Disability Data Advocacy Toolkit Lessons learned

About the author

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Introduction

The Stakeholder Group of Persons with Disabilities, the International Disability Alliance, and CBM Global Disability Inclusion launched the Disability Data Advocacy Toolkit in 2020 in response to growing interest and requests from persons with disabilities and their representative organizations from across the globe. The Toolkit emphasizes the crucial role of data in comprehending the circumstances of persons with disabilities and illustrates how to analyze, utilize, and place trust in data for advocacy. The Toolkit is available in Arabic, English, French, Spanish, in Easy-Read version, and an abridged version in International Sign.

See the Disability Data Advocacy Toolkit options to download.

Fig 1. Disability Data Advocacy Toolkit

A survey was developed and shared with organizations of persons with disabilities to understand how the Disability Data Advocacy Toolkit is being used and how it can be improved as an advocacy resource for organizations of persons with disabilities. The survey was made accessible in multiple languages including Arabic, English, French, Portuguese, Spanish, and a version in International Sign. This report provides the results of this survey and intends to demonstrate the needs of organizations of persons with disabilities in relation to data and their use for advocacy in disability rights.

Sociodemographic results

From the 34 organizations that responded to the survey

44.1% were organizations of persons with disabilities

35.3% were non-governmental organizations

17.6% were governmental organizations

2.9% was a University

Type of disabilities that the organizations supported

- **20** All persons with disabilities
- **5** Autistic persons
- **4** Deaf persons, persons who are hard of hearing or other hearing disabilities
- **3** Persons with physical disabilities
- **2** Persons with intellectual disabilities
- **2** Persons who are blind or partially sighted
- **2** Persons with other disabilities not mentioned
- **2** Persons with a psychosocial disabilities

Sociodemographic results (cont.)

Countries that responded to the survey

Africa:

- Benin,
- Congo,
- Egypt,
- Kenya,
- Rwanda,
- Tanzania,

Asia:

- Bangladesh,
- Bhutan,
- India,
- Nepal,
- Philippines,

Europe:

- Belgium,
- France,
- Malta,
- Portugal,
- Slovakia,
- United Kingdom,

South America:

- Brazil.

Fig 2. Countries that responded to the survey

Organizations aware or using the Disability Data Advocacy Toolki
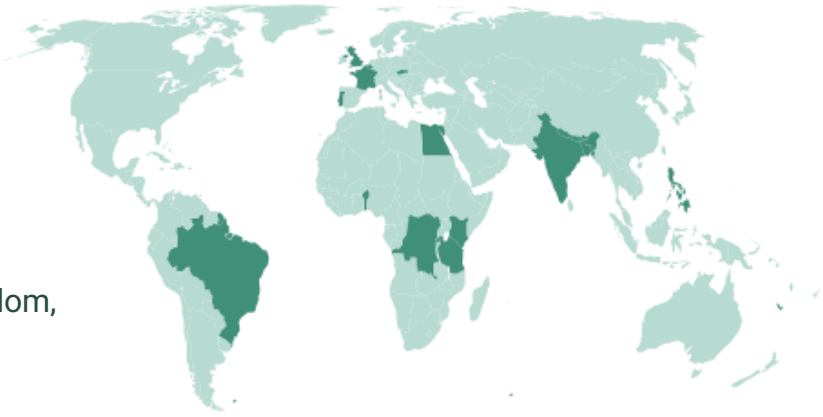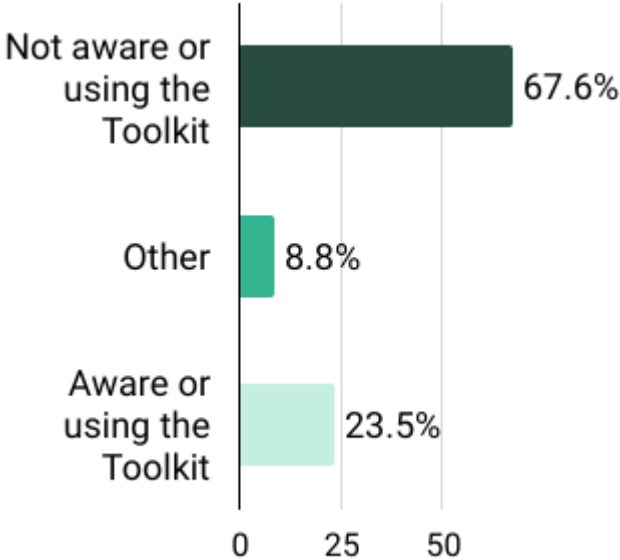
About **67.6% of people who responded indicated not being aware of the Toolkit.** Only 23.5% indicated being aware or using the Toolkit, with 8.8% indicating others, in cases where, for example, were aware, but not using it.

No organization reported attending an event or training that used the Toolkit.

Organizations using the toolkit
How is the Toolkit being used?

"As a tool to improve the capacity building in this specific topic inside our OPD. A few years ago, we saw a movement happening to include a question about autism in the census, there was a big campaign made by parents of autistic children. We have been the only OPD to advocate against it because we were the only one to understand the importance of the WGQ and the risk of having an official number too low as our official data - the data that justify the budget allocation for services. The campaign resulted in a law saying the census should include a question about Autism. The national institute of data made a census last year and completely ignored that law, to use only the basic WGQ [Washington Group Questionnaire] and that was it. The first results are being realised this year and the information in the Data toolkit has been usefull as a tool to explain to people why thats a good outcome and why they should just drop that idea and, instead of that, go to a different direction, advocating for more data collection in a more adequate way."

"Collecting information on people with disability, helps in analyzing interests, and needs of people with disability, can help to respond to different needs of people with disability, can also help in planning and dissemination of information to different stakeholders."

"[We are] currently working on analyzing and visualizing data from a nationwide higher education accessibility survey we've ran in the past few months. We are consulting the toolkit on best practices and what to avoid in presenting our data."

"We are collecting disaggregated data of all the patients we serve using the Washington Group short set questions."

"We are using the tool during workshops on building capacities of OPDs on the importance of data on persons with disabilities on the implementation of the UNCRPD and the 2030 Sustainable Development Agenda (SDGs). We have also used the toolkit to train persons with disabilities and their representative OPDs on citizen-generated data on their roles as OPDs in generating data and evidence on persons with disabilities. To find information on where to find official data.

