

Inclusion Counts: Disability Data Tracker

A data collection and advocacy guideline for
Organisations of Persons with Disabilities



**Spotlight on
adequate
standard of
living and social
protection**

Acknowledgements

This tool was written by Lisa Adams on behalf of Leonard Cheshire, and was developed in collaboration with the UN Office of the High Commissioner on Human Rights. Kate Turner, Dr. Ola Abu Alghaib, Navleen Kaur, Dr. Nora Groce, Ruby Holmes, Maeve O'Reilly and all organisations of persons with disabilities who inputted are thanked for their contributions to this report.

Contents

Introduction	4
Section 1: Background information	5
1.1 Agenda 2030 and the SDGs: What you need to know	6
1.2 What is the CRPD?	7
1.3 What does the CRPD have to do with the SDGs?	8
1.4 Making the link between CRPD Article 28 and SDGs 1, 2 and 6	9
1.5 The critical role of OPDs	12
1.6 How to engage in SDG implementation	15
Section 2: The assessment tool	17
2.1 Introduction to the tool	18
2.2 How to use the tool	18
2.3 Adequate standard of living and social protection assessment tool	20
Section 3: Using the assessment tool in your advocacy	28
3.1 The legal and policy framework	29
3.2 Implementing the SDGs in line with Article 28 in practice	33
3.3 Advocating for changes in laws and policies	35
3.4 Building an advocacy strategy	36
3.5 Different types of advocacy actions	38
3.6 Measures needed to implement SDGs 1, 2 and 6 in practice	40
3.7 Advocating for change	40
3.8 What change looks like	43
Section 4: Data and information for advocacy	45
4.1 The importance of data	46
4.2 The different types of data	47
4.3 How to advocate for data on disability	47
4.4 What data to ask for	48
4.5 Existing data and disability tools	49
4.6 Data principles	50
4.7 What data and information exist to support advocacy	50
4.8 Using data and information for change	50
4.9 Sources of data and information	51
Section 5: Conclusion	52
Annexes	54
Annex I: Glossary of key terms	55
Annex II: Good practice on promoting the SDGs in line with CRPD Article 28	59
Annex III: Advocacy resources	63
Endnotes	65

Introduction

This guideline is intended to be a tool for Organisations of Persons with Disabilities (OPDs) and their allies on how to advocate for the rights of persons with disabilities within the global development framework known as the Sustainable Development Goals (SDGs). The SDGs are part of the 2030 Agenda for Sustainable Development adopted by world leaders at the UN in 2015. The guideline is intended to be used as an advocacy tool for OPDs to engage with government, development agencies and other civil society actors on the implementation of the SDGs in line with the UN Convention on the Rights of Persons with Disabilities (CRPD).

The thematic focus of this guideline is on an **adequate standard of living and social protection**. The guideline will explore how the right to an adequate standard of living and social protection can be applied to the SDGs. In particular, this guideline will look at how the rights enshrined in Article 28 (Adequate standard of living and social protection) can be addressed within the relevant SDGs including: Goal 1 (No Poverty), Goal 2 (Zero Hunger) and Goal 6 (Clean Water and Sanitation). After consultation with OPDs from different countries around the world, access to basic services and social protection was identified as a priority issue within the disability community along with access to work and employment.

This tool will help break down the key elements of CRPD Article 28 and explain how they can be implemented in laws, policies and practices. The tool also provides an overview of what the SDGs are, how civil society can engage in advocacy on the SDGs and how the rights enshrined in CRPD Article 28 can be applied to the SDG framework. It also gives recommendations for how and when to advocate for changes in line with CRPD Article 28 in the framework of the SDGs.

The guideline has three main parts:

- Introduction and overview
- Assessment tool to evaluate where your country or sub-national region is in terms of implementation of CRPD Article 28
- Advocacy strategies to support implementation of CRPD Article 28 within the SDGs

The guideline also includes Annexes with further tools, resources and good practice case studies.

1

Background information



1.1 Agenda 2030 and the SDGs: What you need to know

Agenda 2030 for Sustainable Development is a commitment by all countries to end poverty in all its forms, reduce inequality and save the planet. It was adopted in 2015 by the United Nations and its Member States. Agenda 2030 builds on the Millennium Development Goals but makes explicit references to persons with disabilities in the goals, targets and indicators. Agenda 2030 includes 17 Sustainable Development Goals (SDGs) which are global goals that apply universally to all countries. The goals call for concerted efforts between governments, civil society and the private sector towards building an inclusive, sustainable and resilient future for people and planet.


All of the Goals within Agenda 2030 apply to persons with disabilities based upon the universality of each Goal and the guiding principle of Agenda 2030: **Leave no one behind**. In terms of relevance, out of the 17 Goals, 13 make particular reference to persons with disabilities or vulnerable groups. There are 7 Targets that have an explicit reference to persons with disabilities. In the preamble of Agenda 2030, the definition of vulnerable groups includes persons with disabilities. Therefore, when Goals and Targets reference vulnerable groups, this includes persons with disabilities.¹ Despite the universality of each SDG, there may be some resistance from government or other stakeholders to apply a disability inclusive lens to the SDGs. If this occurs, it is important to note the explicit references to disability while also highlighting the inclusive principle of leave no one behind.

There are explicit references to persons with disabilities in the following Goals and Targets:

- Goal 4: Quality Education – 2 references
- Goal 8: Decent Work and Economic Growth – 1 reference
- Goal 10: Reduced Inequalities – 1 reference
- Goal 11: Sustainable Cities and Communities – 2 references
- Goal 17: Partnerships for the Goals – 1 reference

Persons with disabilities are also explicitly referenced in the ‘Follow-up and Review’ section of Agenda 2030 on data disaggregation (paragraph 74, g).

It is important to note a reference to ‘vulnerability’ that is particularly strong within Agenda 2030. The paragraph below is particularly strong because it calls for the empowerment of ‘vulnerable’ people and places persons with disabilities at the centre of poverty eradication throughout the entirety of Agenda 2030.

 **People who are vulnerable must be empowered. Those whose needs are reflected in the Agenda include all children, youth, persons with disabilities (of whom more than 80 per cent live in poverty)."**

Paragraph 23, The 2030 Agenda for Sustainable Development, UN

The SDGs set a policy framework for sustainable development which means they are not legally binding. They are not enforceable by law and States that have adopted Agenda 2030 do not have a legal obligation to implement the SDGs. However, governments, multilateral agencies, donors and private sector are investing large amounts of money in the roll-out and implementation of the SDGs. Because of the large investment in the SDGs, in many contexts, national governments are prioritising the achievement of the SDGs over the implementation of human rights treaties, including the CRPD.

Making a link between the SDGs and the CRPD is critical. Governments, development stakeholders and private sector are working to meet the goals set within Agenda 2030 and need to work in meaningful partnerships with OPDs. National, local and regional development plans are being drafted to implement the SDGs, with budget allocations to ensure the SDGs are met by 2030. OPDs must be at the table as these plans and budgets are drafted and programmes and policy frameworks are adopted. Leveraging the overarching principle of leave no one behind, OPDs and their allies must be part of the dialogue to ensure the Goals and Targets address the rights of all persons with disabilities. Disability rights advocates have a tool and framework to ensure the SDGs are fully inclusive of persons with disabilities: the CRPD. This sets out the framework, measures and safeguards to ensure persons with disabilities are not left behind.

1.2 What is the CRPD?

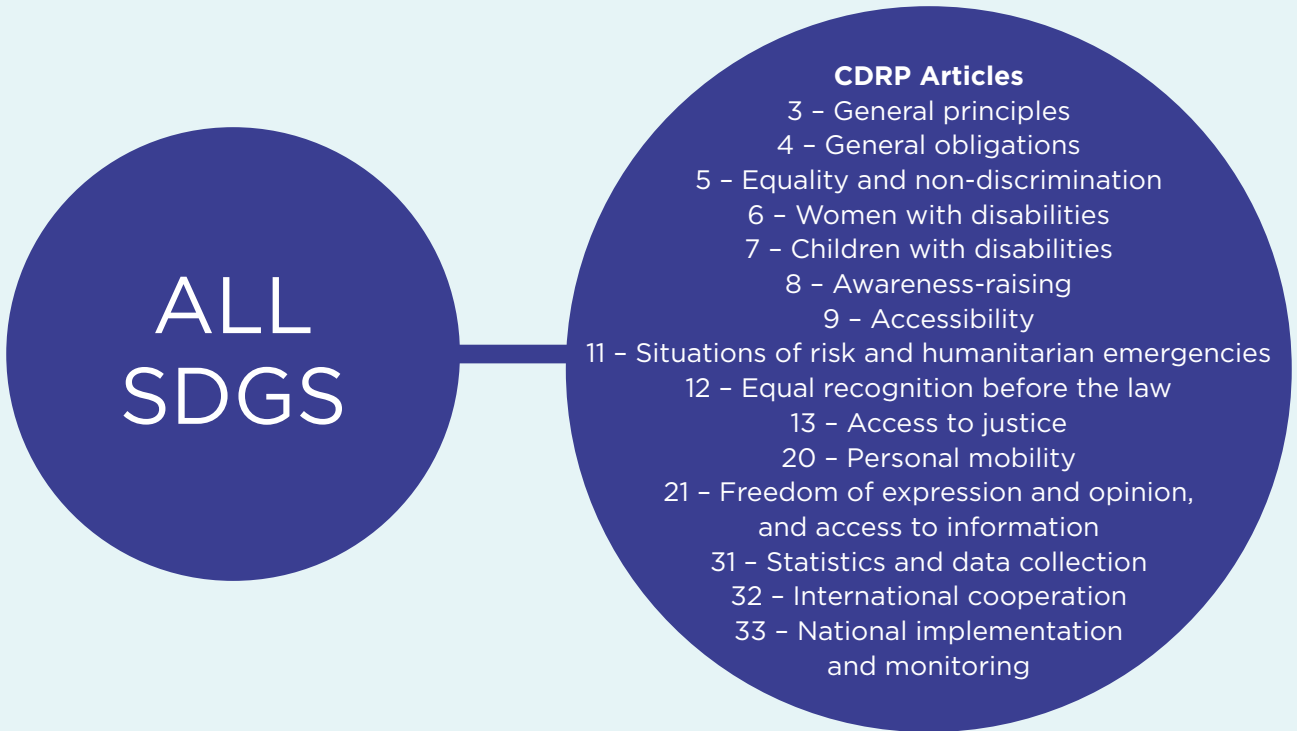
Unlike the SDGs, the CRPD is a legally binding human rights treaty. Once a country has ratified the CRPD, they are bound to oblige by the rights it enshrines by fully implementing the treaty in national law and policies. CRPD implementation is monitored by a treaty body monitoring mechanism known as the CRPD Committee. This is situated within the Human Rights Council at the UN. States are obligated to report on implementation. Civil society can produce shadow reports or parallel reports to the CRPD Committee to highlight issues not addressed in the State's report.

The CRPD provides a framework for the human rights of persons with disabilities. It shifts the predominant disability paradigm from a medical model, where persons with disabilities are recipients of benefits, charity and services, to the human rights model where they are rights holders. This transformational shift is founded upon anti-discrimination and equality and breaks down the idea that disability is a deviation which legitimises segregation and exclusion of persons with disabilities.² The CRPD can also be a roadmap on how to build an inclusive and accessible society founded upon equality and non-discrimination. For states setting out to implement the SDGs, the CRPD is an incredibly valuable tool for understanding how to ensure each Goal is inclusive of persons with disabilities.

1.3 What does the CRPD have to do with the SDGs?

Many of the CRPD Articles are cross-cutting in nature and should be applied across all of the SDGs (see diagram A).

Diagram A: Cross-cutting CRPD Articles apply to all SDGs



Source: IDA and CBM

Each SDG has a specific focus such as health, education or water and sanitation. For many of the Goals, there is an obvious link with specific CRPD articles. For example, SDG 4 (Education) links with CRPD Article 24 (Education). While Article 24 is the most relevant to SDG 4, implementation requires inter-related rights of the CRPD to truly be in line with the CRPD. For example, access to education requires accessible schools and access to information, technology and communication in accessible formats in line with CRPD Article 9 (Accessibility). Access to education for students with disabilities also requires anti-discrimination provisions that are enshrined in law, to prevent students with disabilities from being discriminated against in accessing education. This is in line with Article 5 (Equality and non-discrimination).

It is important to keep this inter-related rights lens when advocating for the SDGs to be implemented in line with the CRPD (see SDG matrix below). While some of the SDGs do not have such an obvious link to a specific CRPD Article (for example SDG 7: Affordable and Clean Energy), the cross-cutting CRPD Articles can still be applied, as all people need access to affordable and clean energy.

In addition, there are essential cross-cutting practices that should run through all of the SDGs. These include:

- Consultation with persons with disabilities.
- Promoting the rights of the most marginalised (ensuring even the most marginalised constituencies are represented and included).
- Data collection and data disaggregation within SDG data collection at the national level.
- The need for effective remedies and sanctions. This means that when a person with a disability is deprived of their rights, there are remedies given to that person, and sanctions delivered to the perpetrator. The remedy should be sufficient for the action that deprived the person of their rights. The sanction should be effective enough to dissuade others from doing the discriminatory or harmful practice again.
- Cross-ministerial coordination. This means ensuring line ministries coordinate on disability issues so that they do not remain an issue under the responsibility of just one ministry.
- Having a gender lens to ensure the multiple and overlapping forms of discrimination women and girls with disabilities face are addressed.



When we consider implementation of SDGs 1, 2 and 6 in line with CRPD Article 28, we should also address these cross-cutting issues.

1.4 Making the link between CRPD Article 28 and SDGs 1, 2 and 6

CRPD Article 28 (Adequate standard of living and social protection) addresses a broad range of rights issues to ensure persons with disabilities access an adequate standard of living and social protection. Article 28 is important because it ensures the right to social protection for the first time in an international instrument, and links this right to an adequate standard of living.

Article 28 is a major step towards disability-inclusive social protection and creates an obligation for States parties to ensure that persons with disabilities receive equal access to mainstream social protection programmes and services as well as to specific programmes and services³ for disability-related needs and expenses.⁴

These issues are also addressed in several of the SDGs including: Goal 1 aimed at ending poverty in all its forms everywhere; Goal 2 to end hunger, malnutrition and ensure everyone has access to healthy and nutritious food throughout the year; and Goal 6 ensuring access to clean and safe water and sanitation for all.

Let's start by breaking down the main attributes of Article 28 and making links to these three SDGs.


CRPD Article 28 (Adequate standard of living and social protection):

- All persons with disabilities have the right to an adequate standard of living for themselves and their families including adequate food, clothing and housing, and to continuous improvement of living conditions.
This attribute establishes the right to an adequate standard of living without discrimination on the basis of disability.
- All persons with disabilities have access to social protection without discrimination on the basis of disability.
This attribute establishes the right to social protection without discrimination on the basis of disability and outlines that social protection should cover the extra costs of disability.
- Measures are in place to ensure persons with disabilities have access to affordable and accessible basic services as well as poverty reduction and social protection programmes.
This attribute ensures States put programmes, policies and services in place to ensure persons with disabilities have access to basic services such as housing, clean water and sanitation and other assistance for disability-related needs, as well as social protection or poverty reduction programmes, on an equal basis with others and without discrimination on the basis of disability.
- Persons with disabilities are free from forced or compulsory labour.
This attribute protects persons with disabilities from forced or compulsory labour such as unpaid work or forced domestic labour.

