greater responsibility for collecting information and documents,
  - Seeking greater integration with other government functions, such as disability assessment and registration, civil registration and taxation.
- Supporting persons with disabilities through the application process, for example, by linking with social workers, or funding OPDs and other civil society organisations to provide such support.
- Accompany registration process with additional services to support persons with disabilities with completing application forms and obtaining identification documents if they are required by the program. Where registration is time-bound, programmes can allow for extension so persons with disabilities can complete the process.
- Compensating additional costs and delays associated with registration, such as transport.
- Where census registration processes are used, they should be designed to support the inclusion of people with disabilities, with particular attention given to training of enumerators.

These recommendations apply not only to initial identification and eligibility verification, but also to reporting of changes in circumstances of recipients.

**ENROLMENT:** Enrolment is the moment when those selected for the scheme officially join it (data is entered into the scheme MIS and membership is confirmed) and they often receive tokens, such as cards, to show they are members. Key approaches to support accessible delivery include:

- Where possible, enrolment should be undertaken at the same time as registration and eligibility determination processes to minimise the need for recipients to travel.
- If enrolment needs to be undertaken separately to registration, the mobility or communication difficulties of any recipients should be taken into account and relevant adjustments should be made to the service to support their enrolment.

**BENEFIT DELIVERY:** As a process that needs to be undertaken regularly, benefit delivery can constitute a major barrier for persons with disabilities accessing the benefits for which they are eligible. Key approaches to support inclusive delivery include:

- Payment systems should provide a range of options regarding where, when and how to receive benefits. These should take into consideration accessibility requirements of diverse groups of persons with disabilities.
- Where recipients are unable to reach payment points (e.g., due to severe mobility issues), implementers should consider alternative approaches. These include **home delivery of cash** or clear procedures for beneficiaries to **nominate a proxy** (usually a friend or family member) that can collect the payment on their behalf.
- Where payments require recipients to open bank accounts, mobile wallets or complete other processes specific to the payment system, this should be done at the same time as enrolment,

and these processes should be accessible, ensuring support for carrying out the paperwork and obtaining supporting documentation as needed. Additional support and training using digital technology to access and use transfers should be provided to those who are less familiar with or lack ownership of mobile devices, such as older persons or women with disabilities.

**COMPLAINT, APPEAL AND SOCIAL ACCOUNTABILITY:** All social protection schemes should establish effective **complaint and appeal mechanisms** for applicants and recipients. These mechanisms should enable citizens to appeal against decisions, file complaints, and provide feedback to implementing agencies. In reality, many schemes in low- and middle-income countries do not have good complaints and appeals mechanisms in place. Key approaches to the development of complaints, appeals and social accountability mechanisms include:

- Multiple channels for complaints should be established so that people with disabilities have options for lodging a grievance or appeal. According to international standards, complaints channels should be simple, impartial, transparent, effective, rapid, accessible and inexpensive.
- Complaint mechanisms can be complemented by social accountability mechanisms that are implemented by independent entities such as ombudsmen, human rights commissions and non-governmental organisations, including OPDs.

**SAFEGUARDING MEASURES:** Each stage of the delivery chain should adopt inclusive safeguarding measures to prevent against violence, abuse and exploitation of persons with disabilities. Disability specific risks should be considered alongside risks related to age, gender and other personal characteristic when designing safeguarding policies and practices. Persons with disabilities, especially women and children, are at a higher risk of violence, abuse, and exploitation due to their increased isolation and limited access to accessible services, including protection services. The risks of violence, abuse and exploitation are exacerbated in times of crisis. Key considerations for safeguarding along the delivery chain may include:

- Involve persons with disabilities and their representative organizations in conducting risk analyses to identifying possible risks barriers associated with the delivery of social protection benefits and designing appropriate safeguarding mechanisms.
- Monitor potential risks related to registration, distribution of benefits, or compliance of conditionalities. For example, routes taken to access benefits must not expose participants to increased protection risks, especially if carrying goods or cash; wait times and distance should be kept to a minimum to ensure participants aren't traveling at unsafe times; associated services should be accessible, inclusive and have their own safeguarding practices in place.
- Ensure that the complaints mechanisms have procedure for reporting abuse, neglect, exploitation, and violence against persons with disabilities and outlines the required response procedures including who and how to contact appropriate authorities when a protection case is identified, and referral to support services. Complaints mechanisms must ensure be safe, confidential and accessible for persons with disabilities and other community members.
- Raise awareness on among participants and other stakeholders, such as OPDs, of what constitutes abuse, neglect, exploitation, and violence and on the complaints mechanism.
- Develop codes of conduct for all involved in the delivery chain, including government, NGOs, suppliers, and financial institutions. Codes of conduct and repercussions for failure to uphold code of conduct should be reflected in contracts and memorandums of understanding. All staff should undergo training and periodic refresher trainings on safeguarding policies and procedures.

## **11.4 GOVERNANCE AND MANAGEMENT INFORMATION SYSTEMS**

Various actions can be taken to ensure governance and management information systems support accessible delivery of social protection for persons with disabilities.

## **APPROPRIATE INSTITUTIONAL AND HUMAN RESOURCE ARRANGEMENTS**

- Adequate institutional arrangements should be in place to provide oversight, and to provide advice and training to staff across the organisation on accessible delivery of cash transfers for persons with disabilities. This could include a specialist disability/inclusion unit placed within the ministry or agency responsible. This should be supported by adequate training on disability and intersecting inequalities stemming from age, gender and other personal characteristics.
- Performance management objectives for programme management and senior staff should incorporate objectives on ensuring accessibility and disability inclusion.
- Sanctions should apply to staff who discriminate against people with disabilities.
- Recruitment processes should be fully open to employing people with disabilities on an equal basis with others.

## **OPERATIONS MANUALS**

- All operations manuals should include fully integrated guidance on how to ensure accessibility for people with disabilities across the delivery chain, in line with the minimum service standards discussed above. Disability considerations should be reflected in shock-responsive elements in addition to routine administrative and delivery functions.
- Operations manuals should include separate annexures to provide guidance on disability inclusion to third parties that are responsible for elements of the delivery chain (e.g., payment systems, MIS).

## **MANAGEMENT INFORMATION SYSTEMS**

Management information systems (MIS) not only underpin the effective functioning of cash transfer schemes, but they are also an important source of information for monitoring.

- MIS should allow identification of persons with disabilities amongst applicants and beneficiaries and their accessibility requirements. Two complementary approaches include (a) linking the MIS to national disability registries and (b) including the Washington Group Short Set of questions (or Short Set Enhanced) during application and/or during enrolment to gather information on disability and as a precursor to enquiring about accessibility requirements.
- MIS should be designed to send automatic messages to staff when they are required to undertake activities related to ensuring access of persons with disabilities. Similarly, MIS should be able to send reports to managers when their reportees have not complied with disability-related activities by the required deadline.
- Interoperability of social protection MIS with disability registry and management information system can enhance case management and planning but careful consideration should be given to privacy and confidentiality of disability related data.