We have also used the toolkit to find strategies on how to engage the government through the bureau of statistics in addressing disability data. To advocate for effective inclusion of the disability agenda and meaningful participation of persons with disabilities in the Leave No One Behind initiative led by the SDG Kenya Forum."

Organizations using the toolkit
Lessons learned

"Not all types of disabilities are captured using the Washington Group"

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"Need training on how to use it and it needs to be updated often"

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"It is important to start with mapping all stakeholders involved in data advocacy."

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"Organizations of Persons with Disabilities are key in generating and using disability data and hence they have to be fully involved in the process. "

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"OPDs at all levels, especially those at local levels must be empowered in order to engage in data advocacy and in data processes."

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"It is important to support OPDs to understand the linkages between the UNCRPD, SDGs and the Global Disability Summit so that these are not seen as parallel processes instead they reinforce each other."

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"There is need for creativity, innovation and out of box ideas when it comes to collecting and using data on persons with disabilities."

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" Inclusive data processes needs a collaborative approach- which brings together different stakeholders for advocacy on disability data – In Kenya our data advocacy is made possible through collaborative platforms (..)- which brings together all nonstate actors in the disability sector and the Inter- Agency Coordinating Committee (IACC)-which is a government led mechanism for coordinating implementation of the UNCRPD and the Global Disability Summit Commitments made by Government."

Organizations not using the Toolkit
Interest and needs to start using it

Organizations showed interest in learning how to use and implement the Toolkit:

"Yes, we've just discovered it and would love to learn how to use it."

"YES, We believe having knowledge on the Data Advocacy Toolkit will improve our advocacy capacity."

"I am curious to see if it would work with our remit."

76.5% organizations said they were not aware or using the toolkit.

From these, almost all said they would like to learn how to use it, with only 1 not

Support needed to start using the toolkit

Trainings

"Training and workshops attending"

"Maybe a technical training session would be very helpful."

"Know the system how we use this and incorporate the policy"

"We need training on practical application of Data advocacy Toolkit for staff and board members of our organization. "

"I need training to understand the tool, know how it is used and where to use it."

"Currently only read about it in this survey but need induction to it. I am new to it and also new in my organization but feel it is important to the deaf rights advocacy."

"Benefits [of the toolkit]"

"How to go about it. Where to start"

Other formats and languages

"I think a descriptive video would be a good idea."

"It would be easier to implement if the document were in Portuguese."

"This can be a webinar or a direct interview with our staff. "

"Want to take it in word file for better understanding."

"More information, language accesibility."

"Time. Way too much to do at work. Could set up a staff training around it for next year. Need to know very precisely what the benefits are for us."

"Our Agency would require recommendations for a tried and tested system for data collection or case management system that can be implemented cross-sectorally (i.e. multiple entities which can access and input relevant data). This system would ideally be no to low cost, so non-profit organizations and NGOs can implement the system(s)."

"[National] Sign Language interpreting"

OPD-generated data
Data collection by OPDs

"We haven't collected data for advocacy yet. **We use traditional methods to identify the strong need of women and girls with disabilities to advocate for**, however we understand the need to include data collection for data advocacy that we look forward to sharpen our stock of knowledge on the topic. "

"Yes, we use data to document which countries have recognized their national sign language and support its development. We have produced best practice guidelines on how to advocate for sign language recognition and disseminated it to deaf people and advocacy organizations."

"As an organization we regularly collect and use data on persons with disabilities. we do this through our various projects- baseline survey reports, project reports such as the project on Enhancing participation of persons with disabilities in data processes, Audits of participation of persons with disabilities in election processes. Also collected information and produced an alternative report on the progress of implementation of the UNCRPD. "

"Due to the limitations of the disabilities classified using the Washington group, we formed our own: VI, HI, PI, MLDA (Mental, Learning, Developmental, Autism) and MD (Multiple Disabilities)."

"Our organization had succeeded to get separate own data of hard of hearing in national census 2021, previous it was mixed with deaf data. We also used media to get data in census

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"Not yet. But we have the data of persons with disabilities who reach out to us on regular basis seeking legal advice and help in litigation to restore their rights."

"We organize a space for debate on disability questions at the national level."

"We prioritise our research in areas which have the potential to make the most critical differences to the lives of 'the other half'. At the moment we are primarily focused on projects which impact directly on human rights issues, particularly inappropriate detentions (e.g. in Assessment and Treatment Units ATUs). "

"We try as much as we can to push forward our members with Down syndrome to participate in media programs and even as committee members. "

OPD-generated data
Data collection by OPDs (cont.)

"Autistic priorities infographic, where the **research, policy and advocacy priorities** were analysed; and the violence against autistic people infographic, that **studied experiences of violence and access to reporting and support services**."

"(..) has **a Case Management System (CMS)**. The CMS is linked with the Social Services, because some service users fall under services such as child protection, fostering, substance abuse and/or domestic violence. (..) We also have our **Annual/Biennial Reports** that are published on our website. We also contribute by submitting available data to its overarching ministries in response to surveys/reports/parliamentary questions, etc. "

"Relevant actions in relation to data are discussed within this forum together with other entities forming part of national line Ministries, and then worked on through a specific working group bringing together [governmental organization], [national] NSO, CRPD (Commission for the Rights of Persons with Disability - [national] disability equality body) and the [national] civil society participation mechanism in terms of Article 4(3) UNCRPD, further to (..) the National Disability Strategy. [Governmental organization] will then **use this data for relevant advocacy within Government and in supranational organizations, in respect of legislative, policy, and practical initiatives aimed at implementing the UNCRPD.** "

"Our OPD rarely collects data. When we do, we usually use **online questionnaires, paying special attention to issues related to intersectionality**, since in Brazil we have people with disabilities living in very different contexts. Sometimes we also **collect qualitative data through direct interviews, to get quotations and histories**, mainly to base campaigns on specific themes. But it's very hard for us to reach some segments and get the representation of all the regions of the country, so, when we can use official data, we always prefer that. Here, **the official data collection is quite good and the results are easily available, so for us it has been more important to understand how to find and use this official data than to collect it ourselves.** We always include that in our campaigns."