Making the link to SDG 1 (No Poverty)


The rights enshrined in Article 28 are closely linked to SDG 1, which sets targets to eradicate extreme poverty and reduce the number of people living below the poverty line. Goal 1 also calls for States to implement social protection systems to increase coverage for poor and vulnerable persons.

SDG Target 1.2 is similar to the first attribute of Article 28:

 **SDG Target 1.2: By 2030, reduce at least by half the proportion of men, women and children of all ages living in poverty in all its dimensions according to national definitions.**

Like the first attribute of Article 28, all persons with disabilities have the right to an adequate standard of living and to live without poverty.

SDG Target 1.3 is similar to the second attribute of Article 28. It says States should:



 **SDG Target 1.3: Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable.**

SDG Target 1.B reinforces Article 28 by asking States to develop policy frameworks based on pro-poor and pro-gender strategies to end poverty:

-  **SDG Target 1.B: Create sound policy frameworks at the national, regional and international levels, based on pro-poor and gender-sensitive development strategies, to support accelerated investment in poverty eradication actions.**

Making the link to SDG 2 (End Hunger)



Article 28 establishes the right to basic services including access to food and nutrition programmes, as well as to a continuous improvement of living conditions. These rights are reinforced by SDG 2 targets:

-  **SDG Target 2.1: By 2030, end hunger and ensure access by all people, in particular the poor and people in vulnerable situations, including infants, to safe, nutritious and sufficient food all year round.**
-  **SDG Target 2.2: By 2030, end all forms of malnutrition, including achieving, by 2025, the internationally agreed targets on stunting and wasting in children under 5 years of age, and address the nutritional needs of adolescent girls, pregnant and lactating women and older persons.**

Like Article 28, SDG 2 calls for States to ensure access to nutritious food year-round for all and to end malnutrition, particularly for those who are vulnerable to being left out.

Making the link to SDG 6 (Clean Water and Sanitation)

Article 28 establishes the right to an adequate standard of living which includes access to clean and safe water and sanitation. It also calls for measures to be in place to ensure all persons with disabilities have access to clean water and sanitation on an equal basis with others. These attributes are closely linked to SDG 6 Targets including:

-  **SDG Target 6.1: By 2030, achieve universal and equitable access to safe and affordable drinking water for all.**
-  **SDG Target 6.2: By 2030, achieve access to adequate and equitable sanitation and hygiene for all and end open defecation, paying special attention to the needs of women and girls and those in vulnerable situations.**

It important to remember that all of the rights enshrined in CRPD Article 28 are critical to implementing SDGs 1, 2 and 6.

Article 28 sets out the framework, safeguards and necessary measures to ensure persons with disabilities have access to basic services needed for an adequate standard of living and have access to poverty reduction and social protection programmes that meet their needs. By ensuring persons with disabilities access an adequate standard of living and social protection on an equal basis with others, CRPD Article 28 is integral to achieving the targets and indicators of Goals 1, 2 and 6 and to leaving no one behind.

As an advocacy message to governments: if Goals 1, 2 and 6 do not address the rights enshrined in Article 28, persons with disabilities will continue to be left out of poverty reduction efforts and face barriers to accessing basic services and social protection. If these Goals do not incorporate the right to access an adequate standard of living on an equal basis with others as enshrined in Article 28, persons with disabilities will continue to face higher rates of poverty and poorer health outcomes than their peers without a disability.

This means that the rights enshrined in the CRPD can provide a lens for ensuring each SDG is fully inclusive of persons with disabilities. If the Targets set in Agenda 2030 are to be met, each SDG must address the rights of persons with disabilities and their full inclusion in global development efforts. Using the framework of the CRPD, advocates can provide governments, UN agencies, donors, development stakeholders and private sector with reforms and measures needed to ensure inclusion of all persons with disabilities.

Unlike the SDGs, the CRPD does not have a finite timeframe and extends beyond the 2030 timeline of the SDG process. However, implementing the CRPD is vital to achieving all of the SDGs and leaving no one behind. Governments should have a vested interest in ensuring all of the SDGs are inclusive, so they can better meet their targets and their obligations under the CRPD.

1.5 The critical role of OPDs

If persons with disabilities are part of SDG dialogue, they can significantly influence outcomes on the national, regional and global levels. Similarly, when persons with disabilities are part of CRPD implementation and monitoring, their contributions lead to more relevant and significant change.

OPDs and the CRPD

Participation of civil society lies at the centre of the CRPD, which recognises participation as a general principle in Article 3 (General principles) that runs throughout the Convention, and as a general obligation in Article 4 (3).

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

CRPD Article 4 (3)

Article 33 (3) (National monitoring and implementation) of the CRPD requires governments to ensure that representatives of civil society, in particular persons with disabilities and their representative organisations, are involved and participate fully in monitoring the implementation of CRPD rights.

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.
CRPD Article 33 (3)

OPDs and the SDGs

Similarly, the SDGs call for partnerships between States, civil society and private sector in the implementation and monitoring of the SDGs. In the preamble of Agenda 2030, there is a clear commitment made to partnerships for more effective implementation of the SDGs and better outcomes for all:

We are determined to mobilize the means required to implement this Agenda through a revitalized Global Partnership for Sustainable Development, based on a spirit of strengthened global solidarity, focused in particular on the needs of the poorest and most vulnerable and with the participation of all countries, all stakeholders and all people.

The interlinkages and integrated nature of the Sustainable Development Goals are of crucial importance in ensuring that the purpose of the new Agenda is realized. If we realize our ambitions across the full extent of the Agenda, the lives of all will be profoundly improved and our world will be transformed for the better.

Preamble: Agenda 2030

Multi-stakeholder partnerships are reiterated in SDG 17 (Means and Implementation):

-  **17.16: Enhance the Global Partnership for Sustainable Development complemented by multi-stakeholder partnerships that mobilize and share knowledge, expertise, technology and financial resources to support the achievement of the Sustainable Development Goals in all countries, in particular developing countries.**
-  **17.17: Encourage and promote effective public, public-private and civil society partnerships, building on the experience and resourcing strategies of partnerships.**

In addition, the Special Rapporteur on the Rights of Persons with Disabilities has issued a report on inclusion of persons with disabilities in decision-making. This is a critical tool for OPDs on the principle of participation in political and public life, which is a human right. Persons with disabilities must be part of decision-making forums, bodies and processes about issues that impact their lives including poverty reduction, development planning and implementation of programmes and policies that can impact their lives. With the focus of this tool on SDGs 1, 2 and 6 and Article 28, the principle of participation holds true when applied to laws, policies and programmes promoting economic growth, employment opportunities and access to decent work.

The report also outlines the importance of effective and meaningful participation with persons with disabilities. Having the inputs of persons

with disabilities can have an enormous impact on government decisions and can lead to improved outcomes in policies and programmes that better suit persons with disabilities.⁵ Decisions that affect the lives of persons with disabilities must be made through active consultation with persons with disabilities and their representative organisations, under the slogan of the global disability movement: **Nothing About Us Without Us**.

This is also stipulated by CRPD Article 4 (3) (General obligations):

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

CRPD Article 4 (3)

This is also mandated in CRPD Article 33 (3) (National implementation and monitoring):

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

CRPD Article 33 (3)

The Committee on the Rights of Persons with Disabilities also addresses participation of persons with disabilities in their General Comment no. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the CRPD. This is another excellent advocacy resource that OPDs can use to push for meaningful engagement and participation in decision-making processes related to the SDGs.⁶

OPD participation in global dialogues can lead to inclusive change

The Australian Department of Foreign Affairs and Trade (DFAT), the Finnish Foreign Ministry (in collaboration with the Abilis Foundation), the International Disability Alliance, the Women's Refugee Commission, CBM International and Humanity & Inclusion worked in partnership to influence negotiations at the World Humanitarian Summit in 2015. This resulted in the development of the Charter on Inclusion of Persons with Disabilities in Humanitarian Action. DFAT, and other members of the group, funded and supported OPD engagement within the Summit, enabling the voices of persons with disabilities to be prominent and influential throughout proceedings. This significantly influenced negotiations.

Source: Australian Government, Department of Foreign Affairs and Trade, Creating a New Business as Usual: Reflections and lessons learned from the Australian Aid Program on Engaging with Disabled People's Organisations in Development Programming and Humanitarian Action (Australia: CBM, April 2019)

It is critical for persons with disabilities and their representative organisations to leverage the importance of partnership in both the CRPD and in Agenda 2030 to advocate for and actively engage in SDG implementation and monitoring. Your contributions count, and they will shape the policies, development plans and budgets of future generations to ensure all persons with disabilities are included.

1.6 How to engage in SDG implementation

There are numerous ways OPDs can engage in SDG implementation at the local, national, regional and global levels. Below is an overview of the different mechanisms and platforms for engagement. Please note that each country context is different, and the outline below is intended to be a guide.

- **National or local civil society SDG platforms:** Each country should have a civil society platform for SDG engagement at the national level. This is a mechanism that is intended to gather civil society inputs to ensure the SDGs are inclusive and that government is accountable for the SDGs. OPDs should be part of these platforms to represent the priorities of persons with disabilities and to guide the group on how the SDGs can be implemented in line with the CRPD.
- **National government SDG focal points:** As States begin implementing the SDGs, most countries establish a government SDG focal point. This may be a line ministry that is responsible for SDG implementation and coordination, or a government body that is established specifically to guide the SDG implementation process. Civil society, including OPDs, have a responsibility to meet with the government SDG focal point to advocate for inclusion in national development plans, targets and goals being set by government to implement the SDGs. OPDs can provide technical guidance to government on how to ensure these plans and policies align with the CRPD.
- **Multi-lateral/development sector working groups on SDGs at national level:** In addition to government and civil society SDG mechanisms, UN agencies and development stakeholders are often engaged in sector working groups on the SDGs. For example, in a given country context, UNICEF may be responsible for a sector working group on SDG 4 (Quality Education) and could be working with other development stakeholders working on education issues in the country (such as Save the Children or Oxfam). OPDs should engage with these working groups to ensure they are addressing quality inclusive education in their programmes and reform proposals.
- **Regional platforms on SDG implementation (UNESCAP, UNECA, UNECLAC):** There are regional mechanisms in Asia and the Pacific, Latin America and Africa to drive SDG consultations in preparation for the High-Level Political Forum (HLPF, see below for more information). Civil society organisations, governments, UN agencies and other key donors and development stakeholders participate in these platforms. These regional dialogues are an opportunity for OPDs to ensure disability rights

are highlighted at the HLPF and to outline the regional disability rights priorities within the SDG framework. For Asia and the Pacific, the regional consultations are organised by UNESCAP. In Africa, UNECA convenes the Africa Regional Forum on Sustainable Development. In Latin America, ECLAC convenes the Regional Forum on Sustainable Development.

- **Global-level engagement: High-Level Political Forum (and other global forums):** On an international level, the HLPF on Sustainable Development is the main platform for government and civil society engagement on SDG implementation. The HLPF is the main United Nations platform on sustainable development and it has a central role in the follow-up and review of Agenda 2030 and the SDGs at the global level. The HLPF is convened once a year and is centred around countries presenting their reports on SDG implementation, known as Voluntary National Reviews.

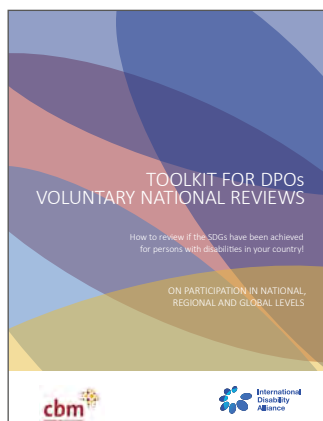
What are Voluntary National Reviews?

A large part of the HLPF is to review national and sub-national reports on progress towards implementation of the SDGs. These reports are called **Voluntary National Reviews (VNRs)**. The VNRs are not mandated; governments do not have to report and can do so on a voluntary basis. These reports are aimed at sharing experiences including successes, challenges and lessons learned to support more effective implementation of Agenda 2030.

- **Reporting and monitoring mechanisms:** In addition to participating in SDG forums and platforms, OPDs can play an active role reporting the situation of persons with disabilities in reporting and monitoring mechanisms. This is an important way to hold governments accountable to commitments made in the SDGs and the human rights treaties they have ratified. This can be done through VNRs and other reporting and monitoring mechanisms such as the Universal Periodic Review, the Committee on the Rights of Persons with Disabilities and other human rights treaty bodies.



IDA and CBM have created a toolkit on VNR drafting for OPDs available at: internationaldisabilityalliance.org/toolkitvnr



2

The assessment tool



2.1 Introduction to the tool

We have developed a tool to assess how CRPD Article 28 (Adequate standard of living and social protection) is being implemented in your context. The tool is followed by detailed information and instructions on how it can be used.

This tool will help you to understand where your country is in the process of implementation. You can use this information to assess gaps and develop strategies for advocacy both in terms of CRPD implementation and for ensuring SDGs 1, 2 and 6 are inclusive of persons with disabilities in line with the CRPD.

Every country is at a different stage of development and implementation in relation to appropriate legislation and policies needed to enable persons with disabilities to access an adequate standard of living and social protection on an equal basis with others. In addition, each country has different levels of political will and attitudinal change. There are also wide variations in how states have traditionally constructed policies and laws related to disability. However, most frameworks for disability issues were based on the medical model, in which services and programmes have been segregated. The various policies, laws and programmes in place will influence the measures that are needed to ensure all persons with disabilities can access an adequate standard of living and social protection on an equal basis. In many cases, it will mean the structures and programmes in place will need to be repealed and reformed in order to comply with CRPD Article 28.

You can use the matrix below to undertake a broad assessment of where progress in the implementation of CRPD Article 28, if any, has been made in your country. If possible, this process should be undertaken as a group activity involving all relevant stakeholders. Once you have undertaken this assessment, it will help you identify the legislative and policy priorities for action and which areas require action to move forward in promoting the rights enshrined in Article 28.

2.2 How to use the tool

Looking at each line of the matrix, you can assess where your country is progressing in the implementation of CRPD Article 28. For example, you will be able to assess: Is your country at the initiating phase or are changes more established? Perhaps in some areas your country is championing changes towards the realisation of the rights enshrined in Article 28, whereas in other areas it may have a bit further to go.

The matrix identifies four different stages of implementation:

Championing

The government is implementing CRPD Article 28 and promoting comprehensive changes in laws, policies, systems and services that have positive impacts on the lives of persons with disabilities in accessing work and employment.

Established

The government has made changes in laws and policies to align with the CRPD but may not have translated policy to start changing systems and services to implement CRPD Article 28 in practice.

Initiating

The government has made initial changes to comply with the CRPD or to support inclusion, but they have not made significant progress to fully implement CRPD Article 28.

Weak to restrictive

The current legal and policy framework does not promote the rights enshrined in CRPD Article 28 or has discriminatory frameworks in place restricting persons with disabilities from participating.

As mentioned earlier, every country will be at a different stage of development and implementation in relation to appropriate legislation, policies and measures needed to access an adequate standard of living and social protection on an equal basis with others. Knowing where your country is in implementing the different aspects of Article 28 can help you understand what is going well, what needs to be changed and what reforms are needed in order to move into the championing phase of implementation.