## **MONITORING AND REPORTING MECHANISMS**

- Guidance and indicators for the monitoring of cash transfer schemes should include a focus on the access and experience of persons with disabilities relating to different stages of the delivery chain. To better understand the disability experience and identify specific barriers that arise due to lifecycle stage, data should be disaggregated by age and gender.
- Regular reports should be produced on disability and accessibility issues, based on the information of the MIS. This might include the number of recipients with disabilities who have not accessed payments and the tracking of complaints raised by people with disabilities.
- Disability should be placed as a standing item on the agenda of management meetings and regular monitoring reports on disability, along with other cross-cutting issues such as gender and age, should be considered.

- Evaluation of programme impacts should disaggregate outcomes by disability status to allow for identification of inequalities between those with disabilities and those without.
- If national panel surveys are used for programme monitoring, they should include the Washington Group Short Set of questions (or Short Set Enhanced) to enable some monitoring to be undertaken of people with disabilities.

See Section 8 for further discussion on disability data.

<b>AWARENESS TRAINING AND DATA DISAGGREGATION</b>	<ul style="list-style-type: none"> <li>• Provide disability awareness training alongside with gender equality training to help staff develop skills in developing inclusive delivery mechanisms</li> <li>• Ensure that all data used for design, monitoring and evaluation allow for disaggregation for disability and include element allowing anticipation of potential barriers faced by persons with disabilities, among others. The use of the Washington group short set or enhanced set of questions is recommended</li> </ul>	
<b>MINIMUM STANDARDS</b>	<ul style="list-style-type: none"> <li>• Develop minimum standards in collaboration with people with disabilities, involving their representative organisations (DPOs). Contract disability expertise to support this work.</li> <li>• Ensure minimum standards are published in accessible formats that are easily available and understood by a broad range of people.</li> <li>• Minimum standards including accessibility requirements should be incorporated in any contracts with private sector contractors.</li> </ul>	
<b>ADMINISTRATIVE PROCESSES</b>	<b>Communication</b>	<ul style="list-style-type: none"> <li>• Ensure communications and information is conveyed in a way that is understood by every recipient.</li> </ul>
	<b>Registration</b>	<ul style="list-style-type: none"> <li>• Streamline the registration process and minimise need for travel.</li> <li>• Provide an option for registration to be undertaken at home for recipients with high support requirements.</li> <li>• Ensure that the registration centres are accessible so that people with disabilities can reach, enter, and use the facilities and services.</li> <li>• Ask applicants about any accessibility requirements and functional limitations</li> </ul>
	<b>Enrolment</b>	<ul style="list-style-type: none"> <li>• Undertake enrolment at the same time as the registration process to minimise the need for recipients to travel.</li> </ul>
	<b>Account opening</b>	<ul style="list-style-type: none"> <li>• Ensure the site, building and facilities for account opening are accessible.</li> <li>• Streamline the process of opening bank accounts by making it possible to be done at the same time as enrolment.</li> </ul>
	<b>Cash-out &amp; withdrawal</b>	<ul style="list-style-type: none"> <li>• Develop payment mechanisms that allow a range of options on where, when and how to withdraw cash. Ensure pay points and self-access terminals are accessible and easy to use.</li> </ul>
	<b>Change management</b>	<ul style="list-style-type: none"> <li>• Provide options that minimise travel for reporting changes in circumstances by recipients. Provide option for home visit for recipients with limitations in mobility.</li> </ul>
	<b>Grievance &amp; redress</b>	<ul style="list-style-type: none"> <li>• Complaints channels should be adapted to consider different types of impairments and accessible forms of communication.</li> </ul>
<b>SYSTEMS AND MANAGEMENT</b>	<b>Human resources</b>	<ul style="list-style-type: none"> <li>• A specialist disability unit should provide oversight, advice and training to staff across the organisation.</li> <li>• Training on disability inclusion should be provided to all staff.</li> </ul>
	<b>Operations manuals</b>	<ul style="list-style-type: none"> <li>• All operations manuals should have fully integrated guidance on how to ensure accessibility for people with disabilities throughout the operations cycle.</li> </ul>
	<b>Management Information Systems (MIS)</b>	<ul style="list-style-type: none"> <li>• MISs should allow identification of persons with disabilities amongst applicants and beneficiaries and their accessibility requirements.</li> <li>• MISs should be designed to provide monitoring reports on specific disability issues across the operational functions.</li> </ul>
	<b>Payment systems</b>	<ul style="list-style-type: none"> <li>• Payment standards should be developed taking into account accessibility and any adaptations that may be required in order to promote dignity and autonomy of all recipients.</li> </ul>
	<b>Financial management systems</b>	<ul style="list-style-type: none"> <li>• The information on disability from the MIS should be linked to the financial management system so that schemes are able to report on how much spending has reached people with disabilities and how much has been spent to ensure accessibility and provide needed individual adaptation.</li> </ul>
	<b>Social accountability mechanisms</b>	<ul style="list-style-type: none"> <li>• All social accountability mechanisms should incorporate some key indicators on accessibility and disability inclusion.</li> </ul>
	<b>Monitoring &amp; reporting</b>	<ul style="list-style-type: none"> <li>• Guidance and indicators for the monitoring of cash transfer schemes should include a focus on the access and experience of persons with disabilities to each mechanism of the cash transfer scheme.</li> <li>• Regular reports should be produced on disability and accessibility issues, based on the information of the MIS.</li> </ul>
	<b>Evaluations</b>	<ul style="list-style-type: none"> <li>• Evaluations should include a review of access and experiences of people with disabilities relating to each mechanism of the cash transfer process.</li> </ul>

## 12 LEGAL FRAMEWORK (TO BE DEVELOPED IN 2023)

*This section is under development and will be completed by Fall 2023.*

### 1. The Importance of Legal Frameworks for Equal Access to Social Benefits for Persons with Disabilities

A robust and comprehensive social protection legal framework is a precondition for translating the human right to social security, health and to an adequate standard of living into tangible entitlements and to secure access to social protection for all, including for persons with disabilities. Such a framework serves as a guarantee making the right to social security enforceable against the State, social security institutions or other actors, as the case may be.

Firstly, a well-defined legal setup provides a clear framework pursuant to which national social protection schemes and programs need to be organized and implemented so as to deliver the statutorily established benefits under the conditions prescribed therein to meet the needs of people with disabilities. It needs to establish the scope of coverage, the types and levels of benefits, the qualifying conditions which need to be met with a view establishing eligibility thereto, marking a shift away from discretionary measures. Overall, sound legal frameworks also help promote the needed consistency, fairness, and accountability in the delivery of social protection benefits and services (Degener, 1995).

Secondly, in combination with other components of national statutory setups and legal frameworks such as in particular labour legislation, education, health or housing, social protection legal frameworks are instrumental in protecting disabled persons' right to non-discrimination and to equality of opportunities, including access to services. By doing so, legal frameworks are a pre-condition to creating inclusive societies where persons with disabilities are capacitated to fully participate and contribute in spite of their handicap (Curran et al., 2019).

Furthermore, legal frameworks also guarantee the sustainability and continuity of social protection schemes and programmes (Aguilar, 2017). Laws and regulations outline the funding sources and mechanisms, categories of persons covered, eligibility criteria, governance structures, and conditions of access to benefits, complaint and appeal mechanisms, etc. They often also establish procedures and entities charged with monitoring their implementation and assessing their effectiveness. Having a dedicated legal framework in place as the result of an inclusive and participatory process, that can be upheld through the judiciary, is a guarantee of predictability and legal certainty and protects beneficiaries and affiliates against swift legislative or regulatory amendments lacking the procedural and participatory guarantees characterizing sound legal reforms processes.

