

REPORT

Disability and the Public Sphere

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Contents

06

Introduction

10

The Recent History of the Disability Rights Movement

12

The Definition of Disability with a Theoretical Framework

17

Data discrimination: Acknowledging diversity, not averages

18

The Importance of Collecting Data on People with Disabilities

21

Collecting Data on People with Disabilities in Conflict Zones

24

How to Improve Data Collection?

26

Conclusion

Introduction

People with disabilities are one of the largest and most diverse minorities within the global population, representing a wide range of abilities, ages, races, ethnicities, religions and socioeconomic backgrounds. An estimated 15% of the world's population lives with some form of disability, in which 2 to 4% of these individuals experience significant difficulties in functioning. It is important to note that the global disability predominance is conceivably higher than previous WHO estimates, which date from the 1970s and indicate around a total proportion of 10%. The additional estimated 5% increase in the instances of disability can be due to several reasons, including the rapid spread of diseases and epidemics, the increased prevalence of targeting civilians

in armed conflicts, the increase in life expectancy, and developments in the methodologies used to measure and identify disabilities.

Despite these numbers, however, persons with disabilities are also the least represented in nearly all areas of life. This lack of representation may result in the provision of inequitable access to education, employment opportunities, the necessary disability-related services, and general exclusion from everyday activities. Even though the right to live is the most fundamental



human right, people with disabilities, more often than not, represent an excluded minority. There are several reasons for this. Firstly, there may be a certain stigma around disability since everyone can face disability, whether physical, mental, chronic illness, old age etc.

The stigma is compiled by the fact that many cultures, since ancient times, connect deep-seated superstitions to people with disability. Falsehoods were usually used to describe disability as “abnormal” or “supernatural”. Therefore, regional and global steps need to be taken to eliminate this long and deep-rooted discrimination against disabled individuals.

Even though science has come a long way in determining

the forms of disability that are not limited to bodily functions, there is yet to be a joint agreement on definitions and internationally comparable information on the incidence, distribution, and trends of disability.

Secondly, scholars often examine disability as either an abstract theoretical issue or a medical problem. Before 1970, disabled individuals were considered unhealthy and defective and should be pitied. They were also victims of circumstances that positioned the issues surrounding disability on an individual and medical basis that had to be cured. This was known as the “Medical Model”. However, with the “independent living movement” that was first initiated in America, this understanding shifted toward a more societal level, which was based on the idea that the barriers confronting disabled individuals could be eliminated by social reconstruction. This became known as the “Social Model”. This social model promotes positive



The **stigma** is compiled by the fact that many cultures, since ancient times, connect deep-seated superstitions to **people with disability**.

Falsehoods were usually used to describe disability as “**abnormal**” or “**supernatural**”. Therefore, regional and global steps need to be taken to eliminate this long and deep-rooted **discrimination against disabled individuals**.

“Recognising and respecting differences in others, and treating everyone like you want them to treat you, will help make our **world a better place** for everyone. Care... be your best. You don't have to be handicapped to be different. **Everyone is different!”**

Kim Peek

attitudes towards disabled individuals via laws and policies that advocate for full inclusion without discrimination.

Thirdly, there is the issue of the lack of representation in media (films, TV series, literature etc.). Even on the rare occasions that disabled individuals are represented, they are usually portrayed as inspirational, endeavouring to be as “normal” as possible by trying to overcome their limitations. Another representation method includes depicting them as emotional characters that should be pitied. Until recently, content producers did not seem mindful of the significant number of disabled individuals worldwide. They also did not seem to be aware of the level of “invisible disabilities” such as psychological disorders, chronic illnesses (such as cancer or diabetes) and learning disabilities that predominate over visible ones. While the issues of disabled individuals may receive some attention in the public sphere and media at times, it is usually limited to individual experiences, major court cases, or trending incidents on social media. Thus, stereotypes continue to prevail because of this denial of the reality of disability and issues of disability, and, as a result, disabled individuals tend to be left to exist on social margins.

Furthermore, history has witnessed how the lives of disabled individuals have been devalued simply because they were deemed less valuable to society than what society considered to be ‘normal’. This idea can be traced back to the theories espoused by the Eugenics movement, inspired by Social Darwinism, which is the scientifically flawed theory of “racial improvement” and “[planned breeding](#)”, which are both sets of beliefs and practices that aim to improve the genetic quality of a human population. Popularised in the early 20th century, Eugenicists believed that they could perfect human beings by eliminating what they termed as hereditary “social ills”. Through this idea, they promoted the use of involuntary and forced sterilisation, segregation and even apartheid against disabled individuals (the most infamous one being Nazi Germany and its mass “euthanasia” [killings](#) of more than 200,000 disabled individuals in concentration camps), as well as social exclusion meant to purge society of individuals deemed to be unfit. One of the results was the creation of “special” environments for people with “special needs”.

Pre-1961 international human rights documents did not directly specifically mention disabled individuals, the most notable being the European Social Charter (1961), the first international treaty including explicit provisions on the rights of people with disabilities. Accompanying the International Bill of Rights, the following texts specifically address the rights of people with disabilities:

- 1971 Declaration on the Rights of Mentally Retarded Persons
- 1975 Declaration on the Rights of Disabled Persons
- 1982 World Programme of Action on Disabled Persons
- 1983-1992 International Decade of Disabled Persons
- 1993 United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities
- 1993 The Vienna Declaration on Human Rights
- 2006 UN Convention on the Rights of Persons with Disabilities (UN CRPD)
- 2019 UN Security Council Resolution 2475

In recent years, disability has been acknowledged as a human rights issue since the United Nations Convention on the Rights of Persons with Disabilities (CRPD) entered into force in 2006. However, despite the weight of the issue, there have yet to be sufficient levels of awareness,

scientific information, and developments in all areas regarding disability and disabled individuals. For example, regarding developmental issues, data shows that disabled individuals face graver socioeconomic outcomes, poverty, and conflicts than individuals without disabilities. Furthermore, although the eugenics movement has been widely condemned, practices such as [forced sterilisation](#) and selective abortion without consent remain widespread, especially in China and India.