Based on the assessment findings, you will identify the legislative (legal) and policy priorities as well as what changes are needed in practice to fully realise the rights enshrined in Article 28. These findings can also guide how SDGs 1, 2 and 6 should be implemented to be in line with Article 28. It is important to remember that as we advocate for implementation of Article 28, it also means ensuring the SDGs are implemented in line with the CRPD. Whether your country prioritises the implementation of the CRPD or the SDGs, you can leverage this assessment to promote change in both arenas. The next section of the guideline shows how to use your findings to promote change.



Please note: The criterion in each box of the matrix is there to provide guidance to assess the level of your county's progress towards implementation of CRPD Article 28.

2.3 Adequate standard of living and social protection assessment tool

Implementing CRPD Article 28 (adequate standard of living and social protection)

Legislative and policy framework				
	Championing	Established	Initiating	Weak to restrictive
Legislation on social programmes and basic services	<p>Legislation on social programmes and basic services⁷:</p> <ul style="list-style-type: none"> • Are inclusive of persons with disabilities to ensure access to all mainstream and disability-specific programmes and services on an equal basis with others • Establishes the right to an adequate standard of living for all with explicit mention of persons with disabilities • Includes anti-discrimination provisions to prohibit discrimination on the basis of disability • Includes provisions for reasonable accommodation in the provision of services • Establishes denial of reasonable accommodation as a form of discrimination • Has effective remedies and sanctions in place <p>➔ A championing government is implementing the laws and policies in practice.</p>	<p>Legislation on social programmes and basic services:</p> <ul style="list-style-type: none"> • Are inclusive of persons with disabilities to ensure access to all mainstream and disability-specific programmes and services on an equal basis with others • Establishes the right to an adequate standard of living for all with explicit mention of persons with disabilities • Includes anti-discrimination provisions to prohibit discrimination on the basis of disability • Includes provisions for reasonable accommodation in the provision of services • Establishes denial of reasonable accommodation as a form of discrimination • Has effective remedies and sanctions in place <p>➔ At the established phase, laws are in place but may not be implemented in practice.</p>	<p>Legislation on social programmes and basic services:</p> <ul style="list-style-type: none"> • Establishes the right to an adequate standard of living, but without explicit reference to persons with disabilities and without reference to equal opportunities, accessibility or reasonable accommodation • Anti-discrimination provisions are in place and are applicable to all but without explicit reference to persons with disabilities <p>➔ At the initiating phase, laws are in place with anti-discrimination provisions but not explicitly referencing discrimination on the basis of disability.</p>	<p>Legislation on social programmes and basic services:</p> <ul style="list-style-type: none"> • Does not establish the right to an adequate standard of living • Does not explicitly include persons with disabilities • Does not include anti-discrimination provisions in accessing basic services <p>➔ A weak or restrictive environment. Laws may not promote the right to an adequate standard of living and the State may not have anti-discrimination clauses in the constitution.</p>

Legislative and policy framework				
	Championing	Established	Initiating	Weak to restrictive
Laws and policies on social protection	<p>All laws and policies regulating social protection:⁸</p> <ul style="list-style-type: none"> • Explicitly refer to persons with disabilities and ensure their equal access to all social protection programmes, including both social assistance and social insurance • Protect from discrimination on the ground of disability, including through the provision of reasonable accommodation • Provide for full accessibility to different social protection programmes and services • Ensure gender equality through protection from discrimination on the basis of gender and disability • Recognise disability-related extra costs⁹ both in the establishment of the level of the benefit as well as income thresholds • Have effective remedies and sanctions in place 	<p>All laws and policies regulating social protection:</p> <ul style="list-style-type: none"> • Explicitly refer to persons with disabilities and ensure their equal access to all social protection programmes, including both social assistance and social insurance • Protect from discrimination on the grounds of disability, including through the provision of reasonable accommodation • Provide for full accessibility within different social protection programmes and services • Ensure gender equality through protection from discrimination on the basis of gender and disability • Recognise disability-related extra costs both in the establishment of the level of the benefit as well as income thresholds • Have effective remedies and sanctions in place 	<ul style="list-style-type: none"> • Laws and policies on social protection are in place but without explicit reference to persons with disabilities • Social protection is guaranteed to all and the law protects against discrimination but without explicit mention of disability-based discrimination 	<p>No laws or policies establishing the right to access social protection are in place:</p> <ul style="list-style-type: none"> • No law or policy exists establishing the right of persons with disabilities to social protection • Laws that regulate access to poverty reduction and other benefits place conditionalities on receiving benefits that create barriers for persons with disabilities (e.g. benefits are given out in inaccessible locations)

Legislative and policy framework				
	Championing	Established	Initiating	Weak to restrictive
Laws and policies on social protection	<p>The legal framework ensures there are no discriminatory provisions including:</p> <ul style="list-style-type: none"> • No legal provision or policy measure requires renouncing legal capacity¹⁰ • Does not contain conditionalities which cannot be fulfilled, or which lead to adverse effects for beneficiaries, in order to access benefits and social protection programmes¹¹ <p>➔ For a championing government, measures and budgets are in place to implement the policies.</p>	<p>The legal framework ensures there are no discriminatory provisions including:</p> <ul style="list-style-type: none"> • No legal provision or policy measure requires renouncing legal capacity • Does not contain conditionalities which cannot be fulfilled, or which lead to adverse effects for beneficiaries, in order to access benefits and social protection programmes <p>➔ For an established government, the laws and policies are in place, but measures needed to implement them are not in place.</p>	<p>➔ At the initiating phase, social protection legislation is in place but does not explicitly establish the right to access social protection, social assistance and/or social insurance for persons with disabilities.</p>	<p>➔ A weak or restrictive environment may not have any laws or policies that establish the right of persons with disabilities to social protection.</p>

Legislative and policy framework				
	Championing	Established	Initiating	Weak to restrictive
Poverty reduction plans and/or social services plans	National plans or policies ¹² related to poverty reduction, economic development and access to basic services explicitly ensure that persons with disabilities, particularly women and children, have access to mainstream and disability-specific programmes and services, on an equal basis with others. There is also a specific plan in place with a budget for implementation on inclusion of persons with disabilities, with measures to ensure their inclusion.	National plans or policies related to poverty reduction, economic development and access to basic services explicitly ensure that persons with disabilities, particularly women and children, have access to mainstream and disability-specific programmes and services, on an equal basis with others. There is not yet a plan or strategy in place to ensure poverty reduction plans have the budgets and tools needed to effectively include persons with disabilities in their programmes.	A national plan related to poverty reduction, economic development and access to basic services exists and is applicable to all without explicit reference to persons with disabilities.	No national plan exists addressing poverty reduction, economic development and access to basic services.
Accessibility standards	National accessibility standards on the physical environment, transportation, information and communication, including information and communications technologies, exist and are in line with CRPD Article 9 (Accessibility), and they are applicable to the workplace (public and private). Implementation regulations and budgets are in place and the standards are closely monitored in practice.	National accessibility standards on the physical environment, transportation, information and communication, including information and communications technologies exist and are in line with CRPD Article 9 (Accessibility), and they are applicable to the workplace (public and private). Implementation regulations and budgets are not yet in place. National accessibility standards exist but only for public structures.	Accessibility standards exist but they are applicable only to new buildings and do not comply with CRPD Article 9.	No accessibility standards have been adopted.

Measures in place to ensure access to an adequate standard of living and to social protection				
	Championing	Established	Initiating	Weak to restrictive
Reasonable accommodation	The State is carrying out awareness raising and training on reasonable accommodation for service providers (public and private in housing, water and sanitation, food and nutrition etc). Provision of reasonable accommodation is regularly monitored and failure to comply is reported regularly.	Public awareness of reasonable accommodation is limited. Few service providers (those working in public and private in housing, water and sanitation, food and nutrition etc) provide reasonable accommodation. Reports of discrimination for the denial of reasonable accommodation are almost never filed.	Some public awareness raising on accessibility is carried out by non-State actors (NGOs, service providers etc) but no awareness raising or training is provided on reasonable accommodation by the State.	No awareness raising or training is provided on reasonable accommodation either by the State or non-State actors.
Training and awareness raising	The State is sponsoring training and awareness raising on the rights of persons with disabilities under Article 28. These campaigns promote positive messages on the right of persons with disabilities to access an adequate standard of living and provide information to persons with disabilities and their families on their rights.	The State is beginning to sponsor awareness raising on the rights of persons with disabilities under Article 28. Some training programmes on Article 28 are being rolled out but only sporadically.	Training of staff within social programmes, basic services and social protection exist. Employment training programmes exist with some references to the rights of persons with disabilities.	No training or awareness raising by the State exists on CRPD Article 28.

Measures in place to ensure access to an adequate standard of living and to social protection				
	Championing	Established	Initiating	Weak to restrictive
Inclusive social protection eligibility programmes	A fully accessible eligibility system is in place to determine who qualifies for social protection benefits that does not discriminate on the grounds of disability. The system determines disability-related extra costs and the support services tailored to the individual, with particular attention to women, children, older persons and migrants with disabilities.	An eligibility system is in place to determine who qualifies for social protection benefits that does not discriminate on the grounds of disability. However, it does not determine disability-related extra costs or the support services individuals may need.	Social protection eligibility programmes do not have disability inclusive assessments in place nor do they determine disability-related extra costs.	No social protection eligibility programmes exist to specifically promote inclusion of persons with disabilities.
Social protection system	There are social protection floors in place providing basic social security guarantees for all, including persons with disabilities, across the life cycle. The social protection floor programmes explicitly protect from discrimination on the grounds of disability, including through the provision of reasonable accommodation, and provide for disability-related extra costs.	There are social protection floors in place providing basic social security guarantees for all, including persons with disabilities, across the life cycle. The social protection floor programmes explicitly protect from discrimination on the grounds of disability, including through the provision of reasonable accommodation. In practice, the social protection floor programmes are not meeting the individual needs of persons with disabilities.	There is a social protection system in place that provides a basic level of income security and access to basic services aimed at reducing poverty for persons with disabilities. This programme is based on economic support for persons who are unemployed and does not cover disability-related extra costs. Persons with disabilities will lose their benefits once they become employed or reach a higher income threshold.	There are no social protection floor programmes in place and limited social assistance schemes.

Meaningful consultation with persons with disabilities on poverty reduction and social protection			
Championing	Established	Initiating	Weak to restrictive
Persons with disabilities ¹³ are regularly consulted and formally involved in the design, implementation and monitoring of all laws, policies and programmes on poverty reduction, basic services and social protection.	Persons with disabilities are consulted on the development of laws, policies and programmes related to poverty reduction, basic services and social protection on an ad hoc basis.	Persons with disabilities are rarely or sporadically consulted on poverty reduction and social protection policies and programmes.	Persons with disabilities are not consulted by government.

Cross-ministerial coordination			
Championing	Established	Initiating	Weak to restrictive
There is regular and formal coordination between the Ministry of Finance, the Ministry of Economic Development and other relevant line ministries (such as the Ministry of Agriculture, the Ministry of Public Infrastructure and Services, Ministries of Social Affairs, Education, Employment, Health and Planning etc).	There is some coordination between the Ministry of Finance, the Ministry of Economic Development and the ministry responsible for disability issues on access to services and social protection for persons with disabilities.	Poverty reduction and access to social protection for persons with disabilities is limited solely to the mandate of the ministry responsible for disability.	There is no cross-ministerial coordination on issues related to poverty reduction and social protection for persons with disabilities.

Targeting the most marginalised			
Championing	Established	Initiating	Weak to restrictive
Policies and programmes are targeted to support those persons with disabilities who are most excluded (e.g. women with disabilities, persons with intellectual disabilities, Deafblind persons etc).	Some policies and programmes are targeted to support those persons with disabilities who are most excluded (e.g. women with disabilities, persons with intellectual disabilities, Deafblind persons etc).	Policies and programmes on poverty reduction do not explicitly address measures to reach the most marginalised persons within the disability community (e.g. women with disabilities, persons with intellectual disabilities, Deafblind persons etc).	Policies and programmes on poverty reduction do not address most excluded groups and do not explicitly include persons with disabilities.

Data collection and disaggregation			
Championing	Established	Initiating	Weak to restrictive
All national data on poverty, access to basic services and social protection is collected and disaggregated by disability. Data is also collected to understand the barriers persons with disabilities face in accessing an adequate standard of living.	All national data on poverty, access to basic services and social protection is disaggregated by disability. Data and information is only seldomly collected to understand the barriers persons with disabilities face in accessing basic services and social protection in some research initiatives.	Some data and information collected by the National Statistics Office is disaggregated by disability.	Data collected on poverty, access to basic services and social protection is not disaggregated by disability.

3

Using the assessment tool in your advocacy



Now that you have carried out your assessment, let's examine the findings and what they mean. We will begin by looking at what laws should address to fully comply with Article 28. In other words, what should laws and policies look like to ensure the SDGs are in line with CRPD Article 28?

3.1 The legal and policy framework

Poverty reduction and access to basic services: Legal and policy changes

The right to an adequate standard of living means that all persons have access to basic services such as water and sanitation, housing, food and nutrition services and can benefit from poverty reduction efforts and social protection. Each country tackles these issues through different legal and policy frameworks. But most often, they are addressed in laws and policies on poverty reduction, economic development, rural development, agriculture, social protection or health.

To set an inclusive legal framework, laws regulating poverty reduction, economic development and access to basic services must explicitly ensure that persons with disabilities, particularly women, children and older persons,¹⁴ have access to mainstream and disability-specific programmes and services, on an equal basis with others with the following provisions:

- Protection from discrimination, by both public and private actors and service providers, on the grounds of disability in addition to gender and age, including through the provision of reasonable accommodation.¹⁵
- Explicit provisions to ensure that persons with disabilities, particularly women, children and older persons with disabilities and in particular, those living in rural areas,¹⁶ have access to mainstream and disability-specific basic services and poverty reduction programmes,¹⁷ on an equal basis with others.
- Requirement for all basic services including food assistance and nutrition programmes, affordable housing programmes, and water and sanitation services¹⁸ to be fully accessible¹⁹ without discrimination²⁰ including programme information and communication and application procedures.
- Prohibition of denial of the right to food, water and sanitation on the grounds of housing or land status²¹ (see Annex II for good practice on the right to land ownership).

Policy changes towards inclusive basic services and adequate standard of living

Policies, national plans and strategies regulating basic services and poverty reduction, for both public and private services and programmes, must explicitly address the needs and rights of persons with disabilities in line with CRPD Article 28. See Annex II for good practice examples on inclusive poverty plans. To do this, States policies must put in place:

- Adoption of national standards and regulations on basic services including housing, water and sanitation as well as food and nutrition services that mandate the use of accessibility standards.
- Requirement for all programmes and services to be fully accessible including for: water and sanitation services and sites, all food distribution sites, food assistance and nutrition services and programmes as well as affordable housing programmes.²²
- Provision of assistive devices to enable persons with disabilities to use basic services such as water and sanitation sites and services (such as toilet chairs), food aid and nutrition programmes etc.
- Elimination of discriminatory policies or practices – such as separate, segregated services, services and programmes in inaccessible locations or creation of barriers in the development of new services and programmes.²³
- A gender equality lens to ensure women and girls with disabilities have safe and accessible access to basic services.²⁴
- Participatory decision-making mechanisms inclusive of persons with disabilities, and in particular, women with disabilities and other marginalised persons with disabilities, in decision-making mechanisms on the management of basic services such as food distribution and water and sanitation, on an equal basis with others.
- Targeting the most marginalised in policies and programmes to support persons with disabilities most excluded from accessing basic services. They should also address the multiple and intersectional forms of discrimination women and girls with disabilities face²⁵ as well as other under-represented groups of persons with disabilities.²⁶
- Cross-ministerial coordination so that the different government agencies and actors involved in basic services and poverty reduction collaborate across sectors on inclusion of persons with disabilities (including private and public sectors as well as NGOs).