The ILO's approach to developing disability-inclusive social protection systems is rooted in its constitutional mandate to set international standards to secure the extension of social security measures to provide a basic income to all in need of such protection and comprehensive medical care (Decl. of Philadelphia).

At the UN level, the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities (CRPD) set out the obligation of State parties to secure right to social security in ways that foster participation and inclusion in society. The [Joint statement on inclusive social protection systems for persons with disabilities](#) provides guidance, on the design of social protection systems that are in line with the CRPD. The CRPD is currently ratified by 162 countries and recognizes disabled individuals as rights holders, promotes their full enjoyment of human rights, and challenging societal barriers. It embraces the social model of disability, influencing law and policy reforms while introducing transformative equality in international human rights law (Degener, 2016).

The social protection rights of persons with disabilities have been specified in the Article 28 of the CRPD, highlighting the importance of ensuring adequate living standards and social protection for individuals with

disabilities, including access to food, clothing, housing, and continuous improvement of living conditions. ILO Recommendation No. 202 proposes an inclusive approach to social protection and disability benefits, advocating for equal guarantees of income security and essential healthcare for persons with disabilities. ILO Convention No. 159 and Recommendation No. 168 emphasize the need for national policies on vocational rehabilitation, employment, and promoting job opportunities for individuals with disabilities in the open labour market

In the context of disability, it is crucial to establish social protection through legal frameworks that are subordinate to the constitution. Social protection programmes should be supported by a national strategy and relevant regulations to ensure their effectiveness. An adequate legal framework is essential for demonstrating a state's commitment to implementing a long-term, legally binding program with sufficient financial and human resources. Without such a framework, individuals with disabilities may struggle to hold the government accountable or identifying the responsible authorities. While not every aspect of a social protection system needs to be established by law, specific details and technical aspects that pertain to disability-related provisions can be more effectively addressed through regulations and operational manuals.

By adopting a twin-track approach, which involves integrating disability inclusion into all social protection programs while also implementing dedicated disability-specific programs, the aim is to create inclusive systems that empower and support individuals with disabilities throughout their lives (Mont & Côté, 2020).

Ultimately, laws can also serve as a powerful instrument to create space for a social model of disability, which is slowly replacing the medical model of disability which has contributed to the stigmatization and marginalization of disabled individuals (Clark, 2023).

## **2. Legislation for Ensuring Inclusive Social Protection for People with Disabilities**

Overall, social protection legal frameworks for disability schemes, as for other social protection schemes, lay down the key parameter for the benefits and their delivery: benefit levels, duration, eligibility criteria, institutions responsible for the administration and delivery, complaints and appeals mechanisms. In line with the conceptual framework of this guidance note, the provisions in international standards, in particular the CRPD and the arguments presented, the legislation for disability benefits and services should ensure that

- benefits are compatible with work and with other life cycle benefits
- people with disabilities have access to both disability specific benefits and services as well as mainstream social protection schemes
- disability determination and assessment mechanisms are affordable, accessible, acceptable and focus not only on the medical condition but also on the needs of people with disabilities, and barriers they face in their environment
- schemes meet the diversity of disabilities and needs along the life cycle (for children, working age and people in old age with disabilities)
- benefits and services are designed so as to maximize the effective inclusion of people with disabilities in social, political, cultural and economic life
- people with disabilities can participate in the design, implementation and monitoring of the social protection legal framework for disability schemes
- schemes are designed in full respect of the principles of equal treatment and non-discrimination

Recommendation No. 131 of the ILO underscores the importance of cash benefits specifically designed to cover disability-related costs and compatible with work and income security/replacement for people with disabilities. In high-income countries, there is a growing trend of integrating benefits that address both income security and disability-related costs. While means-tested income replacement benefits may be reduced when individuals with disabilities start working, disability-related benefits often have higher eligibility criteria or no means testing requirement, enabling individuals to maintain support while

employed in recognition of their higher cost of living. This inclusive approach extends to older individuals who benefit from a combination of old age pensions and disability-related benefits. Recommendation No. 131 of the International Labour Organization (ILO) broadens the definition of disabilities covered under national schemes so as to include also a notion of partial disability, important for making benefits compatible with work.

In low- and middle-income countries, there is a lack of cash benefits specifically focused on addressing disability-related costs and often, schemes are targeted at working age population. Only a few countries provide child disability benefits. Where such benefits do exist, they typically cover support and care expenses, such as caregiver or third-person support allowances, or provide general coverage for extra costs. For adults, disability allowances are provided alongside income security schemes, typically being universal or subject to an affluence means test. Caregiver benefits are relatively rare in low- and middle-income countries, with examples found in Jordan, Iraq, and Vietnam, where family members who give up employment to provide care and support are compensated for their labour (Mont & Côté, 2020).

### **3. Leading the way: Countries Advocating for Inclusive Social Protection for People with Disabilities**

Several countries have incorporated specific provisions within their social protection laws to promote social protection for people with disabilities. They may include disability-specific benefits, access to healthcare services, rehabilitation programs and support for employment and vocational training.

In Japan, the Law for the Welfare of People with Physical Disabilities, incorporated in the Services and Supports for Persons with Disabilities Act, aims to promote the independence and participation of disabled individuals in social and economic life (Article 1). The act provides funding for nursing care services, training services (Article 5 (3)), and community life support services (Article 2), tailored to different types of disabilities. Vocational rehabilitation services and employment support are available, and the Quota System and Levy and Grant System encourage employers to hire disabled workers. Financial support and assistance in Japan are often provided based on an income test and are granted to households rather than individuals. To comply with the Convention on the Rights of Persons with Disabilities, Japan introduced the Act on the Elimination of Discrimination against Persons with Disabilities, which emphasizes the removal of social barriers and reasonable accommodation by administrative organs and private entities. Overall, Japan's disability welfare legislation combines rehabilitation and rights-based approaches, with a focus on integration and participation in society while also considering the country's unique socio-political context and priorities (Lindqvist & Lamichhane, 2019).

The Law on Special Support and Services for Persons with Disabilities in Sweden emphasizes the goal of ensuring "good living conditions" for individuals with disabilities, without explicit limitations on the number of hours of personal assistance they can receive. While stricter assessment procedures have been implemented, leading to fewer people receiving personal assistance services, the redress process in Sweden is based on a strict legal framework. Claimants can appeal decisions through administrative courts, allowing for a fair and transparent resolution. This commitment to legal processes aligns with the social rights-based approach and ensures that individuals have avenues to seek justice and uphold their rights (Lindqvist & Lamichhane, 2019).

Mauritius distinguishes itself from many low- and middle-income countries through its elaborate and multi-faceted framework of social protection interventions. This system includes various levels, each designed to address different aspects of welfare. For example the income security schemes encompass a non-contributory Basic Invalidity Pension (BIP) available to individuals under 60 years old with a disability assessed at a minimum of 60 percent. Remarkably, this benefit allows recipients to engage in employment and may be combined with means-tested social assistance benefits.