OPD-generated data
OPD needs to build capacity

Expressed needs to build capacity on disability data:

1. A training workshop on how to manage/analyze data (75.8%)
2. Disability Data Advocacy Workshop for OPDs (established under the Stakeholder Group of Persons with Disabilities with IDA, UNFPA Asia Pacific, and CBM Global Disability Inclusion) (66.7%)
3. Funding (60.6%)
4. A short informative video that can be used for teaching purposes (51.5%)
5. A technical data webinar series to address evidence-based policy making (48.5%)
6. A small data-related project (45.5%)
7. Technical support (e.g., implementation of software) (30.3%),
8. Access to an external data team (27.3%),
9. Other (6%).

Organizations working with their country United Nations Country Team

Only 1 organization was in contact, working in Disability Equality Training (DET) to advocate for the rights of persons with disabilities and how inclusive design needs to be incorporated in all our settings to make a reasonable accommodation.

In the following chapter, we will assess the availability of disability data in the respective countries where the organizations operate. It aimed to determine the types of data that were accessible and the methods through which individuals could obtain such information.

OPD-generated data
Using data for advocacy

In the survey, it was asked how organizations are using data for advocacy, with key quotes displayed below.

"Since the available disability data focus mostly on composition percentages among the other groups, We mostly compare the published percentage of persons with disabilities among the population with the percentage of persons with disabilities accessing different services provided to prove the gaps in accessibilities."

"Holding meetings to present data and say the action we need. Writing letters demanding action by legislators."

"We use data from baseline surveys on disability inclusion in policy planning, findings from evaluation of initiatives, to engage government at both national and subnational levels on disability mainstreaming in policy planning and implementation, decision-making and resource allocation."

"We use the data to advocate for making policy changes based on their population, make provision of sufficient budget allocation for disability-inclusive development program, government job provision etc. Data supports for evidence-based advocacy"

"Use our OPDs/DPOs and local government for collecting the data everywhere but it's too expensive and also advocacy with social well fair ministry for data gather."

"The data can help in raising the issues of the persons with disabilities and highlight the different needs according to the type of the disability."

"We conduct Disability Equality Training (DET) for policy makers and local governments including legislators. "

"I used to advocate for policymakers as the available data is not in functional approach, also not in line of UNCRPD. also questions how the enumerator decides on multiple disability data. Washington questionnaire needs to be used as toolkit to collect data as it is not used during census. The mostly, person with hard of hearing left out as their definition based on medical approach, disability law also not included all types of hearing loss as disability with giving case studies i am advocating with the government."

"Carry out an analysis and characterization of people with disabilities at a national level and cross-check it with the data from the available social responses. Demand inclusion based on real data."

OPD-generated data
Using data for advocacy (cont.)

"To try to ensure that national laws are improved, and that support reaches those who need it and not because of subjectivities found in not supporting people." "We petition with governmental forced psychiatry statistics. However, the government is in complete denial of any human rights violations by psychiatry. We have no responses to our petitions."

"By answering surveys; justifying actions taken by [us]; justifying required headcount to provide and develop services/support; putting proposals of services/projects forward for consideration (e.g. current PA Reform); publishing reports; conducting research for development; developing trends reports; participating in international forums to network and gain professional feedback and recommendations. " "The data would be useful to support our advocacy regarding why more sign language interpreters are needed in our country. Moreover, it would also support our quest to create services (such as sign language sessions) for families of deaf babies/children. "

"Through Memoranda to the Cabinet of Ministers (for proposed legislative changes/ policy initiatives), proposals for Budgetary/ (administrative) Simplification Measures, and in bilateral/ multilateral negotiations within Government and with supranational entities (ex. during negotiations in Council of the EU Working Parties)."

"Unfortunately, we are not in a position to use available data to advocate for policymakers to change legislation to improve the lives of persons with disabilities as we do not have the data."

"We use in our campaigns, to justify our demands and suggestions."

"We actively advocate for better policies supported by budget allocations to improve the lives of persons with disabilities."

"To point out need for policy change. "

"We use it while in planning and budgeting allocation, but all also other stakeholders should use it in their project planning and funding, strategic papers for funding projects, donors, aids for persons with disabilities."

Availability of disability data
Africa

In this chapter, we will assess the availability of disability data in the respective countries where the organizations operate. It aimed to determine the types of data that were accessible and the methods through which individuals could obtain such information.
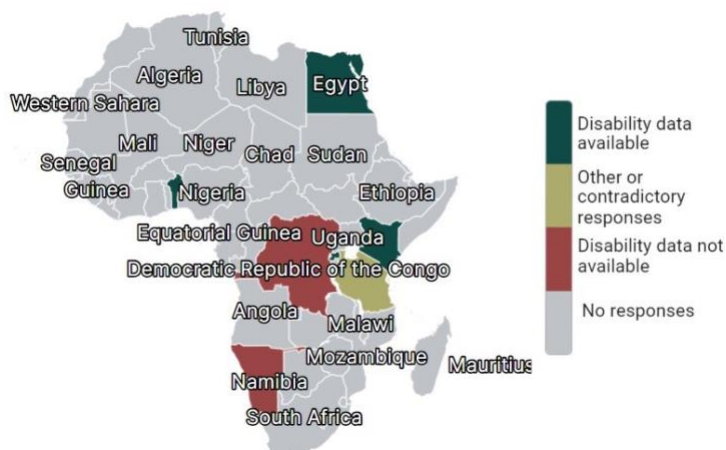

Fig 3. Countries that responded to the survey in Africa

Country	Data availability	Type of data	How to gain access to the data
Benin	yes	Official statistics available in your country, Administrative disability data Sub-national disability data Disability data disaggregated by gender, race/ethnicity, age, socioeconomic status	other
Dem. Rep. Congo	no	-	Download data off the Internet
Egypt	yes	Official statistics available in your country, Disability data disaggregated by gender, race/ethnicity, age, socioeconomic status	Request data from local or national governments
Kenya	contradictory responses	Official statistics available in your country, Sub-national disability data Disability data disaggregated by race/ethnicity	Download data off the Internet, Request data from local or national governments
Namibia	No	-	other
Rwanda	contradictory responses	Official statistics available in your country, Sub-national disability data	Download data off the Internet Request data from your national governments
Tanzania	other	Official statistics available in your country	Download data off the Internet

Table 1. Availability of Data in Africa

Availability of data in countries
Africa

It was also asked if in their country there were Organizations for persons with disabilities (OPD) generated data, if that data is recognized by their National Statistics Office (NSO), or if their NSO used community or citizen-generated data. However, when there were more than two answers for the same country, responses presented contradictory responses.