As part of the UN 2030 Agenda for Sustainable Development, guarantees have been made to “leave no one behind” as part of an effort to specifically highlight the position of disabled individuals in the context of armed conflicts. This action plan from the international community sets a person’s dignity and equality as its fundamental principle. Within the Convention on the Rights of Persons with Disabilities framework, this is essential to confirm the equal input of disabled individuals in all areas of society and establish supportive environments for them. The United Nations Population Fund launched a [new disability inclusion strategy](#) (2022-2025), which intends to put disabled individuals at the centre of UNFPA to accelerate organisational change that embraces diversity and ensures equality.

Today, most of the human rights issues regarding disability and disabled individuals revolve around discrimination and exclusion. Even though disabled individuals are entitled to the same rights as every human being on the planet, the individual and collective disadvantages suffered by disabled individuals are based on a deep-rooted form of institutional discrimination in our society.

Most of the time, changing people’s attitudes and prejudices against people with disabilities is the most challenging obstacle. This environment of stubborn and inherent discrimination against disabled individuals in society consequently results in restrictions on the amount of time, effort, and resources that could be committed to these individuals for a humane understanding and inclusion.

Nevertheless, despite such marginalisation, disability is related to diverse corresponding social issues, hypotheses, classifications, categorisations, attitudes, and representations that contribute to how disabled individuals are perceived and treated. We need to ask ourselves as individuals, societies, and governments:

Where are the voices of disabled individuals?

Why are they left in this situation of exclusion?

Why are disabled individuals excluded in an age of inclusion and diversity?

How do we include disabled individuals in the decision-making and disaster response mechanism processes?

How can we change the social role of disability?

As long as disability is marginalised from other aspects of the human essentials, it will not receive the necessary awareness and discussion.

As TRT World Research Centre, we have initiated a long-term project regarding disability, starting with this report with the primary goal of forming a sound basis of knowledge of the definitions of disability and people with disabilities through a comprehensive description of social and environmental factors. We also aim to create awareness of their issues and analyse some of the recent key data on disabled individuals in order to paint a picture of their current status. In the long run, we aim to focus on more specific issues through comprehensive publications that will be accessible to blind and deaf individuals. We also aim to work with other departments within TRT to create awareness and develop a more accessible platform for the public at large.

While the core international human rights documents contain the substantial capacity to help and protect the human rights of disabled individuals, this potential has yet to be fully understood and implemented. Therefore, through this report, our goal is to provide information on the importance of the definition, history and data inclusion of people with disabilities in order to assist the public, NGOs and governments in taking the necessary actions both on a national and international level to respect the autonomy and dignity of disabled individuals and promote inclusivity, accessibility, and equal opportunity for all.

The Recent History of the Disability Rights Movement

The historical development of disability rights has been in parallel with the development of the concept of disability and growing activism on a global scale. Scientific developments, legal and political changes, and popular mobilisation have all played crucial roles in making a more inclusive society in terms of functioning institutions and social integration. However, this progress has not been easily achieved. For instance, the Eugenics Model developed in 1883 by Francis Galton, a half-cousin of Charles Darwin, has greatly impacted how public perception of disability was shaped. This model suggested a particular form of Social Darwinism in that people were classified into two main groups: those who fit and those who were unfit into the very structure of the existing society. Accordingly, people with disabilities were viewed as the “unfit” segment of society and were excluded from participation in the wider society. Eugenics provided one of the most significant pseudo-scientific justifications for infamous Nazi [policies](#), including segregation, forced sterilisation, and mass murder. With the euthanasia program [Aktion T4](#), approximately 250,000 people with physical or mental disabilities were systematically killed in German-occupied Europe between 1939-45.

In the US, state programs systematically implemented coerced sterilisation against disabled women, justifying it as protection for vulnerable women from unwanted pregnancy. By World War II, these programs sterilised approximately 60,000 persons.

Another impact of the eugenics model was the forced sterilisation of people with physical and mental disabilities, ostensibly done to ensure a healthy society. The ideas of later advocates of the eugenics model, such as Victoria Woodhull, D. Colin Wells, and Lothrop Stoddard, became influential in many European countries and the US during the 19th and 20th centuries.² Their views constituted a “scientific” base for the American legal system that promoted the forcible sterilisation of those who were deemed “unfit” due to mental and physical disabilities (Hawkins, 1997). For instance, the infamous US Supreme Court decision known as *Buck v. Bell* laid the constitutional grounds for legally enforced sterilisation in 1927.³ It is worth mentioning that this clause was referred to by Otto Hofmann, the head of the SS Race and Settlement Main Office, during the subsequent Nuremberg trials after the

Second World War (Bruinius, 2007). Indiana was the first state to enact forcible sterilisation, and 29 states followed suit shortly afterwards. The “scientific” weight of eugenics continued to be an essential reference for enforced sterilisation, as seen in many court decisions during the 20th century (Pfeiffer, 1994). By the 1970s, more than 60,000 people with disabilities had been [sterilised](#) under the dictates of state laws permitting enforced sterilisation in 32 US states.

During the 1960s, with the growing atmosphere of social activism, the disability rights movement began to gain public visibility. People with different forms of disabilities joined the second-wave feminist movements in pursuit of their social demands for equal treatment and to be recognised by state laws. This period was critical because it was the first time people with disabilities began to act collectively. The 1960s, therefore, marked the moment of a major transition from a personal focus to collective endeavours on a broader level.

Furthermore, intersectionality, a “framework for conceptualising a person, group of, or social problem as affected by a number of discriminations and disadvantages” (YW BOSTON BLOG, 2017), became a favoured tool of inclusivity for nearly all social movements. This represented a positive development for persons with disabilities, which meant they were included in numerous social movements.