Cambodia has made significant strides in disability inclusion through the establishment of a Disability Management Information System (DMIS) and the implementation of the Law on the Protection and Promotion of the Rights of Persons with Disabilities. The DMIS serves as a comprehensive database that

collects and manages essential information related to persons with disabilities, their needs, and the services provided to them. This system plays a vital role in improving data collection, monitoring, and evaluation of disability-related programs and policies, ensuring evidence-based decision-making and resource allocation. The Law aims to eliminate discrimination and create an inclusive society by ensuring equal access to education, employment, healthcare, and other essential services. It emphasizes the rights of persons with disabilities to participate fully in social, cultural, and political aspects of life and highlights the importance of reasonable accommodation and accessibility measures.

In the Philippines, registered persons with disabilities are covered by the national health insurance program, PhilHealth, which includes specific benefit packages for both children and adults with disabilities. In Vietnam, eligible individuals with disabilities receive a full waiver on contributions to the compulsory social health insurance program, along with subsidies on co-payments for medical expenses. In Ghana, the National Health Insurance Scheme offers waivers on individual contributions for persons with disabilities registered with the Social Welfare Department, or those who receive the poverty-targeted cash transfer through the LEAP scheme, which includes disabled individuals unable to work.

Fiji has made efforts to design disability-specific benefits to support individuals with disabilities. The Social Welfare Act of 2016 introduced a Disability Allowance, which provides financial assistance to people with disabilities who face additional costs related to their condition. This benefit aims to help cover expenses such as medical treatments, assistive devices, and transportation. Additionally, Fiji has implemented the Bus Fare Subsidy Scheme, which offers discounted bus fares for people with disabilities, enabling them to access transportation more affordably. These disability-specific benefits in Fiji demonstrate the country's commitment to addressing the unique needs and challenges faced by individuals with disabilities (Partnerships for Social Protection, 2022).

In Zimbabwe, the Disabled Persons Act (1992) provides a comprehensive definition of disability, encompassing physical, mental, and sensory disabilities. It includes functional disabilities related to vision, hearing, or speech, which result in physical, cultural, or social barriers that hinder equal participation in society's activities, undertakings, or employment opportunities available to other members of society.

In Zambia, the Persons with Disabilities Act of 1996 considers a physical definition of disability. It includes individuals with physical, mental, or sensory disabilities, including functional disabilities related to vision, hearing, or speech.

## 13 FINANCING

*This section is under development and will be completed by Fall 2023.*

**As with any area of public policy, the question of financing is central to the question of how to extend inclusive social protection schemes.** By its nature, social protection financing is highly context specific, linking strongly to the wider economic and fiscal context, but also being highly political. In this respect, there is no simple recipe for financing disability inclusive social protection. Nevertheless, there are some key tools and approaches that can be used to strategically engage in analysis and policy engagement on financing inclusive social protection systems for persons with disabilities. This section summarises some of these tools and approaches, first, by considering monitoring of expenditure and, second, with respect to setting out pathways to expand social protection provision.

### 13.1 EXPENDITURE MONITORING

**A key foundation for working on social protection financing is to understand the current level and distribution of expenditure.** Being able to measure the scale of disability-related social protection expenditure makes it possible to make comparisons relative to total government expenditure, total social protection expenditure and expenditure on other sectors. This can contribute to discussion about whether levels of expenditure are appropriate relative to scale of needs of persons with disabilities. It also makes it possible to track levels of investment over time. Meanwhile, being able to disaggregate expenditure into different kinds of schemes and benefits can support assessment of how appropriate the distribution of expenditure is between different schemes and benefits.

#### 13.1.1 Approaches to classifying disability-related social protection expenditure

**Identifying disability-related social protection expenditure within national budgets confronts various challenges.** A particular challenge is identifying what is “disability-related”, given that persons with disabilities benefit from not only disability-specific, but also mainstream schemes. Other challenges include precisely identifying what entails “social protection”, and also being able to disaggregate between different kinds of schemes.

**A useful starting point for thinking about disability-related social protection expenditure is a set of well-established statistical frameworks developed by international organisations including the OECD, EU, IMF, UN and ILO.** These are: the OECD Social Expenditure Database (SOCX), the European System of integrated Social PROtection Statistics (ESSPROS) and the Classification of the Functions of Government (COFOG).<sup>19</sup> While they have distinctions in their purpose and structure, they have a number of common features in their approach to classifying social protection benefits, namely:

- They all make it possible to identify disability-specific expenditure. All three frameworks take a “functional” approach to describing social protection expenditure, identifying expenditure by the purpose of a given benefit. All three frameworks have a specific category dedicated to disability-related social protection benefits (or “incapacity-related” in the case of OECD SOCX). Some features and implications of this approach are described in Box 13.1.
- Both OECD SOCX and ESSPROS make it possible to disaggregate benefits by cash and in kind, and also different benefits within each classification. ESSPROS also identifies schemes by whether they

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<sup>19</sup> OECD SOCX and ESSPROS are described in manuals developed by the OECD (Adema and Fron, 2019) and Eurostat (2019). COFOG is described as part of the wider IMF Government Finance Statistics Manual (IMF, 2014).

are contributory and non-contributory<sup>20</sup>, and this distinction is also possible in theory using COFOG.<sup>21</sup>

- The various levels of disaggregation included in SOCX and ESSPROS mean that it is possible to develop custom aggregations, which may be relevant for monitoring disability-related social protection expenditure.

These three classification systems have an advantage of being well documented, with clear guidance on how benefits should be classified. COFOG is one of two main approaches to classify government expenditure described in the IMF Government Finance Statistics Manual (IMF, 2014). While OECD SOCX and ESSPROS have been developed for use by member states, they align well with COFOG (particularly in the case of ESSPROS), and also align closely with social protection frameworks developed by the ILO, rooted in international labour standards (International Labour Organization, 2010, pp. 18–21).

**Box 13.1: Key features of the functional approach to classifying social protection expenditure under OECD SOCX, ESSPROS and COFOG**

The classification of benefits as **disability-related** (under ESSPROS and COFOG) or **incapacity-related** (under OECD SOCX) is made on the basis that the primary purpose of the schemes is to support persons with disabilities. In this sense, these schemes can be considered **disability-specific** (as described in Key Concept 3 in Section 2). A variety of other **mainstream** benefits that are paid to persons with disabilities (often with specific eligibility linked to disability) may be classified under other categories, for example:

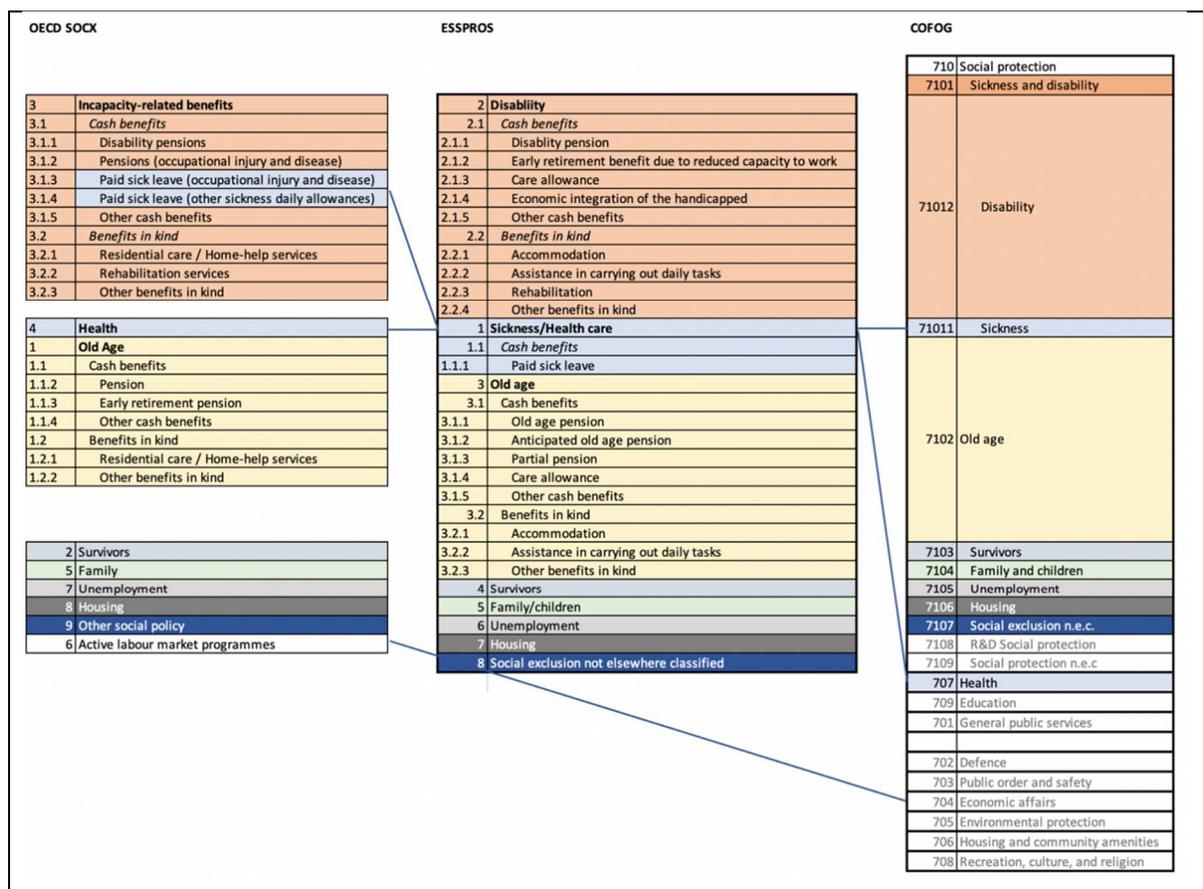
- Benefits paid to older persons are included under the **old age function** in all three classifications. This would apply even to a disability-specific benefit paid to those above retirement age. Some indication of the disability-specific benefits provided to older persons could be established by extracting data on in kind residential care and home-help from total expenditure on old age (expenditure on “care allowance” could also be added in the case of ESSPROS).
- Disability-related benefits paid to children and families are usually classified under the **family and children function**, rather than the disability/incapacity-related function, although there is some complexity as to where this would apply. Parental leave for parents of children with disabilities are also included under the family and children function.
- **Sickness benefits** are included under incapacity-related benefits in OECD SOCX and grouped together with disability in COFOG, but included alongside health in ESSPROS.
- **General social assistance benefits** (for example, benefits paid to poor households without specific reference to other functions) are included under “Social exclusion not elsewhere classified” in COFOG and ESSPROS, and under “Other social policy” under OECD SOCX. This may include benefits paid to persons with disabilities. In some countries, persons with disabilities may also initially receive support via **unemployment benefits**.

**Figure 13.2: Illustration of classification under OECD SOCX, ESSPROS and COFOG**

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<sup>20</sup> One limitation is that this classification is not normally presented alongside the disaggregation of expenditure by function. However, in principle it appears that this data can be merged.

<sup>21</sup> This disaggregation is not included in COFOG (the functional classification of expenditure) but is included in the Economic classification of expenditure (Expense), which is in fact the more widely adopted classification of government expenditure. Many social protection benefits fall within the category of “Social benefits” which are disaggregated in terms of social assistance, social security (social insurance) and employment-related (non-contributory benefits provided for civil servants). The economic and functional classifications can, in theory, be cross-classified, allowing for disaggregation of functional classification by these categories.



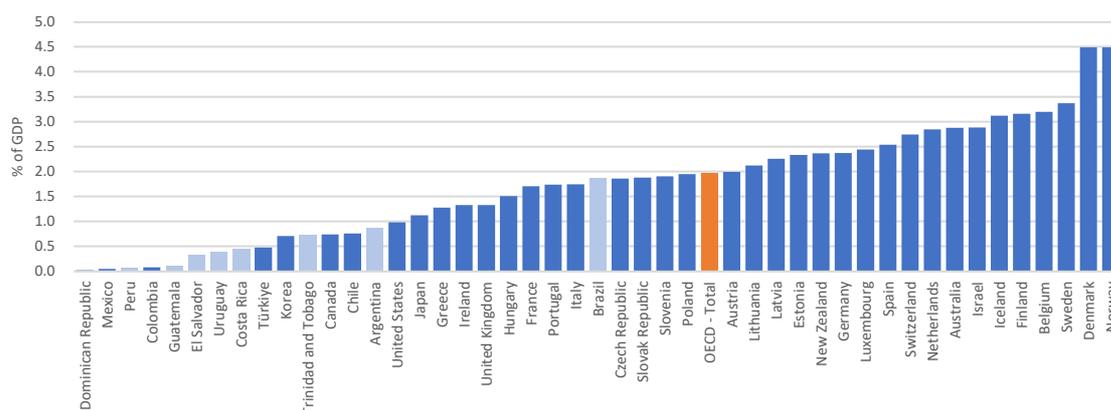
**A level of interpretation is required in classifying the range of benefits within the scope of inclusive social protection with disabilities according to these key classification systems.** As highlighted in Box 13.1, these classifications do not perfectly align with the set of benefits set out within the framework of inclusive social protection for persons with disabilities, as presented in Table 3-1 (in Section 3), even if the disability/incapacity-related functions capture a large share of disability-specific expenditure. One approach to address this would be to develop a framework to collect data on expenditure of a broader array of disability-related expenditure, that could still be cross-tabulated with key statistical frameworks for the purpose of international comparison.

**Another relevant framework for consideration is the System of Health Accounts,** an accounting framework developed by the OECD, Eurostat and the WHO (2011). While the purpose of this framework is to identify total expenditure on health, it is disaggregated in a way that identifies some key types of disability-related expenditure. Most notable is the category of long-term care. This is beneficial given that OECD SOCX, ESSPROS and COFOG can only play a limited role in identifying care and support services. Nevertheless, there are also some limitations with the System of Health Accounts in that it explicitly only accounts for long-term care with a healthcare function, defined as being “with the primary goal of alleviating pain and suffering and reducing or managing the deterioration in health status in patients with a degree of long-term dependency” (OECD et al., 2011, p. 88). This excludes some types of care and support services (such as those related to instrumental activities of daily living), which can be considered within the wider spectrum of long-term care, and care and support services. An important advantage of the System of Health Accounts is it has been adopted across the globe, and the WHO publishes data via its [Global Health Expenditure Database](#). However, it is worth noting that the level of disaggregation is typically more limited in many low- and middle-income countries, meaning that data on long-term care expenditure is more limited.

