

The preconditions necessary to ensure disability inclusion across policies, services, and other interventions

Background

Reforms to improve social inclusion and access to services for persons with disabilities often fall short because of the lack of the essential building blocks or preconditions that are necessary to ensure disability inclusion. These preconditions are the foundational aspects that are indispensable in addressing the requirements and views of persons with disabilities and should be considered in public policy making and programming across all sectors. If the preconditions to disability inclusion are in place, then persons with disabilities can access services across all sectors, such as education, health, justice, etc. A multi-sectoral approach to establish and set up these preconditions, avoids duplication and inconsistencies across sectors and encourages greater efficiency.

UNPRPD's approach

UNPRPD joint programming is designed to respond to gaps in CRPD implementation by focusing on these preconditions and translating them into concrete policies, programs, and services through a cohesive, inter-sectoral approach. The preconditions should be structured according to the national context and anchored in national priorities and will be the focus of situational analyses that informs UNPRPD MPTF programming.

This focus on the preconditions marks a shift in UNPRPD MPTF's programming to concentrate on issues commonly affecting UN entity programming and provides a focal point for joint programming across the diverse priorities of UN entities. It also lays the groundwork for successful governmental reforms to implement the CRPD.

The preconditions

There are six cross-sectoral preconditions for the inclusion of persons with disabilities that are essential to policies, systems, and services. These preconditions apply to all persons with disabilities, but some preconditions may be of more importance to one group of persons with disabilities than another. In addition, the preconditions are inter-related and require a joint approach tailored to the context.

Preconditions for disability inclusion

Equality and non-discrimination

Service delivery
Accessibility
Participation of persons with disabilities
CRPD-compliant budgeting & financial management
Accountability & governance

Figure 1: Preconditions to disability inclusion

1. Equality and non-discrimination

Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others¹. These attitudinal barriers or stigma are grounded in stereotypes, misperceptions, and assumptions about persons with disabilities, which often stem from a lack of exposure to or understanding of the capabilities of persons with disabilities. The nature of disability-based stigma and discrimination is often influenced by the type and severity of impairment a person has. In addition, other aspects of a person's background, such as gender, ethnicity, or socio-economic status, may further contribute to exclusion. Therefore, measures to protect against stigma and discrimination should include consideration of the most marginalized groups of persons with disabilities and intersectional approaches².

As a first step, there must be official recognition of persons with disabilities as a protected group at national and sub-national levels. This involves recognition of each type of disability, which is a critical step in ensuring that each sector is aware of the types of disabilities and their obligations to consider the requirements of each group, thus ensuring that persons with disabilities can access services across sectors. There must be protections in place to prevent and address disability-based stigma and discrimination and to promote equality and non-discrimination, as well as measures to raise awareness to foster respect for the rights and dignity of persons with disabilities. These protections must guarantee access to reasonable accommodations³. Understanding, capacity, and protection of equality and non-discrimination are usually established through a mix of national legislation that ensures recognition to each group of persons with disabilities, awareness raising and capacity building policies and programs, policy guidance on reasonable accommodations, and administrative measures.

2. Service delivery

Service delivery must adopt a twin track approach with both mainstreamed and disability-specific targeting of services to ensure inclusion of persons with disabilities. Persons with disabilities require

¹ Convention on the Rights of Persons with Disabilities 2008, A/RES/61/106, preamble (e).

² See generally, UNPRPD MPTF Strategic Operational Framework: Briefing on Cross-Cutting Approaches.

³ Reasonable accommodations are the necessary and appropriate modifications and adjustments that do not impose an undue burden, where needed in a particular case, to ensure persons with disabilities enjoy their rights on an equal basis with others.

some services that are specifically designed for persons with disabilities, such as disability assessment and referral services and disability support services, as well as disability mainstreamed services.