‘Independent Living’, as a worldwide disability rights movement advocating the idea that people with disabilities are best suited to determine their own needs, policies and reforms related to the specific needs of people with disability, has its origins in these years. From 1960s until 1990, the US Congress passed more than 50 laws on disability rights with a limited scope, such as education and health services reforms. Considering the historical progress of disability rights advocacy, the spirit of collective action and popular mobilisation that took off during the 1960s has played a key role in achieving one of the landmark decisions known as the Americans with Disabilities Act (ADA) passed in 1990. Just 4 months before the passage of the ADA, over 1,000 people marched from the White House to the US Capitol to demand the ADA be passed by Congress. On July 26, 1990, Congress passed the ADA, which would impact the lives of approximately 20% of American citizens. This momentous case is known as Capital Crawl and demonstrates

² Victoria Woodhull was an American leader of women suffrage. Woodhull’s affirmative views on Eugenics and forced sterilisation made her a publicly controversial figure. D. Colin Wells was an American academics whose ideas on eugenics were considerably affected by Woodhull’s writings. Lothrop Stoddard was an American historian, journalist, white supremacist, and white nationalist. He wrote several books which advocated eugenics and scientific racism.

³ The tragic story of *Buck v. Bell* is considered one of the worst Supreme Court rulings. In 1927, Justice Oliver Wendell Holmes, Jr. wrote that the forced sterilisation of “unfit” people, including mental disabilities, is not contradictory to the Due Process Clause of the Fourteenth Amendment to the United States Constitution. Read the official text (see <https://supreme.justia.com/cases/federal/us/274/200/>).

the power of collective action. The purpose of the Americans with Disabilities Act is as follows:

- (1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
- (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
- (3) to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and
- (4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities. ([42 U.S.C. § 12101](#))

The collective spirit of the social movement led to the proliferation of legal arrangements and social reforms in many parts of the world. Below are examples showing the progress of the disability rights movement within the legal frameworks of different countries:

1982- Canada: The Canadian Charter of Rights and Freedoms states that discrimination against people with physical or mental disabilities is legally prohibited. This was the first time such a right was guaranteed in a country's constitution.

1990- China: The Law of the People's Republic of China on the Protection of Disabled Persons was enacted. Accordingly, the law aimed at removing social and institutional barriers preventing the effective integration of people with disabilities into society.

1992- Australia: The Disability Discrimination Act prohibited discrimination against people with disabilities in accessing social services and activities.

1995- United Kingdom: The Disability Discrimination Act 1995 (DDA 1995) banned all forms of discrimination against people with disabilities with regard to access to employment, education, health, and other social services and activities.

2005- Türkiye: The Law on Disabled People aimed to remove barriers to social integration and increase the accessibility of all social services and activities for people with disabilities and their families.

2013- Türkiye: Words considered to be insulting to people with disabilities (such as "gimp" and "faulty") were removed from over 95 of its laws.

Coming to the international level, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted on December 13, 2006. The CRPD has been ratified by 185 countries, making it the most supported convention regarding the human rights of people with disabilities. The significance of the convention also stems from

the phrase "recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". The importance of this is that it does not take disability as a constant and monolithic concept but one that is fluid and progressive. This is also significant because of its emphasis on the interaction between individuals and society, as this report will elaborate this aspect in the next section.

From the infamous Eugenics model to the recognition of disability as an issue primarily related to the existing social structure and insufficient government policies, the development of the disability rights movement has not been a painless process. It has been negatively affected by the groundless pseudo-scientific claims based on Social Darwinism that strove for an ill-considered idea of creating a homogenous society through sterilisation and mass murder. Overcoming the legal and political barriers in this process could only be achieved due to the development of a culture of collective action, which paved the way for a new understanding of disability as a collective and social issue, rather than a personal or private one.

In the **US**, state programs systematically implemented coerced sterilisation against **disabled women**, justifying it as protection for vulnerable women from unwanted pregnancy. **By World War II**, these programs sterilised approximately **60,000 persons**.

The Definition of Disability with a Theoretical Framework



A comprehensive definition of disability is significant not only for understanding the social ramifications of this issue to its fullest degree but also for the effective implementation of policies and projects to be carried out in academic, institutional (e.g., schools, hospitals), and international (e.g., the UN) level. Moreover, understanding a definition through simple and effective descriptions is one step towards overcoming the prejudices surrounding disability. In this context, TRT World Research Centre has made it a preliminary task to examine some of the definitions that have been used to define disability in order to draw out a more inclusive definition, which can be

used in all our future initiatives regarding accessibility for people with disabilities, and public awareness in this field.

It is vital to underline two points in advance before proceeding to the list of definitions used by international organisations. Firstly, there is no consensus among domestic or international organisations on how to define disability. This is due to several factors, including those related to social, cultural, political, or medical reasons. Nevertheless, it would be more productive to compare each definition to reach a more progressive consensus instead of regarding this as a problem. In other words, this will be a process of accumulating knowledge to search for alternatives that meet the needs of all people with disabilities.

Secondly, a theoretical account should be established in order to pinpoint the most appropriate definition(s), as this grounding ensures both choosing the right criteria in the definitions and suggesting policy proposals in line with these definitions. An approach that only considers people with disabilities as a marginalised segment of society does not move beyond a static and deterministic perspective in policy-making processes. In other words, the state would remain limited to a paternalistic character deemed to give certain rights to a marginalised group instead of a social organism in which different groups can actively seek rights and improved opportunities based on collective demands. To avoid this problem, we contend that an ideal definition should not reduce disabilities only to the individual level by ascribing it as a set of physical or mental problems but rather one that contextualises the issue within our everyday relationships that are intersubjective and dynamic. Within this framework, we should consider the conventional liberal approach based on social contract theory, which treats society as a product of a tacit compromise or contract through which individuals come together to establish a state based on a set of norms and values.