Legal reforms

Each country has vastly different systems in place regulating social protection, income security or social assistance. This guideline uses the definition promoted by the Special Rapporteur on the Rights of Persons with Disabilities:

“Social protection is understood broadly to cover a variety of interventions designed to guarantee basic income security and access to essential social services, with the ultimate goal of achieving social inclusion and social citizenship.”²⁷

In order to achieve this for all, laws regulating social protection must ensure the mainstream social protection system is inclusive of and explicitly refers to persons with disabilities and safeguards their equal access to all social protection programmes²⁸ (including social assistance and social insurance) without discrimination on the basis of disability. The legal framework can support this by incorporating explicit provisions for:

- Protection from discrimination on the ground of disability, including through the provision of reasonable accommodation.
- Requirement for fully accessible programmes, information, and application procedures for all social protection programmes.
- Recognition of disability-related extra costs both in the establishment of the level of the benefit as well as in the establishment of income thresholds.
- Benefits paid directly to persons with disabilities in a fully accessible manner.²⁹
- Compatibility between reception of benefits and employment in order to ensure reception of benefits does not exclude persons from employment.³⁰

Unpacking the key elements of disability inclusive social protection in the legal framework

Social protection systems that promote economic inclusion and move away from a welfare approach can play a crucial role in poverty alleviation. They do this by enhancing the economic development of persons with disabilities, thus contributing to their income security and their ability to maintain an adequate standard of living.³¹

In order to do this effectively, states need to address the following elements in social protection policies and programmes:

Inclusion within the mainstream social protection system: Disability must be part of the mainstream system along with specific programmes and benefits for disability-related needs and costs.

Disability-related extra costs: States should provide social protection programmes that cover disability-related expenditures. These benefits and services should be separate from social protection support for income generation.³²

Life-cycle approach: States should prioritise social protection policies that ensure the well-being of children and adolescents with disabilities and their families.³³

Move away from a welfare approach to social inclusion: States should implement policy interventions aimed at economic productivity, employability, income security and ultimately, inclusion in the workforce.

Flexibility: Social protection policies and programmes should be flexible and respond to individual needs. They should also be flexible in their interventions combining income security and disability-related support.

Based on individual needs: Social protection programmes and services should be relevant and adapted to the needs of persons with disabilities in their local context. They should address the barriers and discrimination they face in obtaining an adequate standard of living and provide the benefits and support to enable persons with disabilities to enjoy a life free of poverty.

Setting disability inclusive floors within social protection

In order to have universal social protection coverage, States need to implement nationally defined social protection floors that provide basic social security guarantees for all, including persons with disabilities, across the life cycle.³⁴ National social protection floor programmes and systems³⁵ must include the following key elements:

- Recognition of disability-related extra costs both in the establishment of the level of the benefit as well as in the establishment of income thresholds (the income level that establishes whether or not a family or individual qualify for social protection benefits).
- Responsiveness to specific needs of individuals.
- Protection from discrimination on the ground of disability, including through the provision of reasonable accommodation.
- Full accessibility to the different programmes, information and application processes.
- Benefits must be provided directly to persons with disabilities (in the case of adults with disabilities).
- Provision for government-financed contributions for persons with disabilities (and others) who are unable to contribute or who have limited contributory capacity.³⁶
- Continuity of benefits and services when moving from a contributory scheme to a non-contributory one.
- Conditional Cash Transfer programmes, or similar programmes which condition the receipt of assistance, must include the provision of accommodations and support for persons with disabilities to meet those conditions (e.g. school attendance or health clinic visits).

Disability inclusive mechanisms for determining eligibility to social protection services and benefits

Within the assessment system used to determine social protection benefits, governments should have a mechanism in place that takes into account the situation of persons with disabilities. This mechanism must:

- Be fully accessible in terms of services, information and assessment processes.
- Prohibit discrimination on the ground of disability including through the provision of reasonable accommodation.
- Promote socio-economic inclusion in mainstream programmes and services rather than through segregated or separate services.
- Establish the disability-related extra costs and the required support services.
- Be based on an assessment of an individual's support needs.

See Annex I for more information on the challenges of disability inclusive eligibility systems.

Linking the SDGs and the CRPD in your advocacy

By implementing the changes in laws and policies aimed at complying with CRPD Article 28,³⁷ the reforms also support the achievement of SDG targets for Goals 1 (No Poverty), Goal 2 (Zero Hunger) and Goal 6 (Clean Water and Sanitation), including:

SDG Target 1.B: Create sound policy frameworks at the national, regional and international levels, based on pro-poor and gender-sensitive development strategies, to support accelerated investment in poverty eradication actions.

SDG Target 1.3: Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable.

SDG Target 2.1: By 2030, end hunger and ensure access by all people, in particular the poor and people in vulnerable situations, including infants, to safe, nutritious and sufficient food all year round.

SDG Target 6.1: By 2030, achieve universal and equitable access to safe and affordable drinking water for all.

SDG Target 6.2: By 2030, achieve access to adequate and equitable sanitation and hygiene for all and end open defecation, paying special attention to the needs of women and girls and those in vulnerable situations.

3.2 Implementing the SDGs in line with Article 28 in practice

In addition to making the changes in laws and policies outlined above, States must put in place policy interventions and measures to implement changes in practice including:

1. **Adopt accessibility standards and implementation regulations in line with CRPD Article 9 (Accessibility) and the principles of universal design:** Guided by Article 9 of the CRPD, States must adopt national accessibility standards applicable to basic services including affordable housing, water and sanitation, health and food and nutrition programmes. Using Article 9 and universal design principles in accessibility standards is important for ensuring programmes and services are fully accessible to persons with disabilities and relevant to the local context.³⁸ These standards must have implementation regulations that guide practitioners on how to implement them in practice, and budgets for implementation. These standards can be incorporated into national acts on building and infrastructure (See Annex II for an example of good practice).
2. **Include effective implementation plans and budgets:** In order for policies to make effective change in the lives of persons with disabilities, they need

clear implementation plans to show how to put the measures in place. There needs to be a government focal point or government body that will be responsible for them and how they will be financed. Implementation plans must also have adequate budgets to provide the means for implementing changes on the ground. Implementation plans should also set out a monitoring and evaluation process to ensure the measures being implemented are effective and relevant. Monitoring and evaluation processes also help to hold governments accountable.

3. **Address inequality within policies:** Marginalised and under-represented persons with disabilities who face multiple and intersecting forms of discrimination must be addressed by the policy measures to ensure they are included and provided the support they need to participate on an equal basis. For example, a Deafblind woman living in a rural community will have more barriers to overcome to access services than a man with a physical disability living in an urban area. So how can policies address these inequalities? The goal is for policies to create programmes and initiatives that tackle inequality and facilitate access to an adequate standard of living and social protection on an equal basis with others, while addressing intersectional forms of oppression. This can be done by taking an intersectional approach to equality and addressing the following cross-cutting issues in all policies on basic services, social protection and poverty reduction:

- **Systematic participation of and consultation with OPDs:**³⁹ A key part of building inclusive services and shifting attitudes towards participation is the active consultation with and leadership of persons with disabilities in the design, implementation and monitoring of poverty reduction and social protection measures. Consultation also helps ensure needs and issues of the diverse disability community are incorporated into policies. Consultation can take many forms, but in order for it to be truly effective, OPDs should be formally taking part in decisions. Consultation should be grounded upon co-decision-making with government authorities so that persons with disabilities have a real say in what laws and policies include.
- **Targeting the most marginalised:** Policies and programmes should be targeted to support persons with disabilities most excluded from accessing an adequate standard of living such as women with disabilities, youth with disabilities, and those living in rural areas. These measures could include positive actions or targeted measures to promote and facilitate access to services and programmes.
- **Promoting gender equality:** Although there is a lack of comparable data, available evidence shows that women with disabilities around the globe are less likely to have access to education, be employed or gain access to economic empowerment programmes than men with disabilities.⁴⁰ This means that they are more likely to live near or below the poverty line. States can take a disability and gender inclusive approach to poverty reduction, economic empowerment and social protection initiatives. For example, ensuring gender equity and disability inclusive basic services in schools that address both accessibility and gender-related needs can play an important role in ensuring girls with disabilities stay in school.⁴¹

- **Ensuring cross-ministerial coordination:** All measures regarding access to an adequate standard of living should be coordinated across line ministries including the ministries responsible for social protection issues, disability issues, education, gender, health and basic services and poverty reduction planning, to ensure coordination across all sectors.
4. **Ensuring accessible and inclusive basic services in humanitarian contexts** so that persons with disabilities can safely access basic services such as food, water and shelter during times of crisis.⁴²
 5. **Training and education on CRPD Article 28:** Training on accessibility, inclusion and the diverse needs of persons with disabilities in accessing basic services and social protection should be provided to government branches and ministries responsible for public programmes, basic services and social protection (both national and local), national planning authorities, local government responsible for administering basic services, service providers (from all basic services sectors) from both the private and public sectors, NGOs working on poverty reduction, rural development, health and basic services, community leaders, traditional leaders, community members and persons with disabilities and their families. Trainings should:
 - Be mandatory and built into core poverty reduction, basic services and social protection training programmes.
 - Involve persons with disabilities in the design, implementation and evaluation.

3.3 Advocating for changes in laws and policies

Carrying out legal and policy reform requires a great deal of varied expertise. No one organisation can do this alone. It is a complex process that requires legal expertise, access to decision-makers and government stakeholders with influence, data and evidence to support changes and broad public support for the reforms. Changing laws and policies also takes an understanding of how policy, institutions and social values interact to perpetuate problems, and potentially, solve them.⁴³ This means that advocacy strategies are multi-dimensional and require many different forms to address the issues of exclusion and inequality that persons with disabilities face.

Put another way, advocacy experts agree that advocacy strategies should attempt to solve a problem, step-by-step, by getting at its systemic causes. Building an advocacy strategy should begin by asking key questions like: Why are persons with disabilities historically discriminated against in accessing basic services? What are the specific issues? What are the broader socio-economic roots of exclusion and inequality persons with disabilities face? When you begin to answer these questions, you can then think through what different advocacy actions are needed to tackle each issue.

3.4 Building an advocacy strategy

Let's begin by building your advocacy strategy to address law and policy changes to ensure SDGs 1, 2 and 6 are implemented in line with CRPD Article 28. Complete the exercise below to help with the development of your advocacy strategy.

Step 1: What do you want to change?

This is your advocacy goal. It is good for it to be specific and measurable. For example: The national laws on basic services and social protection are amended to fully align with CRPD Article 28, including provisions for prohibition of discrimination on the basis of disability.

Step 2: Who do you want to target?

These are the actors you want to influence to create the change you are advocating for. For example: Ministry of Finance, Ministry of Economic Development, policy makers, Ministry of Social Welfare, Ministry of Health, National Human Rights Institutes, law makers, media outlets etc.

Step 3: How do you want your targets to change?

These are the changes you want to see your targets making in practice. For example: Government officials within Ministry of Finance, Ministry of Economic Development, Ministry of Social Welfare and Ministry of Health are consulting with OPDs on the implementation of an inclusive social protection policy; the Ministry of Finance is having regular dialogue with persons with disabilities and their allies on the legal changes needed to align with CRPD Article 28; the National Human Rights Institute is advocating for legal reforms in line with CRPD Article 28 and reporting cases of human rights violations persons with disabilities face; policy makers are being trained on the rights of persons with disabilities enshrined in the CRPD; the government SDG focal point is working with OPDs to address CRPD Article 28 in national development plans.

Step 4: Do you have the influence to make these changes?

If not, who else can you work with to provide this influence? For example: National coalition of NGOs on SDGs, human rights lawyers, legal aid organisations, policy research institutes, NGOs and other OPDs active in SDG advocacy and social protection reform.

Step 5: What are the different advocacy actions that can produce these changes?

Each context is unique and requires crafting advocacy actions and messages that are culturally, socially and politically relevant. In section 3.5 you will find a menu of different types of advocacy actions, from coalition building to direct lobbying. This is meant to provide a broad sampling of different types of advocacy.

3.5 Different types of advocacy actions

Finding allies and forming coalitions to build expertise and broaden the constituencies involved in pushing for reforms:

- Other OPDs within the movement (Remember: think about organisations and constituencies who aren't represented by the movement or who may be more marginalised from dialogues on policy and law reform and reach out to them).
- Civil society actors engaged in poverty reduction and social protection reform, youth rights, economic empowerment, women's rights and other civil society actors who are impacted by poverty and social protection issues.
- Legal experts (lawyers, legal aid providers, paralegals etc.) to provide legal expertise in carrying out legal reviews. While hiring legal experts can be costly, looking for legal experts who can provide this guidance pro bono is a good strategy.
- National Human Rights Institutes.
- Ombudsman on human rights.
- Journalists covering human rights issues.
- Academic researchers working on social protection and basic services – rights and policy.

Law and policy reform advocacy:

- Review the current laws on basic services, poverty reduction and social protection to see what the laws include on anti-discrimination and equal opportunities and whether or not they include persons with disabilities.
- Draft legal recommendations that outline the changes needed to social protection laws and laws regulating basic services and poverty reduction.
- Draft policy recommendations that spell out the measures needed to facilitate access to an adequate standard of living and social protection.
- Hold workshops to encourage dialogue between OPDs, other NGOs and policy makers involved in poverty reduction, basic services and social protection.
- Carry out direct lobbying of legislators, policy makers and other public officials to demand changes in the laws that comply with Article 28 (the changes outlined above).
- Participate in SDG platforms to advocate for alignment with Article 28 in policies, targets and strategies addressing SDGs 1, 2 and 6.

Research and media-based advocacy:

- Participate in SDG platforms to promote inclusive implementation of SDGs 1, 2 and 6 outlining how to incorporate Article 28 in laws and policies.
- Commission and publish research on access to social protection, poverty reduction programmes and basic services by persons with disabilities.
- Conduct a media campaign on the rights of persons with disabilities to access an adequate standard of living as part of implementing the SDGs to garner public support for legal and policy reform.
- Produce a social media campaign to address the barriers and discrimination persons with disabilities face in accessing basic services and social protection.
- Document evidence of good practice and changes in lives of persons with disabilities in relation to accessing basic services, social protection and poverty reduction initiatives (showcasing how changes happen in line with Article 28).
- Document cases of human rights violations in relation to Article 28, and use this evidence to demand change.

See Annexes II and III for examples and resources.



