

Disability Inclusion Helpdesk Report No: 74

Query title	Evidence on disability inclusion, open societies and human rights
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Query	<ul style="list-style-type: none">• What is disability? What do we mean by inclusion of persons with disabilities? – definitions, human rights model and movement “nothing about us without us” and international policy framing.• What is the context of disability inclusion and open societies and human rights?• What progress has been made in recent years and what gaps remain?• What is the evidence on disability inclusion in key sectors such as democratic governance and political empowerment; digital inclusion; civil society and civic space, including localisation; international UN conventions and resolutions; modern slavery.
Enquirer	Disability Inclusion Team

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1. Overview

This query first provides an introduction to disability inclusion and models of disability. It then summarises the available evidence on disability inclusion and open societies and human rights, before considering evidence on disability inclusion in key sectors.

Persons with disabilities face challenges to participating in open societies and exercising their full human rights. This includes barriers to participating in democratic processes, being deprived of their liberty and legal capacity through institutionalisation or guardianship schemes, increased risks of violence, and barriers to accessing information and free media.

2. Methodology

This rapid research query has been carried out in five days of researcher and expert time. Material was included from the following sources:

- Literature suggested by Lorraine Wapling, Senior Disability Inclusion Expert .
- Google and relevant electronic databases (PubMed, Science Direct, and Google Scholar) for priority sources using a selection of key search terms used in systematic reviews to identify more recent materials.
- Review of key disability evidence portals and resource centres.

3. Background

a. Defining disability

The [United Nations Convention on the Rights of Persons with Disabilities](#) (CRPD), enacted in 2008, is an international human rights treaty which protects and promotes the rights and dignity of persons with disabilities. The UK ratified the CRPD in 2009. The CRPD's human rights-based approach to disability identifies persons with disabilities as: **'...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'** (Article 1, UNCRPD). One billion people (or 15% of the world's population) experience some form of disability, with disability prevalence higher in developing countries and increasing with age (WHO, 2011).

Impairments (e.g., physical, cognitive or sensory) become disabling when they interact with societal barriers, for example prevailing negative attitudes, behaviours and policies or inaccessible physical spaces and communication systems that exclude the individual(s) from participating fully in society. For example, inaccessible signage or footpaths represent environmental barriers that deny access to markets or workplaces for individuals with visual or physical impairments. Lack of closed captions or sign language interpreters during government COVID briefings would represent environmental barriers for those with hearing impairments. Other types of barriers include attitudinal barriers such as stigma and discrimination (for example where women with disabilities are excluded from shared WASH facilities for fear of contamination), and institutional barriers such as discriminatory laws and policies (such as enforced institutionalisation of people with cognitive or psycho-social impairments).

Impairments can also combine with other key factors and identities to compound the level of marginalisation experienced, for example age, gender identity, ethnicity, sexual orientation, socio-economic background, and rural versus urban locations. People may also experience different levels of discrimination based on whether their impairments are visible or not, or whether they are acquired (especially through conflict or climate-related disasters) or present from early life. The experience of disability therefore varies widely, with at least as much variation amongst persons with disabilities as there is amongst those without disabilities (Stanford Encyclopaedia of Philosophy, 2016).

Persons with disabilities are disproportionately likely to be in poverty (Lee and Fraser, 2020). This occurs due to disparities in access to education and employment for persons with disability, alongside attitudinal barriers linked to disability-related stigma, environmental barriers such as lack of accessible infrastructure, and institutional barriers including limited supportive laws and policies.

b. Models of disability

There are several ways of approaching disability within development, which are often referred to as the models of disability. The UNCRPD's **human rights-based approach places an emphasis on removing the barriers that make impairments disabling.** In contrast, a **'medical model'** approach focuses on 'fixing' the individual, not upon removing barriers external to the individual, whilst a **'charity model'** approach typically positions people with disabilities as separate from mainstream society whose needs are met by others (e.g., housing

people with disabilities within institutions). This query is framed according to a human-rights based approach.

The principle of **'nothing about us, without us'** emphasises the need for persons with disabilities to be included, and provide leadership, on all initiatives regarding persons with disabilities, including policies, legislation and programme interventions. This is a rights-based approach that supports disenfranchised communities to claim their agency, build political power, and choose their own priorities. This can take the form of actively partnering with organisations of persons with disabilities (OPDs) and/or by ensuring that persons with disabilities are active contributors in public forums and decision-making groups.

c. International Policy Framing

Whilst all core human rights frameworks, such as the [Universal Declaration of Human Rights](#), apply equally to persons with disabilities, persons with disabilities have traditionally been invisible and excluded from discussions on rights since they are not explicitly mentioned.

The CRPD is designed to rectify this situation (it did not create any new rights) and as such it sets out what governments need to do to ensure that persons with disabilities can fully enjoy their human rights. It was adopted in 2006 and entered into force in 2008. Amongst other areas, it covers right to life, access to justice, education, independent living, employment, and adequate standards of living. It also highlights the rights of women and children with disabilities as groups that face multiple and intersecting forms of discrimination. Importantly, **there are two specific Articles focused on the need for inclusive humanitarian responses (article 11) and international development (article 32).** There is an [Optional Protocol](#) to the CRPD that gives the CRPD Committee the capacity to accept and examine complaints filed by individuals, and launch enquiries where there is evidence of grave and systematic violations of human rights. The UK ratified the Optional Protocol in 2009.

d. Progress in recent years and gaps remaining

As of June 2021,¹ 182 state parties have ratified or acceded to the CRPD, and a further nine are signatories.² Seven states have taken no action on the CRPD: Botswana, Equatorial Guinea, Eritrea, Holy Sea, Niue, South Sudan, and Timor-Leste.

Highlighting the need for awareness raising, the UN Human Rights Council recently reported that **disability remains largely invisible as a human rights issue** (OHCHR, 2019). Gaps remain in understanding how negative attitudes and stigma oppresses persons with disabilities and leads to violations of their human rights. This is despite the fact that Article 8 places States Parties under obligation to raise awareness in order to combat prejudices and negative stereotypes including through improving how persons with disabilities are portrayed by the media.

Furthermore, **many laws, including those on employment, marriage, voting and property-related rights, fail to uphold the obligations to persons with disabilities that the CRPD sets out** (UN DESA, 2018). For example, in 53% of countries (186 reviewed) dismissal, suspension or termination of employment is permitted without recourse if a person has a

¹ The Status of Ratification Interactive Dashboard can be found here: <https://indicators.ohchr.org/>

² CRPD signatories: Bhutan, Cameroon, Lebanon, Liechtenstein, Solomon Islands, Tajikistan, Tonga, USA, and Uzbekistan.

psychosocial disability.

In most low- and middle-income countries, few significant policies or programs for disability rights have been developed or adequately publicly funded (IDA, 2021a). For example, data from India, Mauritius, Namibia, the Philippines, South Africa and Pacific Island countries indicate that allocations are below 0.5% of GDP, and in some, such as India, allocations are less than 0.1% of GDP, compared to 2.1% of GDP on average in higher income countries.

A series of regional consultations took place during the first half of 2021 between members of the Committee on the Rights of Persons with Disabilities and persons with disabilities through their representative organisations. The meeting outcome document highlighted the following gaps in progress towards equalisation of opportunities:

- Despite widespread ratification of the CRPD, the **medical and charity models persist in many societies and legislative frameworks**. Thus, negative assumptions that persons with disabilities do not have the competence or capability to live independently, that they require assistance and cannot contribute to development continue to dominate the discourse (Africa; Asia and Pacific; Caribbean and North America; Eastern Europe and Central Asia; EU and other Western European States; MENA).
- **Persistence of discriminatory laws that deny or restrict legal capacity** of persons with disabilities and perpetuate institutionalization, particularly persons with intellectual disabilities (Africa; Asia and Pacific; Caribbean and North America; Central and South America; Eastern Europe and Central Asia; EU and other Western European States; MENA).
- **Persistence of social stigma and negative stereotypes** leading to internalised oppression (Africa; Asia and Pacific; Caribbean and North America; Central and South America; Eastern Europe and Central Asia; MENA).
- **Ongoing discrimination**, including the lack of reasonable accommodation³, in access to education, employment and training; health services (including sexual reproductive health services); law enforcement and justice; transportation; and digital and traditional communications (Africa; Asia and Pacific; Central and South America; EU and other Western European States; MENA).
- **Continuing violence against persons with disabilities** in the home, institutional and medical settings and in public, particularly against women with disabilities and people who rely on caregivers (Africa; Asia and Pacific; Caribbean and North America; Central and South America; Eastern Europe and Central Asia; EU and other Western European States; MENA).
- **Poor access to information** that is relevant and in accessible formats, including in emergency situations such as the COVID-19 pandemic (Africa; Asia and Pacific; Caribbean and North America; Central and South America; Eastern Europe and Central Asia; EU and other Western European States; MENA).
- **Ongoing lack of consistent, reliable and disaggregated data** related to the lives of persons with disabilities, which contributes to keeping persons with disabilities invisible in decision making (Africa; Asia and Pacific; Central and South America; Eastern Europe and Central Asia; EU and other Western European States; MENA).

4. Context of disability inclusion and open societies and human rights

³ “Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms (CRPD, 2008).

According to the FCDO, for societies to be open, they must be governed by consent, not command, and citizens must have freedom to debate ideas, institutions must support open, inclusive, and accountable politics and support the rule of law. This includes taking steps to remove laws and practices and tackle attitudes that discriminate against persons with disabilities. These institutional barriers restrict the rights of persons with disabilities to live independently, to be included in the community and exercise their civic, legal, and political rights. Some key areas of concern are discussed below.

Persons with disabilities face barriers to **participating in democratic processes**, such as voting in elections; the right to assemble, organise and associate peacefully; and experiencing accountable and transparent governance. Furthermore, persons with disabilities are underrepresented in decision-making and political participation. UN DESA (2018) found that only 13% of countries have no legal restrictions on the rights of persons with disabilities to vote and only 9% have no restrictions on the right to be elected for public office. In an increasingly digital world, **persons with disabilities face barriers to exercising their civic and political rights in physical and digital spheres** when accessibility is not considered.

An estimated 10% of persons with disabilities live in **institutions or special homes for persons with disabilities**, which restricts their ability to live independently, access education or employment, exercise the right to vote, or make their own decisions (UN DESA, 2018). Abuses have been documented in institutional settings, such as violence, including sexual violence, seclusion, restraint and inappropriate or overuse of medications and electroconvulsive therapy without consent (UN DESA, 2018). This practice is prevalent across all geographic regions and reflects a charity model approach where persons with disabilities are hidden away, rather than enabled to enjoy full human rights. In a global survey run by the International Disability Alliance (IDA) (2021b), 33% of respondents said that their governments put no measures in place to protect the lives, health and safety of persons living in institutions during the COVID-19 pandemic. 50% said that some measures were taken and only 17% said significant measures were in place.

A 2020 Human Rights Watch report found that hundreds of thousands of people with psychosocial disabilities, actual or perceived, are **shackled or locked in confined spaces** in about 60 countries across Asia, Africa, Europe, the Middle East, and the Americas. This can mean persons with psychosocial disabilities are kept chained, including outdoors (HRW, 2018; HRW, 2019) to 'control behaviour'. 12,800 were affected in Indonesia alone in 2018 (HRW, 2018). This is often due to widespread stigma, and discriminatory beliefs that mental health conditions are caused by evil spirits or a previous sin, combined with a lack of accessible/affordable mental health services.

Persons with disabilities face barriers when trying to access justice. Persons with disabilities do not yet have universal, equal recognition before the law and enjoyment of legal capacity (UN DESA, 2018). Some countries explicitly guarantee the rights of persons with disabilities in their constitutions, however, 2% of the constitutions of UN Member States include discriminatory provisions where equal rights are guaranteed but allow for exceptions where impairment can be used as a reason for preventing a person from exercising those rights.

Persons with disabilities also have a high unmet need for legal advice, are less likely to have the financial resources needed to access it and are likely to face a lack of disability awareness amongst legal officers (UN DESA, 2018). This infringes upon the rule of law and ability of judicial systems to be effective, independent, impartial, and free from corrupt influence or coercion, so that each person can access justice and benefit from a fair trial.

It is estimated that millions of persons with intellectual and psychosocial disabilities are **deprived of their legal capacity by being placed under a guardianship** (HRW, 2018). These guardianships have been found to lead to a range of human rights abuses including, involuntary confinement, limited freedom of movement, restrictions on the right to marry, have legal representation or defend their rights in court, and forced medical treatment, including abuses of their sexual and reproductive health and rights (ibid, UN DESA, 2018). A 2016 Human Rights Watch report found that authorities in Serbia had forced many young women with disabilities to undergo coercive medical interventions while under guardianship, including forced insertion of intrauterine devices (IUDs), administration of contraceptive pills without their knowledge, forced or coerced termination of pregnancy, and non-consensual administration of pap smear tests. The Guardianship Law in North Moldova denies people with disabilities access to their money, employment, voting, and decisions regarding whether they are institutionalised (Mehes, 2016). Institutionalisation, shackling, and guardianship schemes deprive persons with disabilities of their liberty and ability to make their own decisions, and they perpetuate exclusion from society.

A key outcome of people with disabilities' limited legal protection is **increased risks of violence and harassment**. One in four persons with a psychosocial disability experience physical or sexual violence in any given year, which is higher than the general population (Hughes et al., 2012 in UN DESA, 2018). This violence can occur in the home, educational and healthcare settings, workplace and in the wider community. Some people with disabilities face additional exposure to violence, including gender-based violence, due to their intersecting identities, particularly, women and girls, LGBTIQ+, older people, and religious and ethnic minorities.

Persons with disabilities face **barriers to accessing information and the media** when it is not provided in accessible or affordable formats. Furthermore, persons with disabilities are rarely represented in the media. When they are represented, it is often as objects of pity, charity or in medical settings, which simply promotes negative stereotypes.

IDA (2021b) found that **during the pandemic some states actively pursued policies that resulted in wide-scale violations of the rights of persons with disabilities**, including the right to life, health, liberty, freedom from torture, ill treatment, exploitation, violence and abuse, inclusive education, independent living, and inclusion in the community. This includes high death rates in institutions.

5. Evidence on disability inclusion in key sectors

a. Democratic governance and political empowerment

Persons with disabilities face multiple barriers to engaging politically including environmental barriers, such as physically inaccessible infrastructure and inaccessible information; attitudinal barriers, such stigma and discrimination; and systemic institutional barriers, such as discriminatory laws, and unequal access to education and financial resources (Virendrakumar et al. 2018). In some countries, there is a gap of more than 30 percentage points between persons with and without disabilities who faced barriers to voting or engaging in politics (UN DESA, 2018). Persons with disabilities are 4 times more likely to find voting problematic than the general population, and report difficulties in finding and travelling to polling stations, queuing, reading ballot papers, filling in the ballot and communicating with election officials (Schur, Ameri and Adya, 2017).

Out of 190 countries, only 62 give all citizens, including persons with disabilities, the right to vote with no exceptions (UN DESA, 2018). 128 have exceptions in their Constitutions, legislations or laws that could be used to deprive persons with disabilities of the right to vote, with 94 of these targeting persons with psychosocial or intellectual disabilities. Only 15 out of 176 countries give all citizens the right to be elected for office without exception, 161 have exceptions for persons with disabilities, with 104 of these exclude persons with psychosocial or intellectual disabilities.

Evidence on what works to make elections inclusive is extremely limited (Price, 2018, Virendrakumar et al. 2018). However, there are some examples of good practice (PPUA Penca, 2013; Virendrakumar et al. 2018):

- Cambodia, Ghana and Indonesia introduced tactile ballot guides and conducted voter awareness raising in local sign languages.
- In DRC, Cameroon and Mauritius voting premises were adapted with ramps and adjustable height booths, or only ground floors were used.
- Home visits were used in South Africa to enable persons with disabilities to register to vote.
- In Malawi specific messages and educational materials were developed for persons with disabilities on voting rights and processes.
- OPDs in Cameroon were trained about the presidential elections, and radio and TV programmes encouraged persons with disabilities to vote.