Country	OPDgenerated data	OPD data recognized by the NSO	Community citizen-generated data recognized by the NSO	Disability measurement
Benin	yes	yes	yes	Based on functionality, such as the Washington Group on Disability Statistics sets
Democratic Republic of the Congo	no	no	no	Based on functionality, such as the Washington Group on Disability Statistics sets
Egypt	no	no	no	Based on a definition of disability
Kenya	contradictory responses	contradictory responses	yes	Based on a definition of disability
Namibia	yes	no	yes	Based on a definition of disability
Rwanda	contradictory responses	contradictory responses	yes	Based on a definition of disability
Tanzania	no	no	no	Based on functionality, such as the Washington Group on Disability Statistics sets

Table 2. OPD-generated data in Africa

Note: According to the review made by the Disability Data Initiative, all countries have WGSS in their surveys. Download the 2023 Dataset review by the Disability Data Initiative.

Availability of data in countries
Africa

Besides Benin and Egypt, people who responded to the survey said that the available data does NOT provide them with accurate information about persons with disabilities, because:

Congo: "We don't have reliable data."

Kenya: "I wish my country to be intentional at all levels to have tools that capture disability and train the users on the use of the tools and why its important to capture disability disaggregated data." , "There are gaps in census data - data on children with disabilities was not collected. Also, the parameters for analysis were limited and the enumerators were not sensitized on use of the functional model. Also, there is very limited administrative data on persons with disabilities. "

Namibia: "Governent do not maintain data across the country. Huge gap between Government and OPDs/NGOs"

Rwanda: "The way they define disability should be internationally/ globally harmonized, one country define disability based on their governing laws (this should be changed, it is one body, one human. I don't see how the USA can define disability in one way and Africans define it in another way.)"

Tanzania: "It does not explain in detail, and it doesn't engage stakeholders. Community engagement is the best option as it reach the grassroot community in both urban and remote areas."

Only 1 of the 7 countries (Egypt) reported that the data was enough for their **advocacy.**
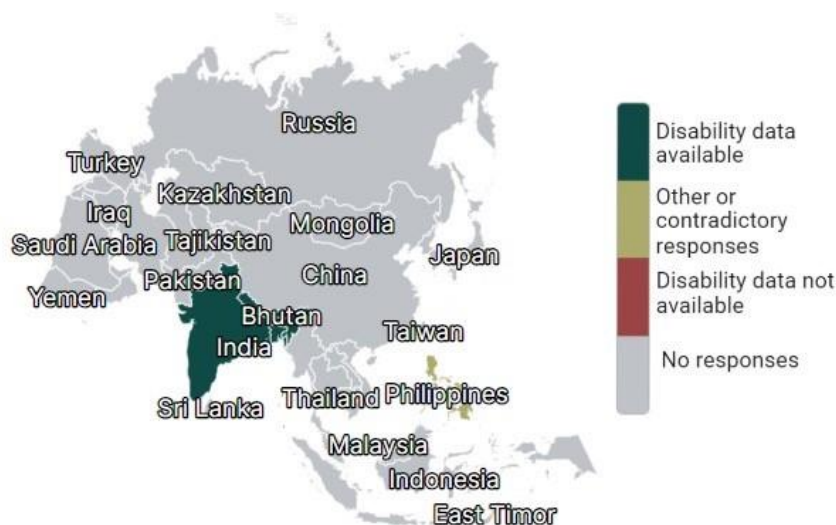
Availability of data in countries
Asia

Fig 4. Countries that responded to the survey in Asia

Country	Data availability	Type of data	How to gain access to the data
Bangladesh	yes	Official statistics available in your country	Download data off the Internet Request data from national governments
Buthan	yes	Official statistics available in your country, Administrative disability data, Sub-national disability data, Disability data disaggregated by gender, race/ethnicity, age, socioeconomic status.	Download data off the Internet Request data from national governments
India	yes	Official statistics available in your country, Sub-national disability data Disability data disaggregated by gender, race/ethnicity, age, socioeconomic status	Download data off the Internet
Philipines	other	-	Download data off the Internet
Nepal	contradictory responses	Official statistics available in your country, Administrative disability data, Sub-national disability data, Disability data disaggregated by gender, race/ethnicity, age, socioeconomic status.	Download data off the Internet Request data from local or national governments

Table 3. Availability of Data in Asia

Availability of data in countries
Asia

It was also asked if in their country there were Organizations for persons with disabilities (OPD) generated data, if that data is recognized by their National Statistics Office (NSO), or if their NSO used community or citizen-generated data. However, when there were more than two answers for the same country, responses presented contradictory responses.

Country	OPDgenerated data recognized by the NSO	Community/ citizengenerated data recognized by the NSO	Disability measurement	Country
Bangladesh	no	yes	Based on functionality, such as the Washington Group on Disability Statistics sets	Bangladesh
Buthan	no	yes	Based on functionality, such as the Washington Group on Disability Statistics sets	Buthan
India	no	no	Based on a definition of disability	India
Nepal	contradictory responses	yes	Based on a definition of disability	Nepal
Philipines	yes	yes	Based on a definition of disability	Philipines

Table 4. OPD-generated data in Asia

Note: According to the review made by the Disability Data Initiative, only India does not have the WG-SS in their surveys, but it does have other functional difficulties. Download the 2023 Dataset review by the Disability Data Initiative.

Availability of data in countries
Asia

For all countries, respondants said that the the available data does **NOT** provide them with accurate information about persons with disabilities, because:

Bangladesh: "Because government did not reach all of disabled home "

Buthan: "It was done only one-time back in 2017 and the data is not very reliable. "

India: "There is no accurate data as of date. a large section of persons with disabilities have not been assessed and certified for their disability."