HELPFUL TIP: As you build an advocacy strategy think about what advocacy campaigns have been most successful in your country. What tactics have worked effectively? Meet with other NGOs that have carried out successful legal and policy reforms and ask them what worked and why.

3.6 Measures needed to implement SDGs 1, 2 and 6 in practice

In addition to law and policy reform, policy measures (which set in place programmes and services) are needed to promote inclusive social protection and access to services for persons with disabilities in practice. Based on your assessment, you have identified what measures exist and what needs to be in place to fully implement SDGs 1, 2 and 6 in line with Article 28. Let's look at what the different measures are that are needed to implement SDGs 1, 2 and 6 in line with the CRPD.

Through policies and programmes, States should ensure actions are taken to promote and encourage inclusive social protection and access to services for persons with disabilities such as:

- **Accessible and inclusive basic services and poverty reduction programmes** available to all persons with disabilities, regardless of their disability. These programmes include housing, water and sanitation and food and nutrition. There are inclusive mainstream programmes in place as well as disability-targeted programmes.
- **Mainstream and disability specific social protection programmes** are available to all persons with disabilities and are tailored to support the individual needs of persons while providing for the extra costs of disability. Programmes are based on socio-economic inclusion and universal coverage.
- **Inclusive social protection eligibility programmes.** Eligibility and assessment frameworks for determining who qualifies for social protection benefits do not discriminate on the ground of disability, account for disability-related extra costs and the support services tailored to the individual, with particular attention to women, children, older persons and migrants with disabilities.
- **Inclusive social protection floors.** Social protection floors provide basic social security guarantees for all, including persons with disabilities, across the life cycle. The social protection floor programmes explicitly protect from discrimination on the ground of disability, including through the provision of reasonable accommodation, and provide for disability-related extra costs.

3.7 Advocating for change

Advocating for these measures and programmes begins with knowing what measures are already in place. If these measures are not explicitly included in the policy framework in your country, the starting point for your advocacy is demanding policies be revised to include them. Reviewing policies was discussed in the previous section on law and policy advocacy.

The other important aspect of advocating for these changes is to know what measures are in place and how they are implemented in practice. For example, if you have a social protection system in place that is inclusive of persons with disabilities, is it being implemented? Does it work in practice or

is it being misused? Do basic services policies mandate accessible services and programmes? Does this happen in practice?

Your advocacy will begin by researching what policies say and looking at how measures are implemented in practice. Let's take a closer look at how to evaluate measures in practice.

Step 1: Identify your goal

Do you want to make a policy review and provide recommendations for policy change? Do you want to evaluate existing measures for their effectiveness? Do you have capacity and scope to do both? The section below outlines steps for carrying out an assessment of the effectiveness of inclusive social protection and basic services measures.

Step 2: Evaluate the effectiveness of existing measures

First, identify which measures you want to evaluate. Do you want to look at basic services programmes? Do you want to see how disability targeted poverty reduction initiatives work in practice? Do you want to address how social protection programmes are reaching persons with disabilities?

List the **measures** you want to assess below.



REMEMBER: You are looking at government measures addressing adequate standard of living of persons with disabilities. There are many NGO initiatives that exist as well. However, for this exercise, you want to focus on what the government is doing since you are advocating to change government measures.

Step 3: Decide who you want to target

These are the actors you want to influence to create the change you are advocating for. Targets could include: policy makers involved in poverty reduction issues, social protection officials, service providers for basic services, water and sanitation service providers, public health officials involved in water and sanitation, food and nutrition service providers, local government responsible for rural development and agriculture.


List the **targets** you want to influence below.

Step 4: Collecting evidence and information

Gathering information and evidence of how measures are implemented in practice is critical for showing policy makers evidence of what is happening in practice and what needs to be changed. There are many ways to gather evidence and information for assessing how measures are working in practice. First, it's a good idea to check if the data you need already exists, for example by checking for reports by other organisations or government departments. One method is to carry out field research by visiting initiatives or services and making observations, and meeting with people who provide the services and the beneficiaries of these services. It can include carrying out interviews or focus group discussions with persons with disabilities, as well as those who provide the services and programmes, to get their perspectives. It could also involve making site visits and documenting your observations and recommendations in a case study (see Annex III for resources on carrying out a case study). Another method is to interview people and write stories about their experiences. For example, you could meet with women with disabilities who took part in inclusive poverty reduction initiatives and discuss how the programme worked, how it impacted their life, and what needs to be changed to make the programme more effective.

Make a plan for which programmes/services you want to investigate and how you will collect information. Be specific about the methodology you will use. Will you carry out interviews and focus groups? Will you develop case studies? Will you collect stories from persons with disabilities about their experiences? Will you document cases of exclusion from services and programmes?

While your findings may not paint an ideal picture, it is important to capture what is working, what isn't working and what needs to be done to fully implement SDGs 1, 2 and 6 in line with Article 28. This information can help policy makers better address what measures are needed and how they can be better implemented to ensure no one is left behind.

 **REMEMBER:** You can use your findings on how measures are implemented in your advocacy on legal and policy reform. For example, if you are advocating for changes in basic services policies, you can include your findings on what measures are missing, which measures are being implemented but need to be improved and recommendations for how to have more effective measures in place.

3.8 What change looks like

Now that you have looked at legal and policy reforms and the needed policy measures to implement SDGs 1, 2 and 6 in line with CRPD 28, let's take a look at what changes in practice will look like once the rights enshrined in Article 28 are fully realised. Put another way, if CRPD Article 28 was fully implemented, what would society look like? Articulating what you want the world to look like is critical for strong advocacy. It helps to build messages to government, decision makers and the wider public around the changes you want in the lives of persons with disabilities. It helps construct a vision of an inclusive society.

Below is a variety of the changes in practice you should see if SDGs 1, 2 and 6 are implemented in line with Article 28:

1. A majority of persons with disabilities are benefitting from social protection in which disability-related costs are determined and covered.
2. The majority of persons with disabilities are using and have continuous access to safe and clean water and sanitation.
3. The majority of persons with disabilities are living in households with access to basic services.
4. The majority of persons with disabilities have access to sufficient and nutritious food year-round.
5. Few persons with disabilities are homeless.
6. Fully accessible government public awareness campaigns are carried out to promote inclusion and inform the public and individuals of their rights and responsibilities as they relate to Article 28.
7. Complaints on the right to an adequate standard of living alleging discrimination on the basis of disability and/or involving persons with disabilities are investigated and adjudicated and the majority of these are responded to effectively by the government.

8. Fewer persons with disabilities are living in urban slums, informal settlements or inadequate housing.
9. The majority of men, women and children with disabilities are not living in poverty in all its dimensions according to national definitions.
10. There are few children with disabilities who are malnourished.
11. Few persons with disabilities, including women and children with disabilities, experience undernourishment.
12. Few persons with disabilities experience severe food insecurity.

What if these changes aren't happening yet? You can use these as messages within your advocacy for what you want to see, the changes you want to happen in the lives of persons with disabilities. It helps give the public, government authorities and service providers a clearer picture of what changes need to happen and what it can mean in the lives of persons with disabilities. One way to do this is to document individual stories about the lives of persons with disabilities in their fight to access basic services, end poverty and be included in social protection. You can tell the story of how they have been excluded or discriminated, how they have overcome these barriers, how they persist in the fight for their rights. This can be done in different media forms such as film, audio recordings or written text (see Annex III for examples and resources on storytelling for social change).

Telling personal stories can be a great way of advocating for change. When someone tells their own personal story, we are more likely to see the world as they see, and this experience can inspire empathy within them. With this empathy, people are more likely to build solidarity and be supportive of the rights reforms they are putting forth.

4

Data and information for advocacy



Advocating for changes in data collection and disaggregation helps to fulfil SDG target 17.18:



By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts.

In doing so, States are complying with their basic obligations under CRPD Article 31 (Data and statistics).

4.1 The importance of data

Data and information are essential to effective advocacy. Awareness campaigns and slogans can generate public attention for an issue. But when confronting governments to push for changes in laws and policies, having data on the numbers of persons with disabilities excluded from the labour force is one of the most effective ways of convincing decision-makers to make change. Data is also essential for shaping effective policies. When you have data showing the kinds of barriers different persons with disabilities face, policy interventions and programmes can be shaped to meet their needs and rights more effectively.

Data is also essential for monitoring and accountability. If the government has laws and policies in place to promote the rights of persons with disabilities, how do we know they are translated into real changes in the lives of persons with disabilities? Monitoring and gathering data can show how effectively programmes, policies and laws are being implemented and make the government accountable for any gaps or non-compliance.

Human rights advocacy can take many shapes and forms. However, when advocating for implementation of human rights treaties (such as the CRPD) or global development frameworks (like the SDGs) civil society needs evidence and data to show governments what isn't being done, what needs to be changed and how to make these changes. For example, when looking at the implementation of SDGs 1, 2 and 6 in line with CRPD Article 28, you need evidence of which policies and laws do not comply with the CRPD. By showing the government which laws and policies do not comply and why they do not comply, you will have a strong message to present to government stakeholders. Similarly, gathering evidence of how poverty reduction programmes and basic services are implemented in practice is another valuable advocacy tool. Is affordable housing accessible? Are water and sanitation services accessible? Do poverty reduction programmes address disability-related extra costs such as accessible transportation or purchasing assistive devices? Do food and nutrition programmes provide information in accessible formats? Presenting this evidence to decision-makers involved

in social protection issues can help to shape policy reform to institute programmes and measures that better align with the CRPD.

Data is another essential tool to advocate for change. National level data on poverty and social issues that is disaggregated by disability is missing in many countries and regions throughout the world. Yet data on the numbers of persons with disabilities is essential for pushing governments to make widespread change. For example, having data that shows the numbers of persons with disabilities living under the poverty line can help to convince governments to institute policy changes to align with CRPD Article 28.

The assessment tool will help to gather evidence and to look for sources of data to support your advocacy.

4.2 The different types of data

Let's go over the different kinds of data and what it is most useful for advocacy.

- **Quantitative data:** This is data that measures quantities such as the number of people living in a certain region of the country or the number of women employed in a certain sector. Quantitative data is generally collected in statistical surveys and censuses. Quantitative data disaggregated by disability can give law makers and policy makers an overall idea about the population of persons with disabilities (e.g. how many persons with disabilities live in a country or region, how many working age persons with disabilities are employed, how many persons with disabilities completed primary education, how many persons with disabilities are living on or below the poverty line).
- **Qualitative data:** This is non-numerical data that looks at qualities and characteristics such as a study on how persons with disabilities are accessing employment services. Qualitative data is collected through methods of observation, interviews and focus groups. Qualitative data can give a deeper picture of the experiences of persons with disabilities, including the barriers they face, the facilitators that support greater inclusion and the solutions most relevant to them for building a more inclusive community. This kind of data is helpful for policy makers to determine the most relevant measures and programmes to support the needs of persons with disabilities.

4.3 How to advocate for data on disability

Under CRPD Article 31 (Statistics and data collection), States have an obligation to disaggregate data by sex, disability and age. As outlined in SDG 8, States and National Statistics Offices (NSOs) can play an important role in collecting and analysing data disaggregated by impairment type, age and sex in relation to work and employment.⁴⁴ This means that OPDs can play a critical role in demanding that government statistical offices collect and disaggregate data on disability. Meeting with NSOs and having a dialogue about the inclusion of disability questions within ongoing surveys and data collection is a good first step in advocating for change.

Most NSOs have one or several staff who specialise in disability data collection. Identify who these people are and meet with them to see if they are already using the Washington Group questions on disability (information below). If they are collecting data on disability, ensure they are analysing and sharing this information. While it is important to collect data, it is only useful when it is analysed and made available. Meeting with strategic partners and donors working on data and information issues is also important. Actors like the World Bank who are funding data collection and other statistics initiatives can push governments to disaggregate data by disability.

Example from Uganda: Using WG questions in the national census

A coalition of OPDs, including the National Union of Disabled People of Uganda, the National Association of the Deafblind of Uganda, Mental Health Uganda as well as the National Disability Council, worked with the Ministry of Gender, Labour and Social Development to advocate for the inclusion of the Washington Group (WG) questions for the first time in a national census in the country. In 2014, the National Bureau of Statistics included 6 of the WG questions in the national census. The disability prevalence rate went from 3.5% from the 2002 census to 13% in 2014 with the introduction of the WG questions.

More information about the 2014 census can be found here:

unstats.un.org/unsd/demographic-social/meetings/2016/kampala--disability-measurement-and-statistics/Session%206/Uganda.pdf

4.4 What data to ask for

In relation to SDGs 1, 2 and 6 and Article 28, government statistics bureaux should be collecting data on persons with disabilities living below the poverty line disaggregated by sex, age and type of impairment. It is critical to have data on persons with disabilities accessing basic services (such as adequate housing, food and nutrition and water and sanitation) disaggregated by sex, age and type of impairment. It is also critical to collect and disaggregate data on access to social protection. It is important to collect information that assesses the barriers and stigma persons with disabilities face in trying to access basic services, poverty reduction programmes or social protection, to complement the quantitative data. The different kinds of information can be collected in standard of living surveys, poverty reduction and economic growth surveys or household surveys. Introduce National Statistics Offices and other national research institutes to existing data and disability tools. They don't have to re-invent the wheel, strong tools already exist!

4.5 Existing data and disability tools

The Washington Group (WG) on Disability and Data has developed a short set of six questions on disability (WG-SS) that can be easily used and integrated into national data collection systems and used in national censuses for disaggregation by disability.⁴⁵ The WG also developed an extended set of questions and other materials to be utilised in other simpler statistical operations. In addition, the WG and the International Labour Organization (ILO) have finalised a qualitative data module, based on the WG-SS, that assesses the reasons that persons with disabilities have lower labour market participation. The WG and UNICEF have also collaborated to develop the Child Functioning Module (CFM). This adapts the WG questions so the two methodologies are compatible.

While the NSO in your country may already be including disability in some surveys or statistics, there are many good reasons to advocate that they use the WG-SS going forward. Firstly, in order to have global comparative data on disability, countries need to use the same methodology. Therefore, pushing for consistent use of the WG is essential. Secondly, available disability prevalence data and statistics are often inaccurate, with lower rates than what is expected (especially given the WHO estimate of 15% prevalence globally).

A big part of the issue is how statistics agencies ask their questions on disability. They will often ask the question: 'do you or a member of your household have a disability?' This doesn't work effectively for several reasons. Stigma and shame around disability make identification difficult, and some people do not self-identify as disabled. In addition, the WG-SS accounts for diverse types and levels of impairment. It also follows the social model of disability, accounting for environmental barriers. It is the best tool available to collect comparable data. It uses universal questions with neutral language that have been tested in 15 countries. It has been endorsed by the UN for use in national censuses to disaggregate data by disability status for monitoring the SDGs. The WG-SS can also be added to existing surveys, such as labour or health, as a way of mainstreaming disability into data collection processes.

While the WG-SS can be part of broader sets of questions used to identify persons with disabilities, they cannot be used as a diagnostic tool to identify beneficiaries for certain programmes or services. The WG questions are designed to identify as many people with a disability as possible to get a prevalence rate. The questions are not detailed enough for use in medically diagnosing an individual. The WG is working to address this, but with the current question sets this population group is not easily identified. While it is important that the WG-SS is not used as a diagnostic tool, the Enhanced and Extended Sets do have questions related to psycho-social disability. The Enhanced Set has the original 6 questions with 4 additional questions. The Extended Set has 38 questions including the 6 original questions.