Disability assessment and referral services - Some disabilities are more difficult to detect than others, particularly invisible or more complex disabilities. Even where a disability is readily identified, there may be a lack of information on the condition, how to make adjustments, or where to go for support. A disability assessment and referral system is intended to identify the kind and extent of disability a person has, to receive information about their disability, and to ensure that they are referred to appropriate supports and services in their communities. Disability assessment and referral systems should be designed to empower persons with disabilities, including access to information, and should be used for advancing the enjoyment of rights and access to services.

While disability assessment and referral systems often link to evaluation and determination of benefits, services, or protections for individuals, they should not be used to impose unnecessary restrictions based on formal assessment, such as requiring a formal assessment in order to request reasonable accommodations or discrimination against certain groups of persons with disabilities (e.g., restricting protections to legal capacity for persons with intellectual or psychosocial disabilities). While assessment and referral systems may help identify those individuals who require specific types of support needs, such as access to community-based care services, they should not have a negative impact on the personal independence or enjoyment of the rights of persons with disabilities⁴. Furthermore, disability assessment and referral systems can also restrict access to necessary supports in order to keep government spending down, which can lead to deprivations of rights. Therefore, disability assessment and referral systems must be valid to avoid ‘false positives’ (i.e., people receiving benefits who do not have a disability) and ‘false negatives’ (i.e., people who should receive benefits but do not), reliable to ensure consistency in the quality of assessment, and transparent and standardized so that the grounds for decision-making are publically known and independently evaluated.⁵

In addition, early identification and intervention for children with disabilities is critical for ensuring their development and should be included in plans for disability assessment and referral systems. However, assessment and referral systems should be designed to ensure that persons of all ages, including older persons, have access to assessment and referral, particularly since the incidence of disability increases with age.

Disability assessment and referral systems are usually implemented through multi-sectoral programs and administrative systems and may be based in national law and / or policy.

⁴ See generally, UN Committee on the Rights of Persons with Disabilities, Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention, CRPD/C/15/4, 24 October 2017, paras. 70-81.

⁵ Bickenback, J. et al. *Assessing Disability in Working Age Population: A Paradigm Shift from Impairment and Functional Limitation to the Disability Approach*, 18 June 2015, p. xi.

Disability support services – Autonomy is a core principle of the CRPD, and for many persons with disabilities, this can be achieved through disability support services. These support services are unique to persons with disabilities and entail the provision of help or assistance necessary to carry out regular activities and participate in society. These disability support services encompass a wide range of formal and informal interventions, including personal assistance, mobility aids, assistive devices and technologies, supportive decision-making, communication support (such as sign language or guide interpreters), and community services. These disability support services are critical for accessing general services, such as housing, health, education, justice, emergency services, and more⁶.

Disability support services are a precondition to living and fully participating in the community on an equal basis with others, and without this support, persons with disabilities face exclusion from accessing services, participating in society, institutionalization, and neglect⁷. The provision of support services should seek to overcome or eliminate social and environmental barriers and should be tailored to the individual. However, a portfolio of disability support services can be designed and implemented to meet the needs of a wide range of support needs. Where public services do not exist, allocation of funding to access disability support services may be necessary, e.g., financial support to families that support persons with disabilities or the hiring of private sector support. Disability support services are usually implemented through direct services, including access to assistive devices and technology, live assistance, or community services, or money to pay for services, and legislative and policy frameworks may also be necessary to enable and guide these services.

Mainstreamed services - Persons with disabilities require access to the same services as persons without disabilities, such as education, vocational training, health, access to justice, emergency services, social protection, recreational services, etc. These services need to mainstream disability inclusion and identify structures, plans, and measures to ensure they are available, accessible, adequate, and affordable for persons with disabilities. Persons with disabilities should have equal access to services that are inclusive and not segregated. These mainstreamed services may also need to link with disability support services to ensure full access to all persons with disabilities. For example, access to Sign Language interpreters to appear in court, access to community-based support mechanism to evacuate in an emergency, or access to an appropriate wheelchair and advice on how to use the wheelchair in order to attend school.