### 13.1.2 Global data on disability-specific social protection expenditure

Available data indicates that disability-specific social protection expenditure ranges from highs of around 4.5 per cent of GDP, to very low levels – especially in low- and middle-income countries. Figure 13. shows “incapacity-related” public expenditure according to the OECD SOCX classification. This classification is selected as the OECD covers a wide range of countries (including beyond the EU) and for the fact that ECLAC also classifies expenditure using this approach for a selection of countries. On average, OECD countries spend around 2 per cent of GDP on incapacity-related public social expenditure, rising to highs of 4.5 per cent of GDP in Denmark and Norway. However, some countries spend much less, especially low- and middle-income countries where expenditure is typically below 0.5 per cent of GDP.

**Figure 13.2: Incapacity-related public social expenditure according to SOCX classification, 2018-2019**

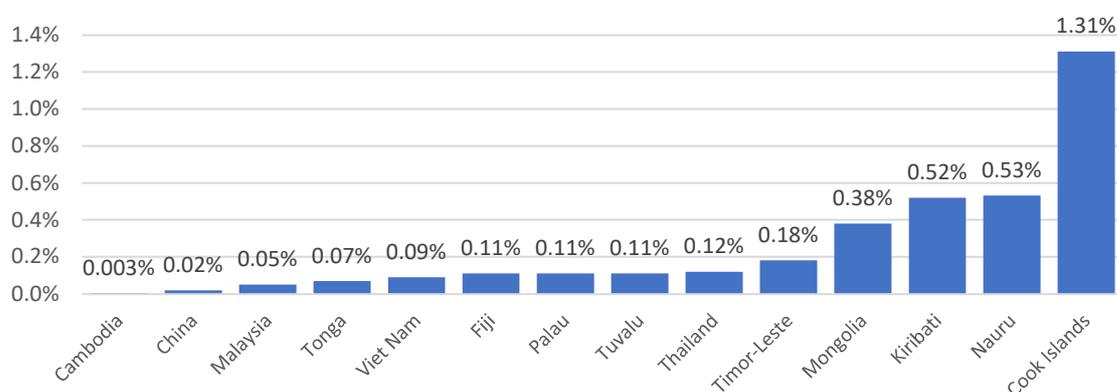


Sources: OECD (2023) and CEPALSTAT (2023) Notes: Data for OECD countries (dark blue) is for 2019; data for ECLAC countries (light blue) is for 2018

Another relevant indicator is expenditure on non-contributory disability cash benefits (shown in

Figure 13. for countries in East Asia and the Pacific). This is a more limited indicator than that in Figure 13. (and not directly comparable), as it excludes in kind and contributory benefits. However, data on disability cash benefits is more readily available in low- and middle-income countries than disability-specific expenditure as a whole. Meanwhile, given these other disability benefits (e.g. contributory schemes and in kind benefits) tend to have more limited coverage in low- and middle-income countries, the indicator still provides a useful reference point. Overall, it reflects the picture provided in Figure 13., with most LMICs spending very small amounts (less than 0.2 per cent of GDP) with the exception of some small island states and Mongolia.

**Figure 13.3: Expenditure on disability-specific non-contributory cash benefits (% of GDP), East Asia Pacific countries**



**Comparison of disability-related expenditure between countries requires some caution given the potential for relevant expenditures to fall under other social protection functions.** As noted in Box 13.1 above, benefits for persons with disabilities may fall under other functions such as family, sickness, unemployment, old age and “social exclusion”/“other social policy”. Analysis in the OECD indicates that a significant portion of support to persons with disabilities is provided under general social assistance (“other social policy”) (OECD, 2022). In some countries, individuals with permanent disability are initially paid a sickness benefit before later transitioning to a disability benefit. This means that, while this data provides broad indications of the scale of expenditure, care is required to understand the configuration of specific social protection systems when making direct comparisons. It also means that data on expenditure under the disability function should ideally be provided alongside a complete picture of social protection expenditure by function.

**The overview here highlights that data on disability-related expenditure is weak in low- and middle-income countries.** In most cases, disability-related expenditure is not available and – even where it is – it may be buried in budget documents, and statistical reports of ministries and funds managing social protection schemes. In the rare case this data is published, this is commonly scheme specific, and hard to compare between countries and across time. Two key actions to improve reporting on disability-related social protection expenditure include:

- **Greater efforts by national governments to report all disability-related social protection expenditure.** This should include an attempt to incorporate the range of schemes that fall within the scope of disability-related social protection. There are significant benefits to aligning with the well-established international classifications of social protection expenditure described above. It also requires greater levels of disaggregation of expenditure, for example, expenditure on different kinds of benefits within a given scheme and expenditure according to different groups of recipients (such as older persons and those of working age).
- **OPDs have potential to play a far greater role in budget monitoring.** Effective budget monitoring provides an important platform for OPDs to engage with government on social protection policy and hold government to account on spending commitments. This entails OPDs having both the resources and technical capacity to effectively monitor national budgets. Box 13.2 outlines some key entry points for OPDs to engage in the budget cycle, which relates to expenditure monitoring, but also some of the aspects discussed below in Section 13.2.

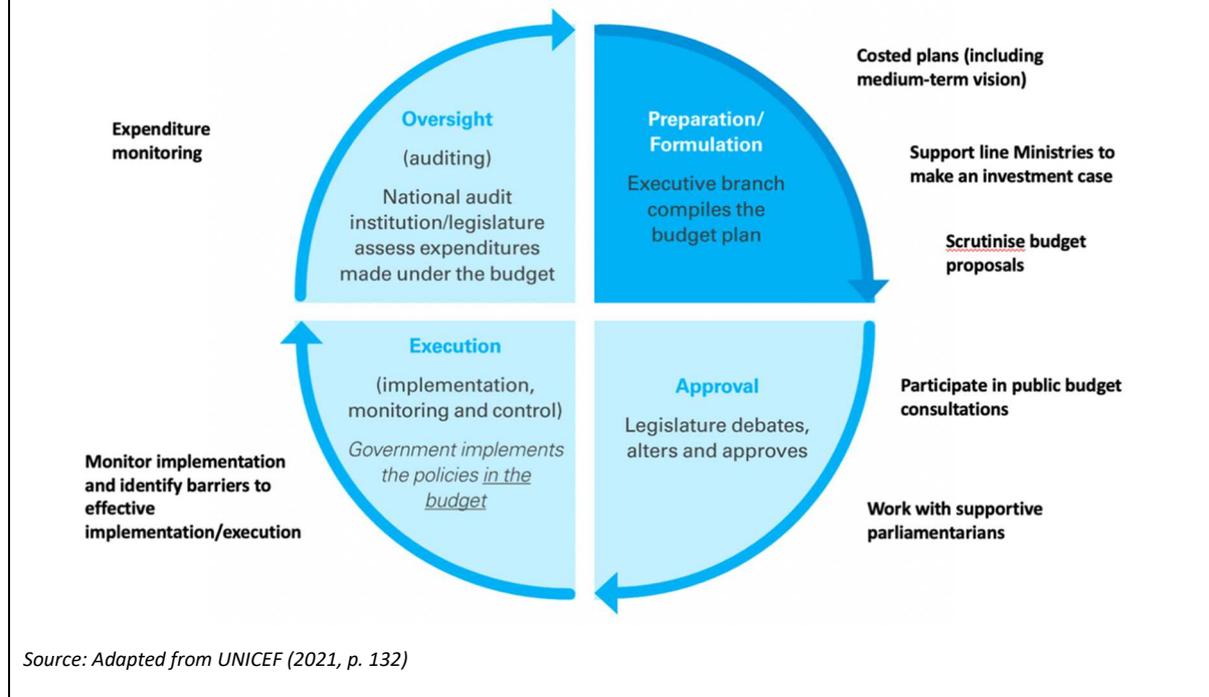
**Box 13.2: Key entry points to the budget cycle for OPDs**