4.6 Data principles

To improve the quality of data collection and disaggregation processes, the Human Rights-Based Approach to Data was developed within the framework of Agenda 2030. This approach sets out principles for data collection such as privacy, participation, transparency and accountability.⁴⁶ It is important to remember that data disaggregation by disability is included in Goal 17: Strengthen the means and implementation and revitalize the global partnership for sustainable development.⁴⁷

4.7 What data and information exist to support advocacy

As you push for more data to be collected on disability, it is important to examine what data already exists that can support your advocacy. The Ministry of Economic Development or Finance may have some statistics on persons with disabilities benefitting from social protection or on the numbers of persons with disabilities living below the poverty line. This may not be on a national scale, but it can still give you a sense of how many persons with disabilities are currently accessing benefits. Research institutes and academic institutions such as universities and colleges may have carried out research on poverty and disability or on disability inclusion and basic services. Other NGOs or development donors may have drafted reports on poverty reduction and social protection that have some statistics of qualitative information on persons with disabilities. Tap into the disability movement itself for data and information. Many OPDs have carried out baseline studies or have a database on persons with disabilities that could give you some data on how many persons with disabilities are accessing basic services and social protection. OPDs may have carried out case studies, interviews or other qualitative studies that can give you information on issues persons with disabilities face in accessing an adequate standard of living. Finally, alternative reports to the CRPD Committee can be a wealth of information on Article 28.

4.8 Using data and information for change

As outlined above, quantitative data is numerical in nature and looks at the numbers of things (such as the number of working age women with disabilities who are enrolled in social protection programmes). Information can take many forms such as case studies, legal reviews, policy gap analyses, research reports or baseline studies. Data is generally used to push for large-scale changes such as law or policy reform. It provides insight into how many persons with disabilities are being excluded and the areas of poverty reduction and social protection where persons with disabilities are facing barriers. This statistical information can push a government to make large-scale reforms. Information on barriers that persons with disabilities face is helpful for pushing policy makers to generate more effective and relevant policy interventions. Data on the numbers of persons with disabilities is also essential for advocating for adequate budgets for implementation.

4.9 Sources of data and information

We have discussed many of the ways your organisation may already be generating critical information through stories of change, documentation of human rights violations, baseline surveys, case studies, legal reviews or policy gap analyses. This is all information you can use to inform your advocacy. See Annex III for a list of resources on how to generate information.

Accessing information on laws and policies in your country can be done through official gazettes and they are often available online. If laws are not available online, the ministry responsible for poverty reduction, basic services and social protection can provide publications of the official gazette where these various laws are listed. NSOs carry out numerous surveys (household surveys, standard of living surveys etc.) that can generally be accessed through their website or offices. Ministries often have their own databases of information which can be accessed through their offices or on their websites. Academic institutions, research institutes and policy institutes have a wealth of data, information and research. Identifying academic and research institutes that have carried out research on disability issues and/or research on poverty reduction, basic services and social protection and meeting with them to find out what research they have is a great starting point.

5

Conclusion



This tool is intended to support Organisations of Persons with Disabilities (OPDs) and their allies to advocate for the rights of persons with disabilities by engaging with governments, development agencies and other civil society actors on the implementation of the SDGs in line with the CRPD.

Central to this tool is the critical importance of the meaningful participation of OPDs in implementation and monitoring processes so that the SDGs, and their key principle of leaving no one behind, are fully achieved in line with the CRPD. Governments are obligated under both the CRPD and the SDG frameworks to ensure that representatives of civil society, in particular persons with disabilities and their representative organisations, are involved and participate fully in the development of policies and programmes and the monitoring of their implementation. Not only is consultation with persons with disabilities an essential requirement, but upholding the right to meaningful participation can lead to better outcomes and more relevant and inclusive laws and policies for all.

The assessment framework within this tool breaks down the framework, measures and safeguards set out under CRPD Article 28 to ensure persons with disabilities have access to an adequate standard of living and social protection on an equal basis. The tool then highlights how OPDs can work in meaningful partnership with governments, development stakeholders and the private sector to implement SDG 1: No poverty, SDG 2: Zero hunger and SDG 6: Clean water and sanitation – in line with CRPD Article 28.

OPDs can and must play a central role in the decisions that affect their lives, under the slogan of the global disability movement: Nothing About Us Without Us. This guideline provides the tools to strengthen the collective voice of OPDs to hold governments accountable for their commitments and shape the policies, development plans and budgets of future generations to ensure all persons with disabilities, including the most under-represented, have equal access to resources, education and training, and have the accommodations needed to access an adequate standard of living and social protection on an equal basis with others.

Annexes



Annex I: Glossary of key terms

Accessibility standards

As described by the CRPD Committee, national accessibility standards must enable persons with disabilities to move from in an “unrestricted chain of movement.”⁴⁸ For example, persons with disabilities must have access to accessible housing, transportation and needed support services⁴⁹ and access to information and communication to be able to fully participate in economic development. This means that accessibility runs across sectors including infrastructure, health, education, labour as well as social welfare and social services.

Basic services

These include basic minimum services that are needed to survive such as housing, nutrition, water, sanitation, hygiene and health (WASH) and electricity. Equitable access to basic services is a critical part of ensuring people have an adequate standard of living. The right to an adequate standard of living is a human right.

Contributory and non-contributory social protection systems and programmes

Social protection benefits within a social protection system can be contributory (financed by the contributions of workers, their employers, and in some cases the State such as social insurance schemes) or non-contributory (financed by taxes). There is no “one size fits all” approach in designing and operating social protection systems. Each country should decide how to make it happen through targeted and/or universal schemes, contributory or non-contributory approaches.⁵⁰

Conditional cash transfer programmes

These are welfare programmes that condition the receipt of assistance upon beneficiaries’ actions. This means that beneficiaries must meet certain conditions in order to access benefits. The government (or a charity) only transfers the money to persons who meet certain criteria. Conditional cash transfer programmes often do not take disability-related needs into account. These programmes must be revamped to take disability-related needs into account. To be inclusive, States should support persons with disabilities in meeting the conditionalities established by conditional cash transfer programmes.⁵¹

Conditionalities associated with benefits

Conditionalities associated with benefits should not be required where there are barriers that prevent persons with disabilities from fulfilling them. For example, cash transfer schemes that are conditional upon school attendance where schools are not accessible to persons with disabilities, or where the absence of accessible transport prevents access to health clinics. Conditionalities should also not lead to adverse effects or infringe the rights of persons with disabilities under the CRPD, for example a requirement to comply with rehabilitation or treatment (including mental health treatment) against one’s will or living in a segregated setting as a condition to receiving benefits.

Contributory capacity

The capacity for individuals to contribute to the economy (formal or informal). Contributions are used to finance social protection benefits systems.

Cross-ministerial coordination

Cross-ministerial coordination means that line ministries (such as the Ministry of Education, the Ministry of Finance, the Ministry of Economic Development, the Ministry of Health, the Ministry of Labour, the Ministry of Social Affairs etc) are working in coordination to implement Article 28 and that the right of persons with disabilities to access an adequate standard of living runs across all of the line ministries as a cross-cutting issue.

Data disaggregation

Disaggregated data is data that is broken down into component parts or smaller units of data. For example, if data is collected on the number of students completing university, it could be disaggregated to show male and female rates of university graduation, and broken down even further to show rates of graduation for male and female persons with disabilities.

Disability-related extra costs

Persons with disabilities incur a range of common daily expenditures that persons without disabilities do not. This includes extra costs for the person and their family to purchase goods and services, such as health care, accessible transportation, assistive devices, personal assistance, house adaptations, mobility aids, appropriate and adapted devices and assistive technologies. These costs can also include extra time needed for travel or the costs of purchasing goods and services not covered by national social protection schemes.⁵²

Effective remedies

These are remedies or reparations to victims of human rights violations. They encompass an obligation to bring to justice perpetrators of human rights abuses, including discrimination, and also to provide appropriate reparation to victims. Reparations can involve measures including compensation, restitution, rehabilitation, public apologies, guarantees of non-repetition and changes in relevant laws and practices.⁵³

Inclusive social protection eligibility programmes

Eligibility and assessment systems that determine access to and levels of social protection benefits. Using disability inclusive mechanisms for determining eligibility so social protection benefits take into account an individual's support needs and establish an individual's disability-related extra costs and the required support services.

Legislation

Legislation is laws and rules made by a government. It is legally binding, so if legislation is broken, the government should have effective corrective actions to enforce legal rights, impose penalties and provide legal remedies to protect rights.

Means-tested or financial assets tests

These do not account for disability-related extra costs or the socio-economic barriers that aggravate the situation for persons with disabilities. Income thresholds are usually determined through direct means-testing or proxy means-testing. These instruments often overlook the extra cost of disability. Furthermore, individual assessments on personal and environmental factors affecting that cost are hardly ever carried out.

Outcome

The end result or the effect of changes made. Outcomes are often changes in behaviour (such as employment services staff providing reasonable accommodations in trainings) as a result of initiatives and reforms implemented. For example, after changes in policies, laws, systems and services to implement CRPD Article 28, the outcome shows increased access to services by 27%.

Policy

A policy lays out the general principles and course of action a government will take on a specific issue, such as education or economic development. A policy sets the principles to be followed to guide the development of legislation.

Reasonable accommodation

In the context of social protection and access to services, reasonable accommodations are necessary and appropriate modifications and adjustments (that do not impose a disproportionate or undue burden) where needed in a particular case, to ensure that a specific person with disabilities enjoys and exercises the right to access an adequate standard of living on an equal basis with others. Reasonable accommodation is an essential part of non-discrimination. It should have immediate effect and be applicable to all rights, including the right to an adequate standard of living.⁵⁴ CRPD Article 2 (Definitions) states that denial of reasonable accommodation is a form of discrimination. Reasonable accommodation is often confused with accessibility, yet they are not the same. Accessibility duties are unconditional, apply to groups of people and imply progressive implementation, whereas the obligation to provide reasonable accommodation is of immediate effect.⁵⁵

Regulations

Are issued by government to carry out the intent of a law. In essence, regulations lay out how a law is to be implemented.

Sanctions

Are penalties or punishments for violating human rights law. These could include: economic sanctions (money a perpetrator must pay to the victim), imprisonment (time in jail or prison) or providing valuable goods to the victim (such as livestock or land).

Social protection

Social protection is understood broadly to cover a variety of interventions designed to guarantee basic income security and access to essential social services, with the ultimate goal of achieving social inclusion and social citizenship.⁵⁶

Social protection floors

Social protection floors are a human rights-based strategy to promote participation and inclusion of the most economically vulnerable poor populations. Social protection floors are nationally defined sets of basic social security guarantees which secure protection aimed at preventing or alleviating poverty, vulnerability and social exclusion. These guarantees should ensure at a minimum that, over the life cycle, all in need have access to essential health care and basic income security.

Universal design

The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. Universal design should not exclude assistive devices for particular groups of persons with disabilities where this is needed. It is particularly important in public facilities such as health care service settings to ensure all persons with disabilities can access services without the need for separate water sites or separate bathrooms and latrines that have been adapted specifically for use by persons with disabilities.

Universal social protection

Comprehensive social protection that guarantees income security and support services for all persons across the life cycle. The objective of universal social protection is to be responsive to the needs of all citizens, including persons with disabilities. Universal social protection is endorsed by the ILO in their Recommendation 202 recognising the principle of universality of protection based on social solidarity. Universal social protection can be achieved through the use of social protection floors recognising that all persons have specific needs in achieving an adequate standard of living.⁵⁷

Defining key concepts

What do we mean by meaningful consultation with persons with disabilities?

This means actively consulting with a diversity of persons with disabilities and ensuring they are the leaders in the designing, planning, implementing and monitoring access to basic services and social protection reforms. A key part of building inclusive workforces and shifting attitudes towards participation is the active consultation with and leadership of persons with disabilities.

What is an intersectional approach?

An intersectional approach takes into account the historical, social, cultural and political context and recognises how different forms of social, cultural, political and economic discrimination impact people with different identities (such as class, race, gender, disability, ethnicity, religion, age and sexual preference).⁵⁸ It means looking at how the intersections of these different identities impacts a person from being privileged to being highly excluded or oppressed. It requires looking at the needs and issues of the most disadvantaged groups in order to tackle discrimination and equality.⁵⁹

What is intersectional oppression?

This arises from a combination of different oppressions that together produce something unique and distinct from any one form of discrimination standing alone. It occurs when persons have multiple identities that are considered oppressed and/or non-majority such as racial minority, religious minority, ethnic minority, disability, gender, or sexual preference.⁶⁰

What do we mean by targeting the most marginalised?

Policies and programmes should be targeted to support persons with disabilities most excluded from accessing poverty reduction, social protection and basic services such as women with disabilities, youth with disabilities, and those living in rural areas. These measures should use an intersectional approach to discrimination.⁶¹

Annex II: Good practice on promoting the SDGs in line with CRPD Article 28

OPDs work with government to design and implement accessibility standards in Uganda

The National Building Control Act of 2013 in Uganda was drafted in compliance with CRPD Article 9 by establishing national accessibility standards to be used in building and infrastructure planning with regulations for their implementation. The Uganda National Association of the Physically Disabled led the advocacy for adoption of national accessibility standards. They also advocated for the adoption of implementation regulations that stipulate the use of accessibility standards in all new buildings and urban planning.

Addressing disability inclusion in development plans and strategies in Rwanda

Rwandan OPDs are working with government to ensure the national poverty programme, Vision 2050 (currently being drafted) and the Economic Development and Poverty Reduction Strategy III 2019-2024, are inclusive in line with the CRPD. Both plans aim to operationalise the SDGs. Rwandan OPDs are working with the government focal point for SDG implementation to ensure the plans are inclusive and uphold the principles of the CRPD. OPDs are also collaborating with the civil society mechanism for SDG implementation to ensure the rights of persons with disabilities are on the agenda.

Advocating for disability inclusive data and development policies in Malawi

Through advocacy led by the Federation of Disability Organisations in Malawi (FEDOMA), the Malawi National Statistics Office included the Washington Group short set of questions in the 2018 General Housing and Population Census. In addition, the government of Malawi consulted OPDs throughout the country in the development of the Malawi Growth and Development Strategy (MGDS III) 2018-2022. The government's current version of the MGDS is progressive in many ways, as it includes specific actions and indicators on disability, although not in all areas. The MGDS operationalises the SDGs in Malawi and was launched in early 2018.

OPDs working with government to ensure disability inclusive economic development plans in Rwanda

The National Union of Disabled Peoples Organisations of Rwanda (NUDOR) is consulting with the government of Rwanda on the inclusion of persons with disabilities in the national development programmes aimed at implementing the SDGs. In September 2017, the Rwandan government approved the National Transformation Strategy (NTS) 2017-2024, one of the main economic development strategies, which explicitly mentions persons with disabilities in regard to education, access to ICT, and health. This strategy was spearheaded by the Ministry of Finance, responsible for overseeing the implementation of the SDGs in the country. There are three clusters in the NTS: Economic, Social, and Governance. Each of those clusters contains development objectives and priorities for the next seven years. Disability is expressly included in the economic cluster (in the information and communication technology component) and the social cluster (in regard to health and education, and indirectly in regard to access to justice), but

disability is not referred to in the employment cluster. While there were explicit references to persons with disabilities, the overall strategy falls short in promoting the rights of persons with disabilities to work and employment. These concerns were raised by Rwandan OPD delegates who attended the CRPD Committee's pre-sessional meeting in September 2018.