Philipines: "It's not specific and not much evidence. Even the online enrolment is not reliable."

Nepal: "The collection of data is mostly on medical approach on non-visible disability. it is not based on functional approach. Also, not in line with UNCRPD. The data provided are not accurate.", "We want to have detailed surveys based on WGQ with trained enumerators and involvement of OPDs."

Only 1 of the 5 countries (Bangladesh) reported that the data was enough for their advocacy
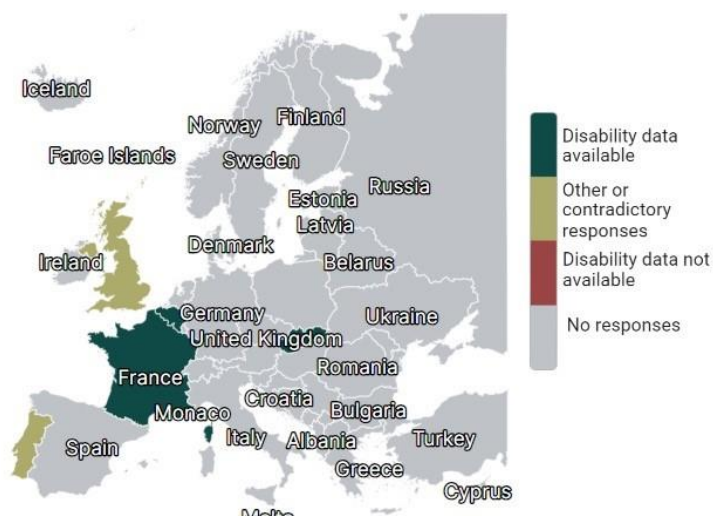
Availability of data in countries
Europe

Fig 5. Countries that responded to the survey in Europe

Country	Data availability	Type of data	Gain access
Belgium	yes	Official statistics available in your country, Sub-national disability data	Download data off the Internet
France	yes	Official statistics available in your country, Administrative disability data Sub-national disability data Disability data disaggregated by gender, age	Download data off the Internet
Portugal	contradictory responses	Official statistics available in your country, Administrative disability data Disability data disaggregated by gender, age	Download data off the Internet Request data from national governments
Malta	contradictory responses	Official statistics available in your country, Administrative disability data Sub-national disability data Disability data disaggregated by gender, age, socioeconomic status	Download data off the Internet Request data from national governments
Slovakia	yes	Official statistics available in your country, Disability data disaggregated by gender	Download data off the Internet
United Kingdom	contradictory responses	Official statistics available in your country, Administrative disability data Sub-national disability data	Download data off the Internet

Table 5. Availability of Data in Europa

Availability of data in countries
Europe

When asked if in their country the Organizations for persons with disabilities (OPD) generated data, if that data is recognized by their National Statistics Office (NSO), or if their NSO used community or citizen-generated data, there were contradictory responses. France and Slovakia had only one answer per country.

Country	OPDgenerated data	OPD data recognized by the NSO	Community/citizen-generated data recognized by the NSO	Disability measurement
Belgium	contradictory responses	contradictory responses	other	Based on functionality, such as the Washington Group on Disability Statistics sets
France	no	no	no	Based on a definition of disability
Portugal	contradictory responses	contradictory responses	contradictory responses	Based on functionality, such as the Washington Group on Disability Statistics sets
Malta	contradictory responses	contradictory responses	contradictory responses	Based on a definition of disability
Slovakia	yes	yes	no	Based on a definition of disability
United Kingdom	contradictory responses	contradictory responses	contradictory responses	Disability is measured both ways in my country (definition and functionality)

Table 6. OPD-generated data in Europe

Note: According to the review made by the Disability Data Initiative, Belgium, France and the United Kingdom have other functional difficulties questions besides WG-SS in their surveys. Malta and Portugal have the WG-SS. Download the 2023 Dataset review by the Disability Data Initiative.

Availability of data in countries
Europe

Only people from Belgium said that the available data provide them with accurate information about persons with disabilities. For the other countries:

France: "The perspective of the available statistics are the medical model, biological psychiatry, psychiatry as a social control institution, and the denial of any human rights violations. The changes should include all the human rights violations by psychiatry, the perspective of the social model of disability, and the human rights approaches to psychosocial disability."

Portugal: "The Census does not ask specific questions about disability, making it difficult to analyze.", "Portugal uses Washington short set group, which doesn't give us insights into autistic people specifically."

Slovakia: "In the field of autism there almost no data."

Malta: "Available data need to be collected ad hoc and not easily available. some entities/ministries need to collect the data when requested.", "We have no access to such data if it exists.", "The data does not always provide an accurate picture of the types of services/support required by persons with disabilities, as public information is often quite generically stored. To gain precise and detailed data, requests need to be made by public service officials and may not always be accessible to rights groups.", "The data available shows the number of Deaf persons registered with Malta's Disability Commission (CRPD). There are other deaf and hard of hearing individuals who are not registered, therefore we do not know about them. The data also does not specify who uses and who does not use sign language.", "Data gathered from different sources is divergent, incomplete, based on differing modes of collection/ assessment, and at times conflicting", "We need to know the number of persons with disabilities we have; the type of disabilities; their education, status, employed / unemployed etc and unfortunately this data is still nonexistent. NGOs need funds to be able to gather this information or else to pay for such data collection. In our opinion, this should be worked best with the collaboration on the State and NGOs."

Availability of data in countries
Europe (cont)

UK: "Most of the available data is inadequately disaggregated to reflect how the situation is like for individual groups of persons with disabilities - i.e. women with disabilities, persons of colour with disabilities.", "Individual local authorities gathered data in different ways. It is hard to extrapolate the national picture from it. Often the data gathers don't have the capacity to be thorough in their work, or don't understand the importance of it. Even in the NHS, different areas have different codes for different aspects of autism. I has made it very difficult to get good autism data out of the dataset. "

3 in 17 of the respondents from 2 out of 7 of the countries (Belgium and Malta) reported that the data was enough for their advocacy.