**There are various stages of the budget cycle (often called the Public Financial Management (PFM) cycle) that provide opportunities for OPDs to engage on the topic of financing.** Figure outlines typical stages of the budget cycle and potential opportunities for engagement, although these will vary from country to country, including according to their level of transparency and how consultative they are. Key opportunities include:

- **Budget formulation:** A costed plan for rolling out inclusive social protection for persons with disabilities (Section 13.2.2) can be used to influence strategic budgeting processes, potentially linked to national development plans (Section 13.2.3). Annual budget preparation provides the moment for line Ministries to develop specific proposals for expanding social protection, something which non-government actors can lobby for.
- **Approval:** This is a key moment for line Ministries to make their case to political actors for a given proposal. OPDs can play an important role budget approval, for example, by participating in public consultations and working with parliamentarians to endorse or challenge Ministerial proposals.

- **Implementation:** Effective implementation (including executing budget allocations) and reporting of activities (including assessing impact) are key to justifying further investments in a given policy. OPDs can monitor implementation and contribute to processes to improve implementation.
- **Oversight:** This stage provides a particularly key moment for OPDs to scrutinise execution and implementation and contribute to further discussion on financing. Monitoring expenditure is a key component of this.

**Figure 13.4: Key entry points into the national budget cycle**



## 13.2 IDENTIFYING FINANCING PATHWAYS

There are various tools which can be used to identify what kind of social protection reforms might be feasible in a given country context. The aim of these tools is to answer questions such as:

- What scale of expenditure on disability-related expenditure might be feasible in the short-, medium- and long-term?
- From what sources might investments in disability-related expenditure be financed?
- What would be the cost of different packages of social protection benefits (cash and in kind)?

Rather than focusing on specific options to finance particular schemes, this section focuses more on pathways to reform. This recognises that expansion of disability-related social protection benefits is typically incremental.

### 13.2.1 Understanding the fiscal context

**Understanding the broader fiscal context of a country is key to identifying and articulating potential pathways to social protection financing.** Social protection financing is often framed in relation to the idea of identifying “fiscal space” for social protection. Fiscal space can be defined as the “room in a government’s budget that allows it to provide resources for a desired purpose without jeopardizing the

sustainability of its financial position or the stability of the economy.”<sup>22</sup> While the concept has some appeal, one limitation is that it implies that there might be some clean policy-specific financing solution available (such as adjusting a specific tax, or reallocating a specific expenditure). In practice, financing (disability-related) social protection usually fits as part of the broader evolution of national budgets in terms of revenue and expenditure. It is also likely that practitioners within the social protection sector may have only a partial influence on these decisions.

There are a number of key areas for consideration for understanding the fiscal context. They include:

- **Levels and sources of revenue:** Do levels of revenue seem appropriate for the national context (for example, in comparison to other countries in similar circumstances)? Are there any proposals to increase revenue through adjustments to tax policy or improvements in administration? Conversely, are revenues falling? Are levels of revenue expected to change in line with economic growth?
- **Debt sustainability:** What are the current levels of government debt and deficit? How is their sustainability assessed? What are key government policy directions to address debt sustainability?
- **Expenditure:** How is expenditure distributed by different sectors and government objectives? Does this reflect key government priorities (allocative efficiency)? Are there expenditures perceived to be inefficient that government is seeking to reduce (which could conceivably be reallocated to social protection)? This links to analysis of disability-related social protection expenditure discussed above. It also requires an understanding of key national government priorities, and where inclusive social protection (for persons with disabilities) is located within these.

Inevitably, many of these questions are likely to be debated, with different perspectives of different national and international actors. Understanding the fiscal context therefore requires an evaluation of a range of different sources of evidence and analysis. Some useful resources include:

- **Budget documents** which should include key data on revenue, expenditure and debt sustainability.
- **IMF Article IV consultation documents** (hosted on country pages of the IMF website (<https://www.imf.org/en/Countries>) are reports of regular discussions that the IMF holds with country governments, mandated by the IMF constitution. They include an analysis of the fiscal context and associated data.
- **Public Expenditure Reviews (PER)** – typically undertaken by the World Bank – are a diagnostic instrument to analyse government revenue and expenditure.<sup>23</sup> They are undertaken on a more ad hoc basis than IMF Article IV consultations.
- Other actors such as **regional development banks, UN agencies, think tanks** and **academic institutions** may undertake analysis of the fiscal context.

**Ideally, this analysis should provide some idea of the budget envelope available for new investments (including disability-related social protection).** In other words, how expenditure could be financed from increases in revenue, reallocation and sustainable government deficit, and how much of this might be allocated to social protection. It is unlikely that this analysis will arrive at a precise figure, but it can provide some parameters. It is also important to consider not only the immediate but medium-term outlook.

### 13.2.2 Costing disability-related social protection

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<sup>22</sup> <https://www.imf.org/external/pubs/ft/fandd/2005/06/basics.htm>

<sup>23</sup> An inventory of Public Expenditure Reviews can be found here:

<https://openknowledge.worldbank.org/collections/c0499ef5-999e-56db-b0e4-3e37a4128828>

**Costing proposed initiatives is important to understanding the scale of expenditure required.** Ideally, this can be combined with the analysis of the fiscal context to identify whether specific policy proposals appear to be affordable. Costing can also be used to test different scenarios in order to understand how adjusting parameters (such as eligibility and benefit adequacy) affect cost.

**Undertaking costing exercises entails identifying the key parameters of different schemes that are proposed.** These parameters required include the following:

- **Cash benefits:** The cost of such schemes is mainly determined by:
  - **The number of beneficiaries:** This is influenced by the eligibility of the scheme in terms of the age group included, the profile of persons with disabilities eligible and the use of means testing. It will also be influenced by the level of uptake of benefits.
  - **The benefit level**, which is usually inputted as a monthly value. One aspect that complicates costing is the existence of different benefits for different sub-groups of persons with disabilities (e.g. for moderate and severe disability, or children with disability).
  - **Administrative costs:** Fully accounting for administrative costs is challenging both conceptually and practically (Lindert et al., 2020, pp. 378–395). Nevertheless, it is standard that costing models include an administrative cost as a share of total transfers (e.g. 10%).
- **In-kind benefits** are significantly more complex to cost than cash benefits, not least as the value of the benefit is influenced by a much broader range of factors (e.g. the price of goods and services, and wages), and the strong influence of uptake. Key parameters to consider include:
  - **Care and support services:** Accurately costing these services requires a level of information that is not readily available, and is complicated by the extremely limited nature of existing formal services in many countries (to use as a reference point). De Heneau (2022) describes a promising approach for estimating costs of long term care services which includes parameters on:
    - **The population with care needs**
    - **The assumed recipient-to-carer ratio (FTE)**
    - **Wage costs** – benchmarked relative to nurses’, teachers’ or average wages.
    - **Other staff costs**
    - **Overheads**
  - **Concessions:** The cost of concessions (such as discounts on utilities or public transport) will depend on the way in which they are organized. For example, in the case of public transport, these may involve:
    - Reimbursement to transport providers when eligible individuals (e.g. persons with a disability card) use a service, as in the UK. This requires understanding of the cost of transport and the level of utilization per eligible individual.
    - A periodic amount provided to persons with disabilities which they can use for public transport, for example, via a smart card (as in Fiji and Thailand). In such cases individuals can spend up to the monthly value, but lost any unspent balance. This value can be costed in a similar way to a cash benefit, however, assumptions need to be included on the average share of the allocation used among recipients.
    - Cross-subsidies from transport providers. This exists where there is a standard schedule for fares for public transport providers which includes a lower rate for persons with disabilities (Estupiñán et al., 2007). Such schemes do not entail a specific fiscal expenditure (although public transport providers may receive other general subsidies, benefits and exemptions), so it is not possible to cost them.
  - **Health care services:** A challenge of costing health care services is separating disability-related/specific expenditures from other health expenditures. In practice, it is unlikely to be feasible to separate the cost of general health services for persons with disabilities (e.g. consultation, treatment, medication) from those accessed by people without disabilities.