However, the government of Rwanda has committed to integrating the Washington Group questions into the National Census (2022) and Demographic and Health Survey (2019/20) questionnaires and to training officials to adequately apply them.⁶² At sectoral level, there is also some effort to integrate the Washington Group questions. For instance, in the education sector, a recent study conducted by UNICEF Rwanda⁶³ pointed to the need to increase data in the education sector on persons with disabilities as a priority issue.⁶⁴

Including persons with disabilities in the Poverty Reduction Strategy (PRSP) in Zambia

The Zambia PRSP addresses a variety of poverty-related issues affecting disadvantaged and poor people, including persons with disabilities. Decentralisation of decision-making is one of the PRSP objectives, therefore the development of a decentralisation policy and its implementation are identified as a matter of top priority to ensure that citizens, particularly women, persons with disabilities, and other disadvantaged groups, actively participate in society. In addition, disability issues are also identified as a cross-cutting issue in the Technical Entrepreneurial Vocational Education and Training (TEVET) system under the PRSP.

Using WG questions in the national census in Uganda

A coalition of OPDs including the National Union of Disabled People of Uganda, the National Association of the Deafblind of Uganda, Mental Health Uganda as well as the National Disability Council worked with the Ministry of Gender, Labour and Social Development to advocate for the inclusion of the Washington Group questions for the first time in a national census in the country. In 2014, the National Bureau of Statistics included 6 of the WG questions in the national census. The disability prevalence rate went from 3.5% from the 2002 census to 13% in 2014 with the introduction of the WG questions. More information about the 2014 census can be found at:

unstats.un.org/unsd/demographic-social/meetings/2016/kampala--disability-measurement-and-statistics/Session%206/Uganda.pdf

Training persons with disabilities to cultivate mushrooms in Thailand

The Food and Agriculture Organisation of the UK food programme worked with Thailand's Department of Public Welfare to training persons with disabilities to produce and sell mushrooms and begin their own agricultural businesses. The 60-day course teaches the basics of producing, processing and selling mushrooms, as well as how to build a mushroom house that will guarantee the necessary dark and moist conditions. Cultivating mushrooms is an important part of Thai agriculture as it is a staple part of the diet. More information about the programme can be found at

fao.org/english/newsroom/action/sd_enabled.htm

Investing in accessible and inclusive organic farming in India

CBM India developed an inclusive organic agriculture for all initiative to train and create employment for persons with disabilities in the field of agriculture. Through this programme, CBM trained over 11,000 farmers in organic farming. To do this, CBM cooperated with local partners across six states of India to train farmers, including persons with disabilities, in organic farming and supported them by providing community loans for the procurement of equipment and machines, beekeeping boxes and livestock.

This initiative was implemented over four years from 2012 to 2016. During this period, CBM established partnerships with seven organisations, and has spread the project from two to six states in India. Within the next three years, CBM and its partners expect to become a self-sustaining agricultural value chain. More information available at:

zeroproject.org/practice/india-cbm

Exercising the right to land ownership in subsistence farming economies

Land ownership is a critical issue for persons with disabilities, particularly women with disabilities who are often stripped of their right to own or inherit land. This is particularly acute in subsistence farming economies where people rely on land to provide them a living. In Rwanda, OPDs are working together with the Rwanda Human Rights First Association (HRFRA) to provide legal aid to persons with disabilities to exercise their right to land ownership. Mukandoli Seraphine, a woman with a physical disability, worked with HRFRA to secure a land title and now lives independently, supporting herself through farming. Before owning land, she was forced to live with her brother's family where she provided unpaid domestic care to his children.⁶⁵

Persons with disabilities participating in public service planning on water and sanitation in Zimbabwe

World Vision Australia (WVA), World Vision Zimbabwe, the Federation of Organisations of Disabled People in Zimbabwe (FODPZ) and CBM Australia worked in partnership to ensure participation of persons with disabilities in municipal water and sanitation public service planning. The project sought to engage persons with disabilities at the municipal level on water and sanitation development through partnerships with municipal actors such as engineers, public health workers, schools and water management bodies. Through civic engagement, persons with disabilities were able to work with municipal actors involved in water and sanitation to improve inclusive water and sewer infrastructures for households, schools and public locations. Persons with disabilities were included in baseline assessments and data collection in municipalities to assess barriers to water and sanitation and develop strategies for creating more accessible solutions. Working together, persons with disabilities, municipal authorities, engineers, public health officials, schools and water management actors carried out accessibility audits of public water sources, school latrines and sanitation and hygiene programmes. With the baseline assessments and accessibility audits, citizens with disabilities were able to engage with community water and sanitation leaders to provide strategies for removing barriers and developing more inclusive services. The project was also important because it helped institutionalise municipal level mechanisms for engagement on disability inclusion.⁶⁶

Water and sanitation agencies partnering with persons with disabilities in Timor-Leste

Four agencies working in water, sanitation and hygiene (WASH) partnered with OPDs in Timor-Leste to host a seven week visit from an engineer and wheelchair user from Australia to learn how to incorporate accessibility into WASH programmes in Timor-Leste, particularly in rural areas. During this time, the government was also drafting the National Basic Sanitation Policy. One of the agencies involved in the inclusive WASH initiative was BESIK, the lead agency advising government on water and sanitation policy development, who was also engaged in the National Basic Sanitation Policy drafting. As a result of BESIK's involvement in the technical training on accessibility, they were able to integrate inclusive guidelines and requirements into the National Basic Sanitation policy adopted in 2012. The policy integrates guidelines on inclusive requirements for rural water supply, water points and public toilets as well as training obligations for WASH agencies, OPDs and government. Implementation of guidelines on accessibility standards for water points and public toilets was launched in February 2011 by the Government of Timor-Leste and subsequently integrated into the guidelines for the National Basic Sanitation Challenges Policy.⁶⁷

Annex III: Advocacy resources

Tools for influencing policy

The Power of Evidence Advocacy: This toolkit was developed for civil society organisations aiming to influence policy change. It provides tools and guidance to civil society organisations on how to use evidence effectively to influence policy change. It provides:

- An understanding of the power of evidence to influence policy change
- Tools for evidence-based policy advocacy
- Training materials on how to deliver a training to others on evidence-based advocacy

odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/251.pdf

Community Tool Box on Influencing Policy Development: This toolkit provides guidance for bringing about policy change in organisations and communities.
ctb.ku.edu/en/influencing-policy-development

International Development Research Centre – How to Write a Policy Brief: This tool provides a step-by-step guide to writing an effective policy brief.
idrc.ca/sites/default/files/idrcpolicybrieftoolkit.pdf

Mental Health Innovation Network Overview of How to Write a Policy Brief: This simple tool provides clear and concise guidance on how to draft a policy brief in understandable language with examples of templates.
mhinnovation.net/sites/default/files/downloads/resource/Tool6_PolicyBrief_14Oct2015.pdf

Tools on data

How to Navigate Digital Data for Human Rights Research: This guide is designed to help organisations integrate new data forms into their human rights work.

benetech.org/wp-content/uploads/2017/08/en-datnav-report_high-quality_web_1-31-2017.pdf

Using Data for Action and for Impact: This article provides a framework to help non-profits and social businesses make better use of data to inform decision-making and evaluate performance.
benetech.org/wp-content/uploads/2017/08/Data-for-Action-and-Impact-.pdf

Audit and assessment tools

Global Health Advocacy Partnership – Advocacy Toolkit: This tool provides guidance for carrying out a social audit and assessing community programmes. It assesses gaps in service delivery and provides tools for how to use this evidence to build effective advocacy for change. This is a good tool for carrying out assessments of labour services and vocational training programmes.
action.org/uploads/images/general/ACTION-Advocacy-Toolkit.pdf

Storytelling tools

The Secret to Better Storytelling for Social Change: Better Partnerships:

This tool describes how to build effective partnerships to tell stronger stories for social change. This article also provides good practice tips for telling stronger stories to influence change.

ssir.org/articles/entry/the_secret_to_better_storytelling_for_social_change_better_partnerships

Transformative Storytelling for Social Change: A guideline for the different ways of capturing stories for change using different formats such as drama, video, social media and other forms of technology. This tool also provides good practice examples.

transformativestory.org

How Can Storytelling Promote Social Change: Theatre artists and professional storytellers offer expertise about how to craft a story which develops empathy and delivers impact in the “Storytelling for Social Change” course led by University of Michigan professor Anita Gonzalez:

youtube.com/watch?v=MECOpp59hqs

Witness: Witness provides resources for human rights campaigning using digital media and video’. Human rights campaigns using digital media and video.

witness.org/resources

Tools for documenting human rights violations

Documenting Human Rights Violations: This guide provides activists with a model of secure, systematic documentation of human rights violations and how to transform this data into evidence-based advocacy for social change.

benetech.org/work-area/human-rights

Human Rights Tools for a Changing World: A Step-by-step Guide to Human Rights Fact-finding, Documentation and Advocacy:

This resource provides comprehensive information and guidance on how to use a human rights framework and human rights methods to facilitate social change.

www.theadvocatesforhumanrights.org/uploads/change.pdf

Human Rights Documentation Tools: Practical guide to human rights documentation with templates and case study examples.

ilga-europe.org/what-we-do/our-work-supporting-movement/funder/daf/tools

Grassroots advocacy campaigning tools

New Tactics Strategy Toolkit: New Tactics in Human Rights has developed this strategy toolkit to support the important work of human rights advocates around the world.

newtactics.org/toolkit/strategy-toolkit

Endnotes

1. It is important to note that vulnerability or vulnerable are not terms the disability community endorses. The preferred terminology within disability rights movements is 'at risk'.
2. Theresia Degener, *Disability in a Human Rights Context* (Bochum, Germany: Department of Social Work, Education and Diaconia, Protestant University of Applied Sciences, 2016), Page 3.
3. Including access to basic services, poverty reduction programmes, housing programmes, access to clean water and sanitation, and retirement benefits and programmes.
4. Special Rapporteur on the Rights of Persons with Disabilities, *The rights of persons with disabilities to social protection*, A/70/297 (2015), Para 20.
5. Report of the Special Rapporteur on the Rights of Persons with Disabilities, A/HRC/31/62 (12 January 2016).
6. Committee on the Rights of Persons with Disabilities, *General Comment No. 7*, CRPD/C/GC/7 (9 November 2018).
7. All social programmes, housing, nutrition, water, sanitation, hygiene and health (WASH), mainstream or disability specific programmes.
8. While there is no internationally agreed definition of social protection, this policy guideline uses the definition promoted by the Special Rapporteur on the Rights of Persons with Disabilities in which: social protection is understood broadly to cover a variety of interventions designed to guarantee basic income security and access to essential social services, with the ultimate goal of achieving social inclusion and social citizenship. This is detailed by the Special Rapporteur on the Rights of Persons with Disabilities in her report on the rights of persons with disabilities to social protection, A/70/297 (2015), Para 5.
9. Persons with disabilities incur a range of common daily expenditures that persons without disabilities do not. They include extra costs for the person and the family to purchase goods and services, such as health care, accessible transportation, assistive devices, personal assistance, house adaptations, mobility aids, appropriate and adapted devices and assistive technologies. These costs can also include extra time needed for travel or the costs of purchasing goods and services not covered by national social protection schemes. Special Rapporteur on the Rights of Persons with Disabilities, A/70/297 (2015), Para 29. According to research on the cost of living for persons with disabilities, it has been calculated that disability-related extra costs can amount to almost 50 per cent of an individual's income. See: J. Cullinan, B. Gannon and S. Lyons, *Estimating the Extra Cost of Living for People with Disabilities*, in *Health Economics*, vol. 20 (5) (2011).
10. Legislation which restricts persons with disabilities in the exercise of their full legal capacity commonly prevents signing of contracts and managing bank accounts, which may prevent persons with disabilities from receiving benefits and support or from exercising full control of the given benefit and support. Social protection programmes must not require any restriction of legal

capacity as a pre-condition to accessing benefits and must be designed to provide adequate accommodations to foster choice, control and autonomy by the individual concerned of their benefits and support.

11. Laws should not contain conditionalities associated with benefits where there are barriers that prevent persons with disabilities from fulfilling them. For example, cash transfer schemes that are conditional upon school attendance where schools are not accessible to persons with disabilities, or where the absence of accessible transport prevents access to health clinics. Conditionalities should also not lead to adverse effects or infringe the rights of persons with disabilities under the CRPD e.g. requirement to comply with rehabilitation or treatment (including mental health treatment) against one's will or living in a segregated setting as a condition to receiving benefits.
12. Which is designed with meaningful consultation with OPDs and contains:
 - Particular measures relating to youth and women with disabilities, persons with specific support needs etc.
 - Clear lines of responsibility, targets and timetable for implementation
 - Mechanisms for cross-ministerial cooperation
 - Allocated budget
 - Monitoring and enforceability mechanism
 - Criteria requiring physical and informational accessibility
13. Including through their representative organisations.
14. For persons with disabilities, multiple and intersecting forms of discrimination make accessing basic services such as food assistance, nutrition programmes and services, water and sanitation even more challenging. For example, in communities where women primarily collect food assistance, travelling alone a long distance to collect food or nutritional supplements can be extra hazardous for a woman with a disability and there is greater potential she can be targeted by violence or harassed. In addition, travelling long distances without accessible forms of transportation for someone with a physical disability can make it impossible to reach food assistance services. In communities where women go out to defecate at night, moving around in the dark can be extra hazardous for a woman with a disability. In many rural areas, diarrhea is a regular occurrence for everyone, but for a disabled person who does not have access to assistive devices or support services, this can place an extra workload on family members and limits a person from accessing appropriate sanitation safely and independently. Source: Jones, H. and Reed, B., Water and sanitation for disabled people and other vulnerable groups: Designing services to improve accessibility, (Loughborough: WEDC, Loughborough University, 2005), Page 9. Available at: dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/30796/20/Water_and_Sanitation_for_Disabled_People_-_Complete.pdf
15. According to the Office of the High Commissioner for Human Rights, UN Habitat and the World Health Organisation, discrimination in relation to access to safe drinking water and sanitation can be rooted in discriminatory laws, policies or measures including: discriminatory water management policies, denial of tenure security, limited participation in decision-making or lack of protection against discriminatory practices by private actors. Source: OHCHR, The Right to Water, Fact Sheet no. 35, (OHCHR: Geneva, 2010), Page 15. Available at: ohchr.org/Documents/Publications/FactSheet35en.pdf