3. Accessibility

Accessibility is necessary for persons with disabilities to live independently, to actively participate in society, and to have unrestricted enjoyment of all rights on an equal basis with others. It refers to the extent to which products, systems, services, environments, and facilities can be used by people with diverse requirements, needs, characteristics, and capabilities to achieve their goals in certain contexts.

⁶ UN Special Rapporteur on the rights of persons with disabilities, Human Rights Council Report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/34/58, 20 December 2016, paras. 13-14.

⁷ *Ibid.*, para. 15.

The CRPD requires States to take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public and to remove barriers and obstacles to accessibility⁸. For example, this means that information must be provided in accessible formats, such as Braille, large print, Sign Language, Easy Read, etc.

Accessibility is usually implemented through standards expressed in laws and policies and implemented in programs or through operating or administrative procedures or public procurement. In addition, awareness raising and technical know-how on accessibility as well as monitoring or regulatory systems are required to ensure practical implementation⁹.

4. Participation of persons with disabilities

The active and informed participation of persons with disabilities in decisions that affect them is consistent with a human rights-based approach and ensures good governance and accountability¹⁰ and the disability movement's motto, 'nothing about us without us'. It is a cross-cutting principle of the CRPD¹¹ and a precondition to inclusive policy making to overturn the common practice of decisions being made on their behalf. Participation of persons with disabilities should be effective and meaningful, ensuring a systematic, timely, and open approach. This also includes the provision of relevant measures to ensure reasonable accommodations to consultative processes, free from stigma, and recognizing every person's legal capacity.¹²

Participation of persons with disabilities is usually through representative organizations of persons with disabilities (OPDs), which are civil society organizations comprising a majority of persons with disabilities – more than half of their membership – and governed, led, and directed by persons with disabilities rooted in, committed to, and fully respectful of the CRPD. Participation may be facilitated through both formal and informal mechanisms, ensuring that monitoring and accountability are cornerstones of the participation¹³.

⁸ Convention on the Rights of Persons with Disabilities, Article 9.

⁹ See CRPD General Comment No. 2 (2014) on Article 9: Accessibility, CRPD/C/GC/2, 22 May 2014, para. 10.

¹⁰ Committee on the Rights of Persons with Disabilities, General comment No. 7 (2018) on the participation of persons with disabilities through their representative organizations, in the implementation and monitoring of the Convention, CRPD/C/GC/7, 9 November 2018, para. 2.

¹¹ See CRPD, preamble and Articles 1, 3, 4, 7, 9, 19, 21, 24, 26, 29, and 32-35.

¹² Committee on the Rights of Persons with Disabilities, General comment No. 7 (2018) on the participation of persons with disabilities through their representative organizations, in the implementation and monitoring of the Convention, CRPD/C/GC/7, 9 November 2018, paras. 21-22.

¹³ For more information, see generally, UNPRPD Strategic Operational Framework: Briefing on Cross-Cutting Approaches.

5. CRPD-compliant budgeting and financial management

A major stumbling block to the implementation of disability inclusive legislation, policies, programs, and services is the allocation of resources to cover the costs of disability inclusion. Persons with disabilities often incur high expenditure due to their disabilities in order to be independent and to effectively participate in society. Since many persons with disabilities cannot afford these costs, they are often excluded. The CRPD cannot be effectively implemented without CRPD-compliant financial planning and regulation and support for the extra costs of disability.

Financial planning and monitoring - To ensure governments are fulfilling their CRPD obligations, the overall public finance management and budgeting system must contribute efficiently, effectively, and on an equitable to take steps to the maximum of their available resources to implement the CRPD. This means that all available means (e.g., public procurement, tax expenditure, revenue generation, grants, etc.) are utilized, central and local public spending (including development assistance) foster accessibility and non-discrimination across sectors, public resources are used to ensure universal access to services, budgeting decisions are made in close consultation with persons with disabilities, and public resources (including policies, guidelines, or regulations) do not contradict CRPD standards, such as segregated education services¹⁴. In addition, principles, such as transparency, participation (including marginalized groups of persons with disabilities), and progressive realization should be applied.