It may be more feasible to separate certain disability-specific expenditures such as rehabilitation and assistive devices. As with the costing approaches discussed so far, costing the provision of such services involves defining the eligible population and the average cost per recipient.

**Existing, readily-available models only make a limited contribution to costing the range of schemes included within an inclusive social protection system for persons with disabilities.** It is common for costing models to focus on cash transfers and to only include the option for a single disability benefit amount which limits the ability to create a more complex package of support. Costing models for in-kind benefits are far more limited, although initiatives are underway to build such models, for example, those developed by the recently developed Care Investment Policy Simulator developed by ILO. UNICEF and ILO are exploring possibilities to build more comprehensive costing models that would combine in cash and in kind support.

### 13.2.3 Setting out a medium- to long-term plan for investment

**In most cases, financing an inclusive social protection system for persons with disabilities is likely to be an incremental process.** In most low- and middle-income countries there will be a mismatch between a package of social protection which is seen to be fully inclusive, and what can be financed immediately given the fiscal context. This will no doubt be amplified by the presence of other policy areas that are competing for the same resources. In this context, there is value in considering financing pathways that entail a gradual expansion of social protection benefits alongside an associated gradual increase in financial resources available.

**Gradual expansion may well happen organically through the national budget formulation process, however, there is a case for proactively setting out a forward-looking vision.** One value of such an approach is that this can be factored into strategic budgeting exercises (such as the development of a medium term financial strategy) which can embed planned measures into future budget planning. It also represents a pragmatic way to engage key stakeholders in the budget formulation process – most notably Ministries of Finance – which reflect a recognition of the fiscal context.

**Gradual expansion of social protection benefits typically happens through incremental adjustment of scheme parameters.** There is substantial precedent for this, both for disability-specific schemes and others such as child benefits and children.<sup>24</sup> Two key approaches include:

- **Adjustment to eligibility criteria:** This might include initially targeting the most severe levels of disability, but expanding to less severe levels over time. It could also include limiting benefits initially to people of certain ages (such as rolling out a child disability benefit before expanding coverage to adults). In principle, eligibility can also be expanded by gradually increasing means-testing thresholds.
- **Adjustment to benefit levels:** A scheme might start with a benefit level that is recognized to be below what is required to address extra costs, to be followed by increases subsequently. Benefit levels can also be adjusted for different groups. For example, benefit levels could be increased initially for those with more severe levels of disability, while remaining at a lower level for those with less severe disabilities.

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<sup>24</sup> See, for example, approaches used in the Pacific context described by Knox-Vydmanov et al. (2023)

## 14 CONCLUSION

In the last decade there has been a growing momentum, reinforced by the COVID 19 crisis, toward universal social protection with increasing attention to the role of inclusive and shock responsive social protection systems.

In parallel, better data have consistently demonstrated that persons with disabilities have greater exposure to risks and vulnerabilities throughout the life cycle than those without disabilities as they face significant disability related costs and barriers which undermine their socio-economic empowerment and resilience. Despite having much higher needs, they do not access significantly more support from social protection systems.

As many low- and middle-income countries are building, expanding or reforming their social protection systems, there is a strong case, in line with the principle of progressive universalism, to prioritise children, working age adults and older with disabilities. However, in doing so countries have to ensure that their efforts to provide more support truly contribute to inclusion in line with principle and provision of the CRPD.

The 2019 Joint statement highlighted several key normative elements required for social protection systems to support the full and effective participation of persons with disabilities:

- The paradigm for social protection for persons with disabilities should shift from mostly focusing on compensating people for an alleged incapacity to work to an approach that acknowledges barriers to participation and promote social and economic inclusion across the life cycle.
- Inclusive social protection systems should provide income security and coverage of health care and disability related costs, including care and support, in ways that improve access to services and promote full participation and inclusion. This requires a context-relevant combination of cash and in-kind, contributory and non-contributory, inclusive mainstream and disability-specific schemes.
- In the development and reform of social protection programs and systems, stakeholders should ensure meaningful participation of persons with disabilities and their representatives' organisations (OPDs).

Each country will find a different pathway to progressively build social protection system in line with those requirements. Practically, there are clear steps that countries can take to make their social protection system more inclusive as developed in this guidance note, including:

- Collect and analysis data to understand the situation of the diversity of persons with disabilities, the barriers they face, the extent of the diversity of their disability related costs and the challenges they face in accessing social protection
- Use context relevant mechanisms to promote meaningful participation and ownership of the diversity of persons with disabilities and ensure accessibility of process and information and invest in mutual capacity building of OPDs and social protection professionals.
- Ensure that the legal framework related to social protection and welfare, health care rights of persons with disabilities, children, older persons as well as gender equality foster consistently development of an inclusive social protection system and cross sectoral interlinkages.
- Develop disability registries and inclusive management information systems based on accessible, comprehensive and reliable disability assessment and determination mechanisms. Ensuring the interoperability of disability registries with other social protection administrative databases can inform eligibility to a range of benefits and services, facilitate case management and policy planning, and enable vertical and horizontal expansion in case of covariate shocks

- Improve income security by considering persistent barriers as well as disability related costs undermining economic activities and access to decent work of persons with disabilities and their families
- Prioritise persons with disabilities in the development and implementation of Universal Health coverage policies and programs, including packages related to rehabilitation and assistive technology.
- Develop flexible combination of inclusive adaptation of mainstream cash transfers with development of disability benefits compatible with work and other benefits, while pursuing progressive expansion towards universal social protection coverage.
- Mobilise all social protection instruments to better address disability related costs by combining cash transfers, in kind support, meaningful concessions and development of gender responsive community care and support systems.
- Increase the accessibility across the delivery chain of both disability and mainstream social protection schemes. This involves adequate training, accessible information and communication channels, data disaggregation, development of minimum service standards, implementation of disability-inclusive administrative and delivery processes and appropriate management and organisational processes.

While the guidance refers to several country examples, there are promising ongoing development across regions that will provide in the coming years more elements on conditions, innovation and steps required to build inclusive social protection programs and systems. It will therefore be a living document with a formal update planned in 2025.

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