16. Making sure that rural women and men who live with disabilities are fully integrated in food security interventions is an essential part of achieving critical development goals: eliminating extreme poverty, reducing malnutrition, and enhancing food security for all. See statement by Libor Stloukal on Disability and Food Security: An Unfinished Policy Agenda: internationaldisabilityalliance.org/fao-food-insecurity
17. As mandated by Article 28 of the CRPD. Article 28 refers to the right to social protection and links it to the right to an adequate standard of living, with reference to adequate food, clothing and housing, and the continuous improvement of living conditions. As such States must take appropriate measures to ensure that persons with disabilities receive equal access to mainstream social protection programmes and services as well as access to basic services and poverty reduction programmes. Special Rapporteur on the Rights of Persons with Disabilities, A/70/297 (2015), Para 20.
18. General Comment No. 15 of the Committee on Economic, Social and Cultural Rights makes clear that physical accessibility and accessible information are inherent components of the right to water without discrimination. See: Committee on Economic, Social and Cultural Rights, General Comment No. 15, E/C.12/2002/11, Para 12 (c)(i), available at: www2.ohchr.org/english/issues/water/docs/CESCR_GC_15.pdf
This means that water and sanitation services, programmes and information must be accessible without discrimination meaning that all mainstream services and programmes should be fully accessible.
19. General Comment No. 12: The Right to Adequate Food, Committee on Economic, Social and Cultural Rights makes clear that physical accessibility and economic accessibility are inherent components of the right to food without discrimination. See: Committee on Economic, Social and Cultural Rights, General Comment No. 12, E/C.12/1999/15, Para 6. Available at: refworld.org/pdfid/4538838c11.pdf
20. In line with Article 9 (Accessibility) of the CRPD, this includes ensuring the locations where programmes and services are administered are fully accessible, information is provided in accessible formats and that the provision of these services is fully accessible and adapted to the needs of persons with disabilities. According to the Committee on the rights of Persons with Disabilities, accessibility must be understood as enabling an “unrestricted chain of movement”. As such, persons with disabilities must have access to accessible housing, transportation and needed support services to get to and from their home to water sources and sanitation services. For example, clean water sources should not demand that persons with physical disabilities wait in long lines or be forced to travel long distances using inaccessible roads to gain access to safe drinking water. Committee on the Right of Persons with Disabilities General Comment No.2: Article 9: Accessibility, CRPD/C/GC/2, Para 15.
21. As specified by the Committee on Economic, Social and Cultural Rights in General Comment No. 12, steps should be taken to prevent discrimination in access to food and resources, with guarantees of full and equal access to economic resources including the right to inheritance and ownership of land and other property, credit, natural resources and appropriate technology. General Comment No. 12, E/C.12/1999/5, Para 26. This is particularly critical

for persons with disabilities, and in particular, persons with intellectual and/or psychosocial disabilities and women with disabilities, who are often denied the right to own or inherit land or property in practice on the basis of their disability and gender. These rights are egregiously denied to women and men with disabilities who have been denied their legal capacity or are prevented from representing themselves.

22. This includes ensuring the locations where programmes and services are administered are fully accessible and that the provision of these services are fully accessible and adapted to the needs of persons with disabilities. For example, food distribution should not demand that persons with physical disabilities wait in long lines or be forced to travel long distances using inaccessible roads to receive food distributions. Latrines and sanitation facilities should be placed in close proximity to households with members with a disability.
23. For example, the construction of new water and sanitation facilities such as new latrines with steps or water pumps with higher handles may make new facilities less, not more accessible to people with some kinds of disabilities. Or the implementation of water and sanitation programmes in schools that are not accessible for students with disabilities.
24. This includes girl-friendly and accessible bathrooms in schools with provision for dignified menstrual hygiene management, to have safe, accessible and well-sited water collection points to help prevent gender-based violence. UNICEF, Gender-Responsive, Water and Sanitation: Key elements for effective WASH programming, (UNICEF: 2017). Available at: [unicef.org/gender/files/Gender_Responsive_WASH.pdf](https://www.unicef.org/gender/files/Gender_Responsive_WASH.pdf)
25. The CRPD recognises the multiple and intersecting forms of discrimination women and girls face. Article 28 requires states to ensure they have equal access to adequate food and nutrition. States can play an active role in promoting a disability and gender inclusive approach to food and nutrition and initiatives. For example, ensuring gender equity and disability inclusive food security programmes that address both accessibility and gender-related needs can play an important role in ensuring women with disabilities exercise greater control over food and nutritional needs in their homes.
26. Such as persons with intellectual disabilities, Deafblind persons, persons with psychosocial disabilities, persons with albinism, persons with disabilities living in rural areas etc.
27. This is detailed by the Special Rapporteur on the Rights of Persons with Disabilities in her report on the rights of persons with disabilities to social protection, A/70/297 (2015), Para 5.
28. As a result of existing barriers, a lack of support and persistent discrimination, persons with disabilities are more exposed throughout the life cycle than those without disabilities to risks and vulnerabilities that are addressed by social protection systems. This makes the value of inclusive social protection systems even higher as it can support persons with disabilities to avoid risks and vulnerabilities, making it more likely they actively participate and secure an adequate standard of living. See International Disability Alliance, Joint Statement towards Inclusive Social Protection Systems Supporting the Full and Effective Participation of Persons with Disabilities, (International Disability

Alliance: January 2018), Page 4. Available at:
www.social-protection.org/gimi/gess/RessourcePDF.action?ressource.ressourceId=54258

29. In many countries, the legal policy framework permits benefits to be paid to a third-party rather than directly to the individual with a disability.
30. If benefits are tied to unemployment, reception of benefits can be a disincentive to returning to work or joining the labour force.
31. As explained by the Special Rapporteur on the Rights of Persons with Disabilities in her report on the rights of persons with disabilities to social protection, A/70/297 (2015), social protection systems that are well-designed can play a crucial role in alleviation and prevention of poverty and economic vulnerability. Moreover, well-designed programmes can help to remove social and economic barriers that impede access to employment, and to secure access to capital and skills development programmes, therefore creating better income-earning opportunities for persons with disabilities. A/70/297 (2015), Paras 8 and 9.
32. When disability benefits combine or bundle assistance to cover disability-related extra costs or access to health care together with income support aimed at reducing poverty, persons with disabilities may lose the entire benefit package (including essential support for disability-related extra costs) if they gain a higher income than the poverty line or minimum income threshold. To avoid this dilemma, States should unbundle or separate income security and disability-related assistance to find a balance between supporting labour inclusion and providing an adequate level of income security. See: Special Rapporteur on the Rights of Persons with Disabilities, A/70/297 (2015) Paras 52-53.
33. Families with children with disabilities are disproportionately more likely to fall below the poverty line, as disability in childhood is often the catalyst for poverty owing to disability-related extra costs, family break-ups and unemployment following the onset of disability. Poverty, in turn, remains the main cause of malnutrition, school dropout, abandonment and institutionalisation of children with disabilities. As detailed by the Special Rapporteur on the Rights of Persons with Disabilities in her report on the rights of persons with disabilities to social protection, A/70/297, 2015, Para 35.
34. The basic guarantees should include at a minimum a basic level of income security and access to essential social services. The Social Protection Floors Recommendation No. 202 (2012) of the International Labour Organization (ILO).
35. Benefits or social transfers can be contributory (financed by the contributions of workers, their employers, and in some cases the State such as social insurance schemes) or non-contributory (financed by taxes). There is no one size fits all approach in designing and operating national floors of social protection. Each country should decide how to make it happen through targeted and/or universal schemes, contributory or non-contributory approaches etc. This is explained in the guide by Valerie Schmitt and Loveleen De, Social protection assessment based national dialogue: a good practices guide, (ILO Decent Work Technical Support Team for East and South-East Asia and the Pacific: Bangkok, 2013), Page 15. Available at www.social-protection.org/gimi/gess/RessourcePDF.action?id=44257

36. When designing social protection systems, States should balance between contributory and non-contributory schemes with provisions for government financed contributions for those with fewer opportunities to contribute. This can strengthen universal protection of contributory programmes. For persons with disabilities, and in particular, women with disabilities, who have higher unemployment rates and are more often employed in the informal sector, they have limited contributory capacity. However, government financed contributory schemes can often play an important role in providing social protection to persons with disabilities and often provide higher benefits than non-contributory programmes. This is detailed by the Special Rapporteur on the Rights of Persons with Disabilities in the report on the rights of persons with disabilities to social protection, A/70/297 (2015), Paras 48-49.
37. The realisation of the rights enshrined in Article 27 (Work and employment) is inter-related to other rights in the CRPD, including: 4 (General Obligations), 5 (Equality and non-discrimination), 9 (Accessibility), 11 (Situations of risk and humanitarian emergency), 12 (Equal recognition before the law), 13 (Access to justice), 16 (Freedom from exploitation, violence and abuse), 19 (Living independently and being included in the community), 24 (Education), 25 (Health), 27 (Work and employment).
38. In many low to middle-income countries, accessibility regulations are taken from industrialized nations and may not be usable or relevant to the local context. Source: Jones, H. and Reed, B., Water and sanitation for disabled people and other vulnerable groups: Designing services to improve accessibility, (Loughborough: WEDC, Loughborough University, 2005), Page 42. Available at: dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/30796/20/Water_and_Sanitation_for_Disabled_People_-_Complete.pdf
39. As specified in CRPD Article 4 (3): General Obligations.
40. ILO, Decent Work for Persons with Disabilities: Promoting Rights in the Global Development Agenda, (ILO, Gender, Equality and Diversity Branch, Conditions of Work and Equality Department: Geneva, 2015), Page 141. Available at ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_430935.pdf
41. UNICEF, WASH Disability Inclusion Practices. Available at: unicef.org/disabilities/files/WASH_Disability_Inclusion__Practices__programming_note_-_Draft_for_review.pdf
42. This includes ensuring gender-sensitive food distribution for girls and women with disabilities in emergency shelters. Source: Wilbur, J. and Jones, H., Disability: Making CLTS Fully Inclusive', Frontiers of CLTS: Innovations and Insights Issue 3, (Brighton: IDS, 2014).
43. Lisa VeneKlasen and Valerie Miller, A new weave of power, people and politics: The action guide for advocacy and citizen participation (Stylus Publishing, 2007), Chapter 10, Page 185. Available at: justassociates.org/sites/justassociates.org/files/new-weave-eng-ch10-mapping-strategies.pdf
44. This is explicitly called for within indicators 8.5.1 Average hourly earnings of female and male employees, by occupation, age and persons with disabilities; and 8.5.2 Unemployment rate by sex, age and persons with disabilities.

45. Washington Group on Disability Statistics: washingtongroup-disability.com
46. As part of Agenda 2030, Heads of State and Government pledged for more systematic data collection and disaggregation to measure the implementation of the Sustainable Development Goals. To improve the quality, relevance and use of data within human rights norms and principles, the Human-Rights Based Approach to Data was developed. To learn more see the guidance note developed by the Office of the High Commissioner on Human Rights at: ohchr.org/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf
47. According to the Committee on the Rights of Persons with Disabilities, the collection of statistical data should be disaggregated by sex, on the employment, both in the public and private sector, of the economically active population with disabilities vis-à-vis the overall economically active population disaggregated by sex, type of work and other relevant factors compared to the employment rates of men and women without disabilities. This is explained in: Guidelines on periodic reporting to the Committee on the Rights of Persons with Disabilities, including under the simplified reporting procedures, CRPD/C/3, Para 187, Page 19.
48. Committee on the Right of Persons with Disabilities General Comment No.2: Article 9: Accessibility, CRPD/C/GC/2, Para 15.
49. Support services are those that enable a person with a disability to participate on an equal basis with others, such as personal assistance services, Sign Language interpretation or assistive devices.
50. This is explained in the guide by Valerie Schmitt and Loveleen De, Social protection assessment based national dialogue: a good practices guide, (ILO Decent Work Technical Support Team for East and South-East Asia and the Pacific: Bangkok, 2013), Page 15. Available at: www.social-protection.org/gimi/gess/RessourcePDF.action?id=44257
51. Special Rapporteur on the Rights of Persons with Disabilities, A/70/297, 2015, Paras 55-56.
52. Special Rapporteur on the Rights of Persons with Disabilities, A/70/297 (2015), Para 29.
53. OHCHR, A/RES/60/147, 21 March 2006, Geneva, available at: ohchr.org/EN/ProfessionalInterest/Pages/RemedyAndReparation.aspx
54. Report of the Office of the United Nations High Commissioner for Human Rights, Equality and non-discrimination under Article 5 of the Convention on the Rights of Persons with Disabilities, A/HRC/34/26 (2017), Para 27. Available at: documents-dds-ny.un.org/doc/UNDOC/GEN/G16/406/73/PDF/G1640673.pdf?OpenElement
55. Ibid, Para 33.
56. Special Rapporteur on the Rights of Persons with Disabilities, Report on the rights of persons with disabilities to social protection, A/70/297 (2015), Para 5.
57. The objective of universal social protection that is responsive to the needs of all citizens, including persons with disabilities, has been endorsed by the World Bank and ILO in a joint initiative and by the ILO in recommendation number

202. This approach is also described in detail by the Special Rapporteur on the Rights of Persons with Disabilities, Report on the rights of persons with disabilities to social protection, A/70/297 (2015), Paras 15 and 16.
58. 40 C. A. Aylward, Intersectionality: Crossing the Theoretical and Praxis Divide (paper distributed at Transforming Women's Future: Equality Rights in the New Century: A National Forum on Equality Rights presented by West Coast Leaf, 4 November 1999) [unpublished]. Quoted in:
ohrc.on.ca/en/intersectional-approach-discrimination-addressing-multiple-grounds-human-rights-claims/introduction-intersectional-approach#fn7
59. Jason Kottke, What is intersectionality? (2019). Available at:
kottke.org/19/02/what-is-intersectionality
60. C. A. Aylward, Intersectionality: Crossing the Theoretical and Praxis Divide.
61. Human Rights Council study on work and employment of persons with disabilities, ILO contribution, (Human Rights Council: Geneva, 2013), Page 140.
62. Government of Rwanda Commitments on Disability, see:
assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/728143/National_Government_-_Government_of_Rwanda.pdf
63. Ministry of Education, A study on children with disabilities and their right to education (Republic of Rwanda: 2016).
64. Interview with Jorge Manhique, Program Officer for Rwanda and Malawi, Disability Rights Fund (October 2018).
65. Interview with Disability Rights Fund Program Officer Jorge Manhique from Rwandan field visit 2017. More information available at:
disabilityrightsfund.org/achieving-rights/rwandan-women-with-disabilities-claim-their-land-rights
66. C. Mvere, A. Carroll, E. Ravengai, A. Chadzima, & A. Newmarch (Zimbabwe), Ensuring Availability and Sustainable Management of Water and Sanitation for All: Creating environments to support people with disabilities in public service delivery, WEDC briefing paper 2365 (2016). Available at:
wedc-knowledge.lboro.ac.uk/resources/conference/39/Mvere-2365.pdf
67. J. Fernandes, S. Cooke and H. Nguyen, Building Skills in Disability Inclusive WASH: Perspectives from a DPO in Timor-Leste (WaterAid: 2012). Available at:
inclusivewash.org.au/wp-content/uploads/2018/09/Case-Study-07_Building-skills-in-disability-inclusive-WASH.pdf



Leonard Cheshire

66 South Lambeth Road
London SW8 1RL

Email: info@leonardcheshire.org

Phone: 020 3242 0200



Leonard Cheshire Disability is a registered charity no: 218186 (England and Wales), and no: SC005117 (Scotland) and a company limited by guarantee registered in England no: 552847. VAT no: 899 3223 75. Registered office: 66 South Lambeth Road, Vauxhall, London, SW8 1RL.