A relational understanding of the individual and society allows us to think critically about the conceptions of the environment in which people try to survive. Accordingly, the knowledge that disability refers to the environment or society in which no one has a prior right to choose is needed for an ideal definition. The other point that needs to be addressed in a proper definition is the degree to which it necessitates *rectificatory* justice for policymakers. When the society in which everyone abides by a set of norms is considered a constructed entity -as in the theory of social contract - it is easier to find effective solutions to everyday inequalities. This point is addressed by John Rawls (1971) in his seminal work, *A Theory of Justice*, where he offers



a thought experiment in which a group of individuals are to decide basic rights and duties and to determine the division of social benefits among all members of the society. However, in this hypothetical scenario, this group of individuals do not have any background information about their status and class in society after distributing benefits, rights, and duties. As Rawls states, they are expected to decide behind a *veil of ignorance*. Since this group of people will know nothing about their class, gender, race, or religion, they must act impartially and equally. Rawls contends that a society can be designed as impartial and equal only if we adopt this point of view. Thus, justice can only be achieved in this way. Yet, the Rawlsian account for such a social designation has some shortcomings when it comes to the concept of disability and people with disabilities since he does not mention –and even excludes– people with disabilities in the hypothetical thought experiment, which he calls the Original Position: “But given our aim, I put aside for the time being these temporary disabilities and also permanent disabilities or mental disorders so severe as to prevent people from being cooperating members of society in the usual sense.” (Rawls, 1993: 20). In the end, the Rawlsian social contract discussion ends up with an idealised society vision based on the equal distribution of rights without discrimination. However, the missing point in this framework is whether people with disabilities will be able to use these resources as they wish. In addition, Rawls signifies two moral capacities that are prerequisites for a fair system of social cooperation among citizens: a capacity for a sense of justice and a capacity for a conception of the good (Brighouse, 2001). Even though people with physical disabilities are included in the Original Position that lays the grounds for a just society, the exclusionary notion based on the necessity of a sense of justice and conception of good hinders people with cognitive disabilities from effectively participating in the designation of a just society in Rawls’ thought experiment. Only those with these moral capacities are seen as eligible for social cooperation in a just social order. In other words, the Rawlsian social contract perspective presents individuals with physical and mental disabilities as newcomers⁴ to society. Thus, this standpoint does not consider them a normal population segment. It also makes it difficult to ensure that people with disabilities are included in the designation of social structures in line with their demands, such as access to basic services and the right to be protected from attempts against human dignity.

To avoid the problem of ableism and exclusion, exceeding the inherent limitations of the Rawlsian framework is necessary by including people with disabilities in forming

a society that is expected to have enough capacity to fulfil their requirements. In this regard, Nussbaum’s Capabilities Approach offers some useful insights. It can be seen as a critical expansion of the Rawlsian theoretical framework in an inclusive way. She provides a list of ten core capabilities that centre around the idea of human dignity: life, bodily health, bodily integrity, senses, imagination and thought, emotions, practical reason, affiliation, other species, play, and control over one’s environment. Combined with the fundamental idea of human dignity, an ideal definition that seeks to promote social awareness and recognition of people with disabilities should consider some of these capabilities. For instance, Nussbaum (2011) defines affiliation as follows:

Affiliation: (A) Being able to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.) (B) Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin (p.34).

For definitional purposes, an ideal definition should be the one that gives utmost importance to the actualisation of affiliation as a core capability in both social and institutional terms. Here the phrase “to be able to imagine the situation of another” should be taken as a basis for making appropriate reforms that promote the social integration of disabled individuals, not by forcing them to comply with the embedded rules, norms, and modes of the existing social systems and institutional structures but making the social systems and institutional structures suitable and inclusive per se.

Since the issue of people with disabilities touches upon many aspects of everyday life, from public services to social inclusion, it can be evaluated within a tripartite framework consisting of individuals, society, and institutions. This approach exceeds the limits of previous understandings of the issue that was reduced to the provision of some social rights on a legal basis. However, the issue is not limited only to a question of legal provisions. It is also closely related to

⁴ They are referred to in these terms as they are not included in the designation of society in terms of having a say and right to state their own demands and claims about just society, i.e., access to services, human dignity etc.

how we improve the environment, society and institutions so that people with disabilities or caregivers can access them easily:

To secure a capability to a person it is not sufficient to produce good internal states of readiness to act. It is necessary, as well, to prepare the material and institutional environment so that people are actually able to function (Nussbaum, 2002, p. 132).

A similar approach was developed by Amartya Sen, a notable scholar in the field of developmental economics. Regarding the concept of development, he distinguishes between entitlements and capabilities (Sen, 1983). In broad terms, the former refers to the legally guaranteed rights and liberties that individuals can have. However, the essential point is related to the capabilities that imply whether individuals can enjoy the rights and liberties provided by the legal framework. Therefore, the issue of people with disabilities should be contextualised in a way that determines whether they can use their rights in social, political, and economic settings without any potential risk that may make them unable to do so. To put it differently, and perhaps more succinctly, the fundamental question is whether the society and institutions, which are two parts of the tripartite relationship, have a disability in providing a conducive environment for people with disabilities to actualise their rights and freedoms.

In Nussbaum's list of ten capabilities, there is a point listed as "control over one's environment". She defines this point as "being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association". This point leads us to think about how, for instance, people with disabilities can participate in democratic processes such as elections. Can any definition of democracy that substantially or procedurally excludes people with disabilities be considered democratic? How does representative democracy work in a way that promotes the rights of people with disabilities through a set of reforms and institutional arrangements? We should expect these critical and constructive questions from a comprehensive definition. It is evident that Nussbaum's list of ten capabilities can be interpreted in numerous ways to develop a genuine definition of disability. However, the central idea that should always be kept in mind is the concept of human dignity and the preparation of material and institutional environments in which people with disabilities can function.

With these theories in mind, we have collected below the list of different definitions used by prominent international

organisations on disability and people with disabilities.

"Disability results from the interaction between individuals with a health condition, such as cerebral palsy, down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support."