South America

Fig 5. Countries that responded to the survey in South America

Table 7. Availability of Data in South America

Country	Data availability	Type of data	Gain access
Brazil	yes	Official statistics available in your country (e.g., from national statistical authorities), Administrative disability data Sub-national disability data Disability data disaggregated by gender, race/ethnicity, age, socioeconomic status	Download data off the Internet

Table 7. Availability of Data in South America

Country	OPDgenerated data	OPD data recognized by the NSO	Community/citizengenerated data recognized by the NSO	Disability measurement
Brazil	no	no	no	Disability is measured both ways in my country (definition and functionality)

Table 8. OPD-generated data in South America

According to the review made by the Disability Data Initiative, Brazil has other functional difficulties questions besides WG-SS in their surveys. Download the 2023 Dataset review by the Disability Data Initiative.
For the organization from Brazil, the available data does provide them with accurate information about persons with disabilities and was enough for their advocacy.

Availability of data in countries
Conclusion

Most countries where we obtained more than one answer per country, received contradictory responses on what disability data is available, if organizations of persons with disabilities collect data or if their National Statistics Office recognizes OPD or citizen-generated data. This shows a lack of transparency on what disability data available is available and of accessible ways to access it.

Only 11.8% of the responses reported that the available data provides them accurate information about persons with disabilities (in Benin, Egypt, Belgium and Brazil).

Only 17.6% of the responses reported that the available data was enough for their advocacy (in Egypt, Bangladesh, Belgium, Malta and Brazil)

What is next?
Data priorities for OPDs

Indicators sometimes covered by current disability national surveys or census, that organizations consider priorities:

Employment	Education	Gender	Age groups

Violence against women	Disability type and categorization

Indicators normally not covered by current disability national surveys or census, that organizations mentioned as priorities.

Human rights violations

Harmful practices

Sexual and reproductive health and rights, including forced sterilisation

Child Sexual Exploitation

Number of avoidable disabilities, such as avoidable blindness or caused by practices of gender-based.

Physical, sexual, and medical abuses in institutions and the medical abuse, drugging, and labeling of children

Psychiatric abuse, such as contention, isolation practices and deaths in psychiatric hospitals, forensic psychiatry settings and forced psychiatric treatments in administrative retention centers, all remedies against forced psychiatry, institutionalization, treatments and rights violations and their outcome.

All the human rights violations by psychiatry. The outcomes of recourse against human rights violations by psychiatry.

Independent living, education and employment

Number of persons with disabilities in segregated and mainstream education

Number of people in institutions

Number of personal assistance users

Number of disabled people in sheltered workshops

Number of persons living in the community and in institutions.

Administrative data of persons with disability like how many are in jobs, how many children are out of school, how many have started businesses, how many have good earnings, etc

What is next?
Data priorities for OPDs (cont)

Access to services and needs

| Technical needs on data collection and management |

Difficulties accessing rights and public services

Specific needs of persons with disabilities, and support available compared with needed

Early intervention and continuous monitoring service trends to identify emerging needs and adapt programs to meet evolving needs within the disability community better.

Measure the outcomes and impact of services on the lives of persons with disabilities, ensuring the effectiveness of programs

Statistics on sign language users

Political participation and civic engagement

Disability Inclusive Disaster Response

Types of support used for children and young people with disabilities in schools

Number of disabled people with access/inaccess to healthcare (mainstream and disability specific)

Number of disabled people in politics.

Percentile of improvement in the lives of people with disabilities according to the support given

Access to justice

Technical needs on data collection and management

Community engagement.

Data kept by entities/ministries of Health, Education, Transport, Employment

Data whose collection has involved consulting persons with disabilities themselves on best way to frame tools and implement them.

More training on data management and analysis.

Prioritising which data is needed.

Supported with evidence, surveys, studies, etc.

Mandated inclusion of disability data for governments.

Improvement of disability type and categorization, including for autistic people.

There is various data which are not noted during the data collections hence can't be fully trusted for the support of the advocacy.

Data that can be verifiable at any point and not doubted.

Data priorities for OPDs (cont.)

Technical needs (cont.)

Mapping data gaps with stakeholders.

Increased funding for data projects

Increase budget to the national census processes to include more than the basic questions of WG-SS

Have disability data up-to-date and collected on regular basis

Advocacy for unification of the disability indicators in all different official data collection mechanisms in our country

Disability registers and national data plans, based on the Inclusive Data Charter

Disaggregated, accurate data, reflecting an intersectional perspective collected, processed and reported using a uniform method

Need awareness on disability rights, persons with disabilities needs proper understanding on UNCRPD along with local government. Then we can get proper respondents about disability, then we can get accurate data.

Improve reliability and quality of data

Linkage to best practices for learning

While collecting data program persons with disabilities also needs to be include in decision making then we can get proper data.

Qualitative data and data taken through community engagement

A comprehensive data based on the top three priorities mention above (Total number of disabilities in the country per gender and age, types of disabilities, location and education level)

Ensuring data availability on physical and informational accessibility is crucial for the inclusion and participation of persons with disabilities in society.

Capturing and making it available for research in the areas of usage of services such as public transportation, health, education, vocation, employment, related grievances, disposal rate etc.

You find population, gender, and type of disability, this is not detailed enough.

Data that is complete and shows the various types of disability.

What is next?
Challenges on Disability Data

Availability of data: In some cases, disability data is not available or included in census or national surveys. It is important to add disability data to every mainstream survey and data source, and not only when is disability-related.

Comparability: Disability data can be obtained from different data sources (e.g. census or survey), that use different methodologies to measure disability, indicators or cover different time periods, making it harder to compare.

Capacity: some organizations don't have the budget and human resources capacity to start collection, analysing or reporting disability data.

Methodological issues: Disability data has a range of quality of data depending on the source, and some collection methodologies might not fully match with methodologies used in different countries, especially when considering different cultural perspectives.

Leadership, not consultation: Persons with disabilities and organizations that are representative of them are many times not consulted or involved in the data process, but even when they are, it is normally based on limited involvement, not taking leadership of disability data.

Disaggregation: Disaggregation of data is not always provided, being by gender, age groups, ethnicity or other types of intersectionality. It is important to introduce disability disaggregated data in every survey and census developed, as well as initiaties that gather data globally, which makes it harder to assess besides basic needs indicators.

