

# Why Disability Data Matters:

Review of Leonard Cheshire's latest disability data and the Disability Data Portal



**Leonard  
Cheshire**



# About Leonard Cheshire

Leonard Cheshire supports individuals to live, learn and work as independently as they choose, whatever their ability. Led by people with experience of disability, we are at the heart of local life – opening doors to opportunity, choice, and support across the globe.

Leonard Cheshire works internationally to highlight the importance of disability data reporting and accountability when working to achieve the Sustainable Development Goals (SDGs). We also research disability and poverty, and work with the United Nations, World Bank, International Labour Organization, national governments, disability organisations and development actors to influence policy and make sure everyone can live as they choose.

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## Acknowledgments

This report is authored by Leonard Cheshire. The Disability Data Portal expansion and ‘Why Disability Data Matters’ report is led by Marcus Loney-Evans (Policy Advisor – Disability Data and Inclusion) with significant inputs from Elaine Green (Head of Influencing, Campaigns and Public Affairs), and Dr Mark Carew (Senior Researcher – Disability Data and Inclusive Policies). Lucy Bentley (Writer and Editor) provided support with editing and finalisation.

We would like to thank the following organisations and individuals who were instrumental in the Portal’s expansion and bringing to light this report’s findings:

- Sophie Mitra, Professor of Economics, Fordham University, Principal Investigator: Disability Data Initiative
- Maria Martinho, DPhil, Division for Inclusive Social Development (DISD), United Nations Department of Economic and Social Affairs (UN DESA)
- Every youth with disabilities who contributed their powerful testimonies on the Disability Data Portal via the ‘Missing Voices’ series. This web series portrays just some of the experiences found by Youth reporters in Kenya, Zambia and the Philippines, depicting the daily challenges and discrimination faced by people with disabilities, particularly relating to health, education and employment.
- Every Organisation of Persons with Disabilities (OPD) in Bangladesh and Kenya that has submitted OPD-generated disability data via our new ‘Inclusion Counts’ website. Leonard Cheshire believes this tool can