World Health Organisation (WHO)

"A person with a disability is a person who has a physical or mental impairment that substantially limits one or more major life activity. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability." **Americans with Disabilities Act (ADA)**

"In addition to ADA's definition, the disability includes, but is in no way limited to, mental health disabilities, chronic illnesses, intellectual disabilities, and hearing and vision disabilities." **Disability & Philanthropy Forum**

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." **United Nations Convention on the Rights of Persons with Disabilities (CRPD)**

"A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)." **Centres for Disease Control and Prevention (CDC)**

As stated at the beginning of this section, there are definitional differences among different organisations. In order for this diversity to be seen as advantageous, a comparative examination of each definition is required. Considering our theoretical framework that focuses primarily on the concept of human dignity and the emphasis on the environment in which people with disabilities can function, the definition by the United Nations Convention on

the Rights of Persons with Disabilities (CRPD) comprises the most promising idea of “changing the environment, not the people” and will be used as the primary definition in the rest of this report. Together with the CRPD’s definition used by the UN Department of Economic and Social Affairs-Disability, the report will conceptually highlight the word *interaction* used in different definitions to emphasise the *intersubjective* aspect of the issue that gives way to discuss further social awareness. The gist of our brief theoretical discussion that has led us to settle on the definition used by the CRPD as a guiding framework can be summarised in terms of four main ideas:

1. As stated in the basic definition, the issue of disability cannot be considered independently of the interaction of the disabled individual and society.
2. The approach to be taken as a basis for all reforms and policies should focus on human

dignity and is far from all kinds of discrimination, in addition to the points stated in the definition.

3. Ensuring public awareness is vital for the sustainability of all policies and reforms since the issue is not limited to the disabled individual(s) but the environment or society in which they survive and should thrive.

4. The central idea of policy-making and reforming is preparing material and institutional environments in which people with disabilities can function. It is not only an issue of making legal reforms or allocating resources but also giving people with disabilities and caregivers easy access to them without any barriers.

We hope that a comprehensive definition will provide a theoretical basis for making social policies that can succinctly answer our thought-provoking questions in the introduction.



The definition by the **United Nations Convention on the Rights of Persons with Disabilities** (CRPD) comprises the most promising idea of “**changing the environment, not the people**” and will be used as the primary definition in the rest of this report.

Data discrimination: Acknowledging diversity, not averages



Data collection is an integral part of the policy-making processes in the field of social research. It provides both the general public and policymakers with a comprehensive understanding of the population in terms of demographics, preferences, and demands. In this context, data collection on people with disabilities is of great significance because it directly impacts the political decisions, social projects, and legal reforms designed to improve the living conditions and standing of disabled individuals in society. As indicated in the previous section, the CRPD definition holds that persons with disabilities include those with long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. The term interaction in this definition sheds light on the nature of the relationship between people with disabilities and the community. Therefore, in order to improve social conditions, the problems experienced by these individuals should be examined in the light of statistical data that addresses these individuals directly. As mentioned, the term disability covers many situations, and people with disabilities are not a homogeneous group. Thus, there are significant inequalities, with those living in poverty, women, and older people more likely to experience disability than others. In 2011, the World Health Organization (WHO) estimated that 15% of the global population has some sort of disability. This figure has been frequently cited and continues to provide a useful starting point for discussion. However, according to WHO, "there is an urgent need for more robust, comparable, and complete data collection" in disability statistics.

For example, school attendance rates differ among people with a disability: children with physical disabilities generally manage better than those with intellectual or sensory disabilities. Similarly, the most excluded from the labour market are those with mental health issues or learning disabilities. People with more severe disabilities often experience more significant disadvantages. Other

examples include women and girls with disabilities who experience double discrimination because of their gender and disability and are especially vulnerable to violence and abuse, and the discrimination of those with invisible disabilities (Disabilities that are not visible, such as a chronic illness, a psychological issue etc.) who face different challenges in times of war.

The other point related to the data collection on people with disabilities is the level of democratic participation and inclusiveness. Since people with disabilities have long been seen as a marginalised segment of society, public opinion polls have faced some difficulties of generalisability, particularly at the sampling stage of the data collection process. In this respect, it begs the question of just how many of the surveys regarding disabilities are, in fact, accessible, let alone inclusive?

Accessibility data collection is one of the most significant challenges. For example, cities collect data to analyse the behaviour of pedestrians, but does it differentiate between the many types of disabilities? Similarly, GPS has become an essential tool for many drivers and pedestrians, but what about those who cannot see or use a wheelchair? In this context, navigating through urban spaces with different abilities demands accessing distinctive, standardised, and extensive data about pedestrian pathways. However, this data is often unavailable, and even if it is, it is more often than not limited and inconsistent.

After a brief examination of the issues regarding the collection of data on people with disabilities, this section seeks to find answers to the following questions:

- 1. Why is collecting data on disabilities a significant part of public policy-making?**
- 2. How can international organisations deal with data collection challenges in conflict zones?**
- 3. How can data collection be improved to understand people with disabilities better?**

The Importance of Collecting Data on People with Disabilities





Persons with disabilities tend to be unidentified, underrepresented or even excluded from official statistics. There can be several reasons for this, such as considering people with disabilities as a low political priority, inadequate capability and technical limitations. It is estimated that 80% of people with disabilities live in developing countries, and 22% of people in the poorest communities in low-income countries have a disability. Furthermore, Women, men, girls and boys with disabilities are often among the poorest and most marginalised in any community. Due to the obstacles they face, they are often overlooked in development processes or have not been able to benefit from development activities equally. Disability-inclusive structure and planning outcomes demand consciously compiling information from and about people with disabilities.

While considering data collection about people with disabilities, one must acknowledge their existence as a diverse group: each person's experience of disability is unique and shaped by many aspects, such as their gender, age, type of impairment, education level, cultural context, etc. However, the issue with data collection, unless otherwise stated, is usually based on averages and refers to an almost homogenous group. Engaging with all members requires disaggregated data to support the complexity of disability, particularly the intersections of disability exclusion and gender-based inequalities.

To understand why specific data collection regarding people with disabilities is significant, let us take a look at the two statements below:

- A. *"There are millions of people with disabilities in the world."*
- B. *"According to the WHO estimates, approximately 15% of the world population –over a billion people– live with some form of disability. Comparatively, women are more likely to have physical or mental disabilities than men, and older people are more likely to have disabilities than young people. Also, there are more disabled individuals in developing and low-income countries than in developed countries. The difficulties faced by people with disabilities are multiplied by the lack of accessibility to social services in low and middle-income countries."*

Understandably, statistical data presents a rather concrete picture of a significant social reality by

offering numbers and details on age, gender, etc. in a given country. Through the disaggregated data method, more inclusive projects can be carried out through policy-making that affects the integration and interaction of people with disabilities in society. For example, through a preparation process in which up-to-date data are taken into account, public buildings such as schools and hospitals built in a given neighbourhood can be improved, and the factors that make it difficult for people with disabilities to access these services can be eliminated. Utilising the statistical information obtained from data collection, public buildings can be designed with access facilities well suited for their designated purpose.