CRPD-compliant budgeting and financial management is usually implemented through budgeting processes and include legislative and policy measures, administrative procedures, cross-sectoral cooperation, and regulatory and oversight systems.

Regulation and support for the additional costs of disability - Persons with disabilities are diverse and have different requirements, depending on their disability, the level of accessibility, and the environment. Often, the cost of meeting these requirements is not affordable to persons with disabilities. They incur direct costs or expenditure due to having a disability, such as the cost of purchasing a wheelchair, accessing therapies, or hiring a Sign Language translator, and they incur indirect costs, such as lower levels of income, limited access to education, or opportunity costs of family members giving up work to provide support.¹⁵

These additional costs must be regulated and factored into policy, programs, and planning, so that services are accessible to persons with disability, thus decreasing the need for persons with disabilities to bear the burden or be excluded outright due to these additional costs. Strong accessibility standards, the provision of reasonable accommodations, and access to disability support services can help to ensure the additional costs of disability are reduced and the additional costs of disability should

¹⁴ Center for Inclusive Policy, Clarification needed: Inclusive, Disability responsive or CRPD compliant budgeting?, May 2019.

¹⁵ UNPRPD MPTF and Leonard Cheshire, Inclusive Social Protection for Empowerment of Persons with Disabilities: Considering the Disability related Extra Costs in Social Protection, March 2020, p. 4.

be considered when devising strategies for these other preconditions. The additional costs of disability are often regulated and supported through a combination of social protection measures, provision of publicly available disability services, accessibility standards, provision of reasonable accommodations, as well as regulations and legal and policy frameworks.

6. Accountability and governance

Governments are obliged to ensure that they have the appropriate governance and accountability systems in place to implement the CRPD. This includes systems to collect information, including statistical and research data to inform policies¹⁶, national implementation and monitoring systems¹⁷, and effective coordination across sectors.

Inclusive evidence and data gathering systems - There are significant gaps in reliable information on persons with disabilities at international, national, and sub-national levels, including qualitative and quantitative research and evidence on what works for disability inclusion and internationally comparable data collection. This often results in inaccurate figures on the number of persons with disabilities accessing services and a lack of consensus on the necessary interventions to implement the CRPD, thus stifling inclusive policies. The multiplicity of approaches and models for disability inclusion leads to a lack of cohesion in priorities or lack of collaboration between actors, including government ministries.

Significant advances have been made in addressing the gaps in disability-disaggregated data in national censuses and surveys by the Washington Group on Disability Statistics, including internationally agreed methods through a Short Set of Questions, an Extended Set of Questions, and a module on Child Functioning¹⁸. There is increasing pressure to collect better disability-disaggregated data across a range of sectors as a result of the SDG indicator framework¹⁹. However, the adoption of the Washington Group Questions by National Statistics Offices remains low.

Administrative data routinely collected by individual ministries as part of operating and managing government programs can provide some data in persons with disabilities. However, there are shortcomings, as administrative data can only provide information on those participating in the programs, may not define disability in line with the CRPD (e.g., eligibility for disability benefits), and may not be comparable with persons without disabilities. Programs that target the general population, such as education or health through management information systems (MIS), should improve collection of administrative data on persons with disabilities, so that mainstream services can better accommodate persons with disabilities²⁰.

¹⁶ Convention on the Rights of Persons with Disabilities 2008, A/RES/61/106, Article 31.

¹⁷ *Ibid.*, Article 33.

¹⁸ See generally, the Washington Group on Disability Statistics, washingtongroup-disability.com.

¹⁹ There are 11 references to disability indicators in the global indicator framework.

²⁰ Mont, Daniel. *UCL Working Paper 32: The Use of Administrative Data in Disability Inclusive Policies*.

There are a number of international and national research institutes, universities, and civil society organizations (including OPDs) conducting qualitative and quantitative data on disability inclusion. However, research and evidence on disability inclusion remains low in comparison with research on other international development issues and the majority derive from the disability sector where disability mainstreaming was not the focus.²¹

Inclusive evidence and data gathering systems should use a targeted and mainstreaming approach to inform inclusive policy making. This is usually achieved through policies and programs led by National Statistics Offices (e.g., national censuses and household surveys) and statistical and administrative data collected led by individual ministries and sub-national government bodies, as well as qualitative and quantitative data and research conducted by of universities, think tanks, research institutes, foundations, OPDs, and CSOs and commissioned by governments, civil society, and private sector.

National accountability mechanisms – UN Human Rights Monitoring Mechanisms, such as UN Treaty Bodies (including the CRPD Committee), UN Special Procedures, and the Human Rights Council, as well as the monitoring and reporting mechanism of the SDGs offer numerous international platforms for monitoring and reporting in order to hold governments to account on human rights obligations and SDG commitments. Some of these mechanisms, such as UN Treaty Bodies, also have complaints mechanisms on rights violations²². In addition, some countries may be held to account through regional bodies that also receive State reports and may have complaints mechanisms. These international monitoring and reporting and complaints mechanisms are essential for advancing the rights of persons with disabilities.

However, national accountability mechanisms for monitoring CRPD implementation and making complaints on rights violations are equally important, and many countries do not have them or maintain ineffective or inaccessible mechanisms. In addition, national independent monitoring mechanisms for SDG implementation often do not include persons with disabilities, resulting in exclusion of persons with disabilities in SDG planning processes.

States are obliged to designate one or more focal points within government for matters relating to the implementation of the CRPD as well as an independent mechanism to promote, protect and monitor the implementation of the CRPD.²³ National government and independent monitoring mechanisms play a critical role in progressing and promoting the CRPD and may carry out a range of responsibilities, such as coordination between disability actors, review of national laws and policies, complaints mechanisms, monitoring and reporting on CRPD implementation, and more. Depending

²¹ International Center for Evidence in Disability, ICED Conference on Evidence in Disability Inclusive Development, 5-6 November 2019, London.

²² However, this function is limited, as claimants must exhaust all domestic remedies before making a complaint, and most UN Treaty Bodies, such as the CRPD Committee, require States to sign up to the complaints mechanism through an Optional Protocol.

²³ Convention on the Rights of Persons with Disabilities 2008, A/RES/61/106, Articles 33.1 and 33.2.

on their functions, national monitoring mechanisms are often arranged through separate ministries or sub-ministry departments, national human rights institutions, national disability commissions, civil society networks or partnerships, and sub-national human rights or disability commissions or councils. There are also a number of national and sub-national government mechanisms, such as complaint mechanisms at ministry level, and independent mechanisms on a range of issues, such as women's rights, Indigenous rights, children's rights, where disability mainstreaming and accessibility should be considered. These mechanisms may be set up via legislation, regulation, policy, or through other formal or informal processes.

Coordination across sectors - In order for the cross-sectoral preconditions for disability inclusion to be a success, actors across sectors need to coordinate and cooperate. This involves building intensive, long-term partnerships and coordination between government, civil society organizations (including OPDs), private sector, academia, and international organizations, including UN entities, to plan, coordinate, and implement policies, programs, and systems to support the preconditions. In addition, it requires coordination across the various thematic or policy sectors, such as education, health, social affairs, gender, employment, economy, finance, procurement, etc., to ensure that the cross-sectoral preconditions work practically across sectors. Moreover, cross-sectoral coordination ensures shared accountability for developing and maintaining the preconditions, making them an integral element within each sector and bringing ingenuity and learning from each sector.

Coordination across sectors is often led by government and is usually implemented through programs, administrative systems, formal bodies, and clearly defined processes and may be standardized through law or policy.