There are very few examples of how governments have included persons with disabilities as political candidates, election officials, and observers. Whilst data is limited, **there is evidence that there is extremely low representation of women with disabilities in political leadership roles** (UN DESA, 2018). In 2017, there were no female parliamentarians with disabilities in 14 out of 18 countries in the Asia and the Pacific region (ESCAP, 2018). Representation was low in the remaining 4 countries ranging from 0.3% to 6.3%.

b. Digital inclusion

Several global commitments, including CRPD, the SDGs and UN Disability Inclusion Strategy, highlight the importance of digital accessibility to ensure that “no one is left behind” in our increasingly digital world. Among 14 countries, only 19 per cent of persons with disabilities use the internet, compared to 36 per cent of persons without disabilities (UN DESA, 2018). This may be due to a lack of accessible technology and the lower capacity of households with persons with disabilities to afford internet access. Women with disabilities are two times less likely to use the internet than men with disabilities. Access and use of the internet can support persons with disabilities to access healthcare, education, employment, and government services, as well as enabling participation in political and public life and online disability communities.

Research conducted by GSMA (2020a) found that there was a **large gap in smartphone ownership between persons with disabilities and persons without disabilities** in eight countries.⁴ The largest gap was found in Nigeria, where persons with disabilities were 80 per cent less likely to own a smartphone. In Kenya, the country in the survey with the smallest gap, there was still a gap of 63 per cent. Women with disabilities often had the lowest levels of mobile ownership and mobile internet awareness and usage (GSMA, 2020b). Lower levels of

⁴ Bangladesh, Brazil, India, Kenya, Mexico, Nigeria, Pakistan, Uganda

awareness around mobile data and reduced access to smartphones led to fewer persons with disabilities using mobile data than persons without disabilities.

During the COVID-19 pandemic, children with disabilities faced increased barriers to education as online tools used to navigate the COVID-19 restrictions, particularly school closures and need to socially distance, did not take the accessibility needs of persons with disabilities into account (DID Helpdesk, 2021). Girls with disabilities are at risk of not returning to school after the pandemic due to economic hardships, parental preferences, early marriages or becoming pregnant during lockdown (IEI, 2021).

Access to assistive technology is important to enable persons with disabilities to live independently and participate fully in society. However, UN DESA (2018) found that in several developing countries more than half of persons with disabilities who require assistive technologies are not able to receive them. Barriers include inadequate products and unaffordable / lack of transport to reach providers.

c. Civil society and civic space, including localisation

Civic space is closing in many countries, and concerns have been raised that some COVID-19 restrictions will lead to longer-term clampdowns on civic voice and increased hostility and backlash (Meaney-Davis et al., 2021). This makes it challenging for OPDs to build their institutional capacity and deliver a broad strategy.

Only 2% of foundation funding for human rights and less than 1% of bilateral and multilateral funding went to disability rights initiatives in 2018 (Human Rights Funders Network, 2021). People with disabilities were the only population for whom human rights funding declined between 2017 and 2018 (a 14% decline of USD 9 million). This reduces the ability of OPDs to build capacity, build movements and advance their agendas. Funding for people with disabilities tends to focus on equality and freedom from discrimination, health and wellbeing rights, while issues such as civic and political participation receive considerably less support (Human Rights Funders Network, 2021).

Local organisations of persons with disabilities are almost never engaged in humanitarian responses, for a range of reasons including a lack of funding and a lack of awareness among humanitarian actors of OPDs (Buscher, 2018). This restricts the reach of OPDs and their expertise and slows the localisation agenda. For example, research with OPDs in Bangladesh, Nigeria and Zimbabwe found that people with disabilities and OPDs were largely excluded from planning government responses to the COVID-19 pandemic, many OPDs could not access government officials in the early stages of the pandemic, and government responses were often only adapted to be more inclusive after successful advocacy by OPDs (Meaney-Davis et al., 2021).

There are examples of governments **restricting protests by persons with disabilities** and their families. In 2018, protests demanding an increase in state disability benefits were restricted in Poland; protestors faced mistreatment and smear campaigns, and journalists had restricted access, limiting the ability of the media to cover the protests (CIVICUS, 2018). Protestors with disabilities have faced heavy handed police response, using water cannons and tear gas in Bolivia (Booth, 2016), and violence in Tanzania (Akewi, 2016). Some disability activists have launched digital protests, including [Inva Protest](#) an online protest against domestic violence against women with disabilities in Russia.

d. International UN conventions and resolutions

In addition to the CRPD discussed above, there are a number of Human Rights Council resolutions that relate to the rights of persons with disabilities, covering topics such as [habilitation and rehabilitation](#), [mental health](#), [right to work](#), [climate change](#) and [rights of the child](#).⁵

Five goals and seven targets of the [Sustainable Development Goals](#) under the 2030 Agenda for Sustainable Development explicitly refer to persons with disabilities, including goal 4 on education, goal 8 on employment and goal 10 on reducing inequalities. The commitment to 'leave no one behind' means that persons with disabilities must be prioritised.

The [Sendai Framework for Disaster Risk Reduction 2015-2030](#) recognises that persons with disabilities and OPDs have a critical role to play at all stages of disaster risk reduction planning and requires all disaster risk reduction policies to integrate a disability perspective. The [Charter on Inclusion of Persons with Disabilities in Humanitarian Action](#) represents a commitment to ensure that humanitarian action is inclusive of persons with disabilities. [Security Council Resolution 2475 \(2019\)](#) calls for Member States and parties to armed conflict to protect persons with disabilities in conflict situations and to ensure they have access to justice, basic services and unimpeded humanitarian assistance.

e. Modern slavery

Persons with disabilities are at **increased risk of modern slavery** as they are more likely to be socially isolated and living in poverty. Data is scarce, however, the agency fighting modern slavery in Nottingham City Council reported that almost 60% of its clients had a disability, mental health condition or cognitive impairment in 2019 and 2020 (Lambert, 2020).

There are documented cases of persons with disabilities being targeted by traffickers or being enslaved across geographic regions. In West Africa and Europe persons with disabilities, including children, have been trafficked for the purpose of begging (United Nations Office of Drugs and Crime, 2016). In South Korea, there are documented cases of persons with physical and learning disabilities being trafficked and forced to work on fishing vessels, and salt and cattle farms, often in remote locations, where they experience verbal and physical abuse, non-payment of wages, long work hours, and poor working and living conditions (US Department of State, 2017; US Department of State, 2021). In China, persons with intellectual and developmental disabilities, including children, have been released from modern slavery where they were forced to work in brick kilns (Schoenmakers, 2016). There are documented cases of **modern slavery abuses affecting persons with disabilities in institutional settings**: trafficking for sex and forced labour in Mexican institutions (Ahern et al., 2020), trafficking rings, organ harvesting, child pornography and prostitution in Ukrainian orphanages (Matthews et al., 2015) and sex trafficking of patients in a Guatemalan hospital (Disability Rights International, 2012).

Children with disabilities are also more vulnerable to exploitation, including modern slavery and trafficking, as they often face economic hardships and social isolation (UNICEF, 2021). This is particularly the case for children with disabilities who live in institutions.

Survivors of modern slavery and trafficking with psychosocial disabilities face barriers to

⁵ A full list can be found here: <https://www.ohchr.org/EN/Issues/Disability/Pages/HRCresolutionsandevents.aspx>

accessing the support they need. In Cambodia, survivors face barriers due to social stigma and a lack of staff with the skills required to support them (Aberdein and Zimmerman, 2015).

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About Helpdesk reports: The Disability Inclusion Helpdesk is funded by the UK Department for International Development, contracted through the Disability Inclusion Team (DIT) under the Disability Inclusive Development Programme. Helpdesk reports are based on between 3 and 4.5 days of desk-based research per query and are designed to provide a brief overview of the key issues and expert thinking on issues around disability inclusion. Where referring to documented evidence, Helpdesk teams will seek to understand the methodologies used to generate evidence and will summarise this in Helpdesk outputs, noting any concerns with the robustness of the evidence being presented. For some Helpdesk services, in particular the practical know-how queries, the emphasis will be focused far less on academic validity of evidence and more on the validity of first-hand experience among disabled people and practitioners delivering and monitoring programmes on the ground. All sources will be clearly referenced.

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