The significance of data collection on people with disabilities is not limited to improving access to public buildings and services. Qualitative data such as interviews and surveys can help fill gaps in between hard data. In this way, for example, access problems experienced by visually impaired or hard of hearing individuals on digital platforms can be understood, and accessibility services can be provided and improved. Overall, the data collection process helps ensure the effective functioning of the individual-society-institution triangle in terms of integration and interaction.

What can be said about the people living in different geographies that lack even basic infrastructural development? Data collection approaches need to consider that women, men, boys and girls with disabilities may often be forced to hide or be less visible within their communities and households as a result of cultural practices and systems that disempower them. To have a unified approach, data collection should be globalised by widening the scope of information exchange. Since there are substantial infrastructural gaps between high-income and low-income countries, each country would need to provide updates and statistical information about people with disabilities to international organisations to develop a unified approach towards data collection. In that regard, the World Health Organisation (WHO) achieved a milestone in 2012. The Module Disability Survey (MDS) was developed in order to provide detailed information about people with disabilities based on the International Classification of Functioning, Disability, and Health (ICF) which utilises the CRPD definition as a ground. The WHO defines the MDS as the following:

The Model Disability Survey (MDS) is a general population survey that provides comprehensive information about the distribution of disability in a country or region. By collecting detailed and nuanced information about how people with different levels of disability conduct their lives, it identifies unmet needs as well as barriers and inequalities. The MDS helps Member States develop policies and services and

provides the data to monitor the progress of countries on meeting their obligations regarding the Sustainable Development Goals and the Convention on the Rights of Persons with Disabilities (WHO, 2022).

On a global scale, this WHO initiative represents a prospective model moving forward. Instead of limiting the scope of this problem to the individual level as a part of one's own private matter, such initiatives make the difficulties of people with disabilities globally more visible, thereby shifting the focus from a narrow individual level to a global unit of analysis. Moreover, these initiatives can stimulate other international organisations to assist middle and low-income countries in financing and institutionalising public initiatives on disability. In order for MDS to be up to date, it is essential to establish communication channels for information exchange with local and regional authorities. Nevertheless, it should be underlined that neither the WHO nor any other international organisation has a legally binding authority to request contemporary information. Data collection depends heavily on the effective functioning of local authorities in coordination with NGOs and other public institutions. It is also important to highlight that understanding the disability context on a regional scale and collecting disability-disaggregated monitoring data is required for equitable development as the proposed [Sustainable Development Goals](#) (SDGs).

While considering data collection about people with disabilities, one must acknowledge their existence as a diverse group: **each person's experience of disability is unique and shaped** by many aspects, such as their gender, age, type of **impairment, education level, cultural context, etc.**

Collecting Data on People with Disabilities in Conflict Zones

In order to ensure that persons with disabilities are protected and assisted during times of conflict, reliable and timely information is needed regarding people with disability in conflict zones and the barriers they face. Disability-disaggregated data are insufficient, especially when it comes to humanitarian situations, which has accumulated substantial political commitment to improve data availability. However, international organisations such as the UN and its agents, CRPD, and humanitarian non-governmental organisations are still in the developing stages of improving their data collection processes in conflict zones to implement the Convention's article 11:

"States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters".

International organisations such as the **UN** and **its agents, CRPD**, and **humanitarian non-governmental organisations** are still in the developing stages of improving their data collection processes in conflict zones to implement the **Convention's article 11**.



and article 31:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

The gradual advancement towards enhancing disability-disaggregated data in conflict zones is partly a result of the wide diversity of the crises themselves. Different emergency contexts present unique challenges for data collectors and impact persons with disabilities differently.

From Ukraine to Yemen, disabled people and caregivers face severe problems in armed conflicts. Since it is widely observed that civilians in armed conflicts can be attacked and left injured and physically disabled thereon, we have to make an important distinction. While there are people who face disability as casualties of war, with veterans that sustained physical impairments at the centre stage, we have to clarify that there are other people with disabilities whose impairments existed before a conflict, including those with mental disabilities and chronic illnesses. The latter group tends to be dismissed, even though they represent a:

"particularly marginalised and vulnerable groups, who are subjected to a myriad of abuse, including unlawful killings, rape, forced marriage, and other forms of sexual violence, forced evictions, and limited access to health services, food and water, and other essential services" (Rohwerder, 2018).

Disabled people, who had struggled with serious difficulties even before these difficult conditions arrived, are in further distress when it comes to survival, nutrition, shelter, and other basic needs in conflict areas. At this point, the significance of disabled inclusive data collection comes to the fore. We do not have detailed information on the extent to which the assistance provided by international aid organisations in refugee camps in conflict zones or humanitarian corridors determined by international agreements covers people with disabilities. In this regard, it should be underlined that the principle of "[no one should be left behind](#)" can be realised in light of data on the difficulties experienced by disabled people in conflict zones.

For example, Somalia is one of several ongoing crises that have been in a state of conflict for several decades. The underlying conflict that perpetuates Somalia's crisis persists and periodically spikes since it began in 1991 with the overthrow of Mohamed Said Barre. What is more, the fragility of the country's state institutions, geopolitical factors, and the rise of radical groups further complicate the issue of not only peace-making but also delivering aid to those who are in need. Somalia has appealed to the international community for humanitarian assistance annually for decades. As a result, Somalia's crisis has widespread consequences on persons with disabilities, including internal displacement, food insecurity, and lack of health and education services. Furthermore, the conflict produces an estimated 7,000 new wounded people annually resulting from explosives remains of the war (Rohwerder, 2018). Data depicting Somalia's demographics are limited because of the decades-long conflict, with the last limited census occurring in 1975 (United Nations, 2014). Thus, statistics on the number of persons with disabilities are non-existent, adding to the factors mentioned above. The international community's engagement is critical to address some of these data collection issues. In 2014, the UN Population Fund launched a nationwide survey in Somalia to collect data on the characteristics of the Somali population (United Nations, 2014). However, although this report included gender and age factors, it did not include disability.