What is next?
Challenges on Disability Data (cont)

Functional difficulties vs. disability groups: most of OPD-generated data tend to focus on the type of disabilities that they support, or the person identifying themselves as having a disability, not using the functional difficulties group. Not disaggregating by disability type might miss the specific needs or barriers of a particular group in the community.

Barriers and facilitators: most data focuses on general indicators of employment, education, and others, identifying the absence/presence of persons with disabilities access to certain indicators, but it does not assess the barriers and facilitators to that access. OPDs are aware of the lack of access to employment but might need data on how to improve that or the actual barriers persons with disabilities are feeling.

Accessibility of data: a lot of the data available on disability has language barriers or might not be accessible for persons with disability to access.

Funding: OPDs mention the lack of funding for data projects and advocacy work. There have been very good national and international projects to monitor disability rights that were closed due to difficulty finding constant funding revenue to support it.

Data reporting: there is a need for best practices in data reporting that are accessible. Long reports are also time consuming, which makes it difficult to be sustained by voluntary work.

Advocacy: what data is needed to support the advocacy objectives and support policy implementation is important to be discussed for every type of disability. Different groups have different access barriers and facilitators and needs.

What is next?
Challenges on Disability Data (cont)

The need for community-level qualitative data: there are some quantitative data available publicly, even though not for all countries. However, qualitative data of specific needs and priorities are rarely gathered. The use of personal experiences and stories for advocacy is one of the most powerful ways to create exploratory data on needs and understand data gaps. We need individual qualitative experiences to grasp the collective systemic barriers.

Data interpretation: When indicators disaggregated by disability are included in surveys and census, it does not mean it is fully representative of persons with disabilities. The definition of employment, for example, can integrate different types of employment, including sheltered workshops or underpaid employment. Interpreting the data and the definitions used can be difficult and create further difficulties in comparing data across countries.

Access to ethics committees and scientific publishing: OPDs struggle to have access to ethics committees, especially when they are local and regional organizations. This can make it harder for their data to be scientifically accepted and validated, and to publish the results. OPD data are normally not accepted by national statistics offices.

Limiting access to raw data: Even some of the countries that have disability data available, might not make the raw data available for download or only share specific reports. This can limit OPD advocacy that want more detailed information not available in those reports or to cross-reference specific variables.

What is next?
Data and the models of disability

Research on functional difficulties and disability inclusion is crucial to ensure an accurate representation of different types of disabilities. It is important to recognize that aggregating various disabilities into one category of needs may not be representative, as the needs can differ significantly and sometimes even contradict one another. To effectively advocate for the specific needs of each disability type, it is essential to have well-defined difficulties, needs, and priorities, to ensure accurate profiling and data utilization. Although the Washington Group Short Set has been extended, these extensions are not commonly incorporated. Even when they are, organizations note that certain disabilities, particularly chronic conditions, and autistic or neurodivergent persons, are not adequately represented as a distinct group. While these disabilities may fall under the categories of self-care or communication, it does not provide organizations with a separate group for data analysis.

To address this gap, further research should be conducted to understand the disabilities that cannot be isolated through functional difficulties questions, and a potential expansion of the questions to cater to these disabilities can be developed, ensuring their inclusion in data collection. This is particularly important for groups like autistic individuals who are often underrepresented in data despite facing significant barriers.

The social model of disability emphasizes not only identifying difficulties but also recognizing the barriers and facilitators that individuals with disabilities encounter. Consequently, there is a need for more comprehensive guidelines, tools, and surveys to assess these barriers and facilitators based on the specific type of disability. This expansion should cover various common domains such as employment, for example, but go beyond mere employment status, including the type of employment, remuneration, and availability of reasonable accommodations.

Differences in approaches between organizations of persons with disabilities and governmental surveys commonly arise in the identification and grouping of persons with disabilities. While the use of the social model of disability and functional difficulties is widely accepted as the framework for identifying disability, organizations of persons with disabilities tend to group individuals based on their diagnosed or self-identified disabilities from their members and frame their data needs within the Human Rights model of disability to advocate with the results.
This can pose challenges when comparing data across different organizations and when attempting to cross-reference it with data from census, national surveys, or healthcare services, and demonstrates a need for further conversations on what data OPDs need. More insights on this topic will be discussed in the following pages.

What is next?

Data and the models of disability (cont)

From Medical to Social to the Human Rights Model of Disability: In countries where functional difficulty questions are utilized for census purposes, it is evident that this approach does not extend to other databases or sources of disability data. Consequently, a disconnect arises, as two distinct models are employed: the census or national surveys using WGQ versus other country-specific data sources using methods such as diagnosis for identification. These other sources include hospital and health care data, disability assessments and social services, disability services data, employment and education, disability benefits, and various others. The absence of a standardized methodology to align functional difficulty questions with disability identification forms further perpetuates this disconnection, contributing to incomparable data. Each country also has their procedures and definitions when it comes to assessing and obtaining legal disability status. Some countries certify this status based on a defined percentage threshold denoting "incapacity," others rely on diagnosis, while others assess barriers and difficulties. Persons with disabilities may find themselves excluded from national data and surveys due to not being able to meet the criteria for national disability status, while still being included in the census data.

Data for census and governmental surveys, based on the social model of disability and functional difficulty questions	≠	**Data for disability in health care, disability assessment, access to benefits** and others, based on the medical model of disability. Diagnosis or codes, such as the International Classification of Diseases (ICD)

Expanding the assessment of functional difficulties for additional disabilities, researching harmonization and centralization of disability data across platforms, and incorporating it in different national levels, could facilitate the integration of the models and their comparability. There is a pressing need to broaden the scope of functional difficulty questions beyond governmental surveys and census initiatives to all national data. Adequate funding and resources must be allocated to support advocacy efforts by organizations in this regard. However, we need to consider giving the step beyond the social model into the Human Rights Model of Disability (Degener, 2017). This model aligns with the CRPD and the SDG indicators, contemplating advocacy into their framework. Disability data methodologies framed within the model, such as OPD-generated data, can further support the development of data that OPDs need.

Degener, T. (2017). A New Human Rights Model of Disability. In: Della Fina, V., Cera, R., Palmisano, G. (eds) The United Nations Convention on the Rights of Persons with Disabilities.
Springer, Cham. https://doi.org/10.1007/978-3-319-43790-3_2

What is next?
Data and the models of disability (cont.)

In addition to the requirement for harmonization, it is crucial to acquire comprehensive data on the priorities of OPDs, which could facilitate the expansion of data collection efforts and the development of relevant statistical indicators to appropriately measure key indicators that are not being included. Please refer to the examples below, which are based on the identified data priorities and effective data responses.

Employment: how many persons with disabilities are in paid employment? How many have been provided reasonable adaptations? How many are in sheltered workshops or unpaid/underpaid employment?

Housing: how many persons with disabilities are institutionalized or in the community? How many don't have access to accessible housing?

Education: how many children with disabilities are in mainstream vs special education? How many youth have access to support services for staying in school?

Assistive devices: how many persons with disabilities have access to assistive devices they need? How long do they take to access them? What are the barriers and facilitators to adquire them?

Violence and abuse: how many persons with disabilities were exposed to abuse in a medical setting (e.g., forced sterilisation, restraint and seclusion, unapproved treatments, etc.)? How many persons with disabilities experienced domestic violence? How many persons with disabilities were victims of violence?

Policy: how many countries legally authorize forced sterilisation or forced abortion? What policies are improving the quality of life of persons with disabilities? What countries have accessible elections where persons with disabilities can fully participate? How many political candidates have a disability?

What is next?
Data and the models of disability (cont.)

Intersectionality: how intersectional identities, such as being race, indigeneity, gender, or migrant status, impacts access, barriers and facilitators?

Disability types: What are the differences on the needs, barriers and priorities between different disabilities? What are the specific data needed among different disabilities? How can we better include underrepresented disabilities in the disability movement?

Health: How long does it take for persons with disabilities to receive their diagnosis? What are the barriers to appropriate and timely health care for disabilities?

Access to services: What are the barriers and facilitators to create disability-inclusive services? What are the services that improved quality of life? What are the good practices? What is the impact and outcome of the service in the lives of persons with disabilities?
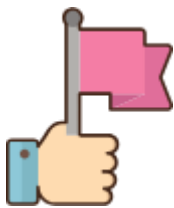
Independent living: How many persons have access to independent living schemes, such as personal assistance? What programs are being implemented to improve independent living, and which ones are the most effective? How many persons with disabilities are in situations of homelessness?

Justice: How many discrimination complaints had legal consequences? What is the percentage of persons with disabilities that report violence, that gets justice, compared with persons without disabilities? How many persons with psychosocial disabilities are imprisioned due to mental health issues, dementia, or other disabilities?

Psychiatric institutions: How many persons with disabilities are being institutionalized in psychiatric units? What are the number of deaths, incidents of isolation and average internment time of persons with disabilities in psychiatric units?

Advocacy: What are the priorities of persons with disabilities? How many of the national/local organizations actively involve persons with disabilities, or are disability-led? What data does persons with disabilities and representative organizations want?

Recommendations

Based on the results of this survey, it is recommended the following steps:

1. Training for national and local organizations: It is recommended the development of online training in partnership with local organizations for translations. A train-the-trainer program could potentially empower persons with disabilities who are experts in data to train organizations in their country. Training would also be a good opportunity to contact national and regional organizations and understand the specific needs associated with different regions.

2. Translation and accessibility of the Disability Data Advocacy Toolkit: The translations in more languages as well as other available formats, such as Microsoft Word, were requested by the survey participants.

3. Database of disability data resources: Centralized website or page with disability data resources, guidelines, methodologies, tools and practical frameworks. An expansion of the Toolkit to an online page of resources could provide organizations with further insights, training, and simplify the process of data gathering for organizations that don't have researchers. It could also contain good practice examples and different templates for data presentation, such as policy briefs, press releases or infographics available for download.

4. Database with National Statistic Office information on disability data per country: The United Nations Statistics Division (UNSD) has a database of main statistical agencies by country, but it would be helpful to make a database with information on specific details of disability data availability and where to access it. This could be done in partnership with local organizations. See UNDS Country statistical agencies.

Recommendations (cont.)

5. Developing guidelines of what data stakeholders need for their advocacy: Creating guidelines, with organizations of persons with disabilities, especially regional organizations, on the disability data needs and priorities, per type of disability. This would include main and detailed indicators, barriers and facilitators to accessing services, human rights violations, and others, to understand how we can close the gap on organizations of persons with disabilities' data needs, and the data that is being developed.

6. A disability rights monitoring tool with continuous funding: Utilizing the guidelines on methodology, trainings and tools, it could be developed a centralized system to report on data that organizations need, where the data is developed and gathered by local organizations of persons with disabilities and a centralized team creates a disability rights monitoring tool. However, it is important to ensure this will have continuous funding.

7. Research on frameworks of disability data for advocacy: Researching how to fully integrate national data systems within a human-rights model framework of disability data could support the shift from the medical model data.

Conclusion

There is a notable disparity in the responses of individuals within the same country regarding the availability of data pertaining to disabilities. This underscores the need for centralizing information on disability data and providing comprehensive countryspecific data to organizations. Organizations of persons with disabilities must receive funding and resources to advocate for the inclusion of functional difficulties questions in national surveys, as well as expanding the scope of related inquiries. It is also crucial that national entities and governmental departments actively engage in data disaggregation across all governmental areas, such as in employment, disability, education, migration, social, justice, economy, and health to ensure that organizations have access to up-to-date, accurate information regarding the status and advancements in the rights of persons with disabilities in their respective countries.

The OPDs data priorities show that more than a shift from the medical model to the social model of disability in data, organizations and advocates show an interest in a reframing data from the medical model to the human rights model of disability, to support their advocacy. Finding the barriers in society is not enough anymore, and it is essential to collect data with the intent to foster political change.

Above all, we would like to emphasize the urgent need for qualitative data on personal experiences and individual barriers and facilitators faced by persons with disabilities. In order to effectively address systemic barriers, it is essential that no one is left behind, and that all intersectional factors and characteristics that exacerbate such barriers are considered.

The participation and leadership of organizations of persons with disabilities and advocates with disabilities, in determining their own priorities and needs is of utmost importance to fully represent, support, and advocate for the rights of all persons with disabilities.

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