Just as it contributes to the inclusiveness of regional or local projects designated by social policy-making, data collection in conflict zones similarly helps to determine alternative strategies for international aid organisations to reach people with disabilities more effectively. To have a more inclusive agenda, it is necessary to have an indicator that provides a detailed account of the extent to which people with disabilities are reached in aid allocation, evacuation, and replacement processes. When data collection approaches are standardised, disaggregating data by disability in humanitarian action becomes possible.

Number of people with disabilities in conflict zones⁵

CONFLICT ZONES	NUMBER OF PEOPLE WITH DISABILITIES
SYRIA	~ 5.5 MILLION
UKRAINE	2.7 MILLION
YEMEN	4.8 MILLION
SOMALIA	~ 1.5 MILLION
AFGHANISTAN	4.4 MILLION
SOUTH SUDAN	1.8 MILLION
MYANMAR	5.9 MILLION
ETHIOPIA	~ 15 MILLION
PALESTINE	93.000
IRAQ	+1 MILLION

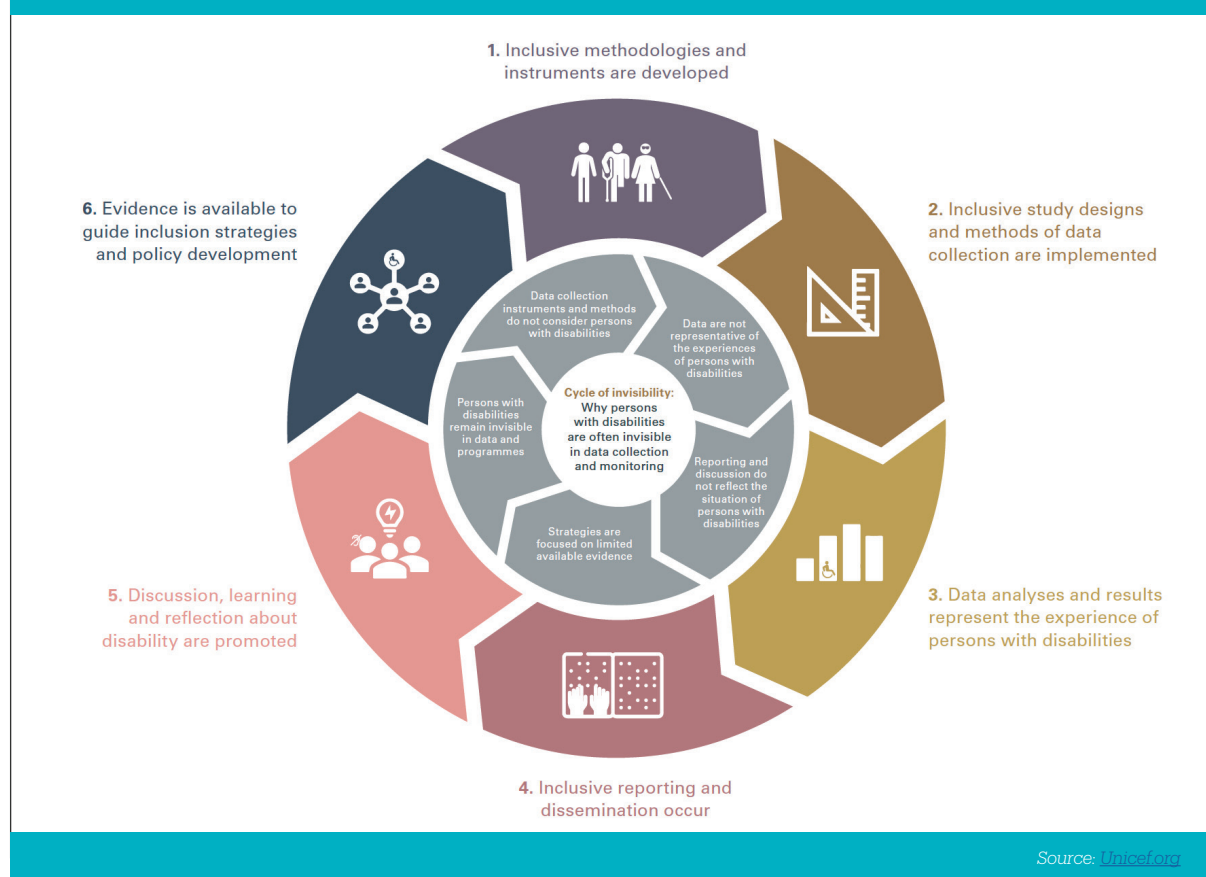
Providing rapid and effective response in conflict zones depends on obtaining comprehensive data. Governments and organisations must dedicate resources to address the barriers that prevent equitable access and participation of persons with disabilities in all aspects of society. Furthermore, they must aim to implement practical strategies to make their data collection and monitoring efforts disability-inclusive. This becomes much more manageable if international organisations cooperate with local authorities. In this context, it is crucial to increase the effectiveness of the WHO's Model Disability Survey, which depends mainly on information flows from local sources. Quantitative data on the lack of infrastructure and facilities in conflict zones represents a significant step

in terms of providing guidelines for aid organisations and the international community in a broader sense. Persons with disabilities who received humanitarian assistance in conflict zones should be registered. This number should then be compared with pre-existing data on people with disabilities, and this framework should be subsequently and consistently updated. Together with quantitative data, interviews with people with disabilities and/or their caregivers can be very influential in increasing social awareness. Media platforms can disseminate the individual stories of these people in a way that the general public may take a keen interest and understand the urgency of the matter.

⁵ The data is a compilation of the most recent statistics taken from different international organisations such as UN, EDF, WHO, AIHRC, and national bureaus of statistics. Since data collection is a much harder issue in conflict zones, some of the statistics are outdated -as in the case of Somalia whose data is from 2008. The data on Syria and Ukraine makes a distinction between people with disabilities before the armed conflict began and people with disabilities as a result of armed conflict. However, in other cases, especially in the Sub-Saharan Africa, it is hard to collect data that diversifies the sample based on pre-war and post-war injuries.

How to Improve Data Collection?

Breaking the cycle of invisibility related to persons with disabilities



Disability inclusion within data collection is an important process. To guarantee a good output, all people with disabilities should participate fully. However, collecting data on people with disabilities is ultimately a complicated route that necessitates a sophisticated understanding of the focus group and method, as well as ethical considerations.

The type and quality of data are directly affected by the definition of disability in data collection tools. Clarifying the definition is crucial as it determines who is identified as having a disability and is included in the assessment. At the same time, it also determines who will be considered in developing the necessary guidelines and programmes. As such, stigmatising labels while collecting data about persons with disabilities also significantly impacts

the quality and scope. Disability statistics have been primarily centred around the medical model of disability, which highlights illnesses, disorders and the existence of specific impairments. Measures developed from this perspective have treated disability as dichotomous and have categorised persons with disabilities as those with specific impairments (Dubois et.al., 2009). Unfortunately, this approach has limited the views of persons with disabilities to stereotypes such as 'wheelchair users' or having a visible disability, resulting in verbal abuse and humiliation. In other words, they limited the scope of research and solution methods. Therefore, researchers who conduct interviews and surveys on this "sensitive" issue should receive comprehensive training. In the case that researchers may sometimes reduce the definition of disability to its physical dimension, i.e. visual impairment while forming the questions in the data collection process,

they may overshadow the definition of disability related to its social dimension that signifies the interaction between people with disabilities and the society (Blaser and Ladner, 2020). For the focus group, it should be first noted that the concept of disability is not monolithic, meaning that there are several types of physical and mental disabilities. In this context, it is necessary to evaluate each type of disability separately in the data collection process to avoid an aggregate data problem that lacks any categorisation and detail. When examining focus groups, age and gender classification should be made only to the extent determined by medical standards to ensure no selection bias. Also, it can sometimes be necessary for researchers to conduct interviews with caregivers who are personally knowledgeable about the problems experienced by those they care for. They can be another focus group whose first-hand observations directly reflect these problems. Therefore, the data collection process must necessarily be inclusive to embrace people with disabilities and those responsible for their daily care. With regards to method, it should be a primary concern for researchers in different

organisations to combine qualitative and quantitative works. The very reason for mixed methods is that numerical assessments have limitations on the extent they can paint a detailed picture of reality, especially in crisis situations. Qualitative approaches, such as interviews that focus on individual stories, should also be conducted to add texture and context to the hard data. Lastly, ethical considerations have great significance in all statistical works, not only in the process of collecting data on people with disabilities.

Nevertheless, in the context of people with disabilities, researchers should be much more attentive and sensitive to the concept of human dignity. Regarding ethical issues, researchers who aim to conduct interviews should use the framework of the MDS. The latter provides a comprehensive [Survey Manual](#) for preparing questions in compliance with ethical considerations in the context of disabilities. Finally, suitable training should always be the primary consideration for all researchers to perform qualified and ethically appropriate data collection.



Collecting data on people with **disabilities** is **ultimately** a **complicated route** that necessitates a sophisticated understanding of the **focus group** and **method**, as well as ethical considerations.

Conclusion

Being disabled is part of the human condition. Nearly everyone can expect to be temporarily or permanently disabled at one point in their lives, and those who make it to old age will experience escalating challenges in their ability to function. Disability is complicated and the responses needed to tackle the disadvantage of disability are numerous, systemic and will change depending on the context. Having a comprehensive and common definition of disability is one of the most important initiatives that should be taken on a global and regional scale because it constitutes a significant step toward a common methodology and a common goal in social programs and projects. The definition must be inclusive of all disability types, physical, mental, chronic illnesses, invisible and visible. However, while doing so, one must remember that each disability is unique and can affect every individual differently based on age, gender, physical features, geographical location etc. Thus, in order to achieve a more inclusive, encompassing data collection process for people with disabilities, states and international organisations should focus on developing new forms of information collection and data processing, an innovation that comprises, for instance, a new index measuring the overall performance of humanitarian aid organisations in terms of the extent to which they cover people with disabilities when they allocate aid.

Disability rights are human rights. Putting them on the top of political, social, and economic agendas is a must. Despite the existence of disability for millenaries, guidelines are relatively new. Thus, addressing the void between policy and practice on the ground is a vital step. People with disabilities are subject to multiple and deep-rooted human rights violations, including neglecting their access to most basic needs and rights, such as the right to feel safe, the right to access public services etc. These violations occur whenever there are gaps in legislation, policies, or resources. What is more, when considering the current global environment, including ongoing armed conflicts, natural disasters, migration, etc.,

people with disabilities are not seen as a priority, especially as people flee and systems are broken. Women and children become more vulnerable during times of crisis; thus, specific emergency appeals must prioritise their safety.

Furthermore, people with disabilities must also be aware of their rights and where to go if they are denied their rights. For this reason, international organisations must create awareness on all levels that incorporates people with disabilities, their caregivers, teachers, social workers, doctors, architects, etc.

Data assist the process of decision-making regarding disability policies and programmes. Recognising the number of people with disabilities as well as the circumstances in their lives, can enhance future efforts to eradicate barriers and offer services that ensure the inclusion of people with disabilities. With this awareness in mind, actions must prevail to stimulate more inclusive data collection, emphasising the uniqueness of each disability. Thus, this report is merely the first among a series of publications, including a policy brief in which we will present a set of recommendations. For the moment, this report aims to highlight the reasons for the exclusions of people with disabilities through a historical and deep-rooted background while also reflecting some of the recent initiatives of countries to make up for long-needed laws and regulations that support people with disabilities. We hope that with the information and example provided in this report, the importance of intersectionality in disability data collection is more transparent. For example, Data collected at the national level should be internationally comparable. The data and information to assist national policies on disability should be consulted in a wide variety of places, including data from statistical agencies, administrative data collected by government agencies, reports prepared by government bodies, international organisations, NGOs and disabled people's organisations, as well as the usual academic journals. This information, including good examples, needs to be disseminated among a wider network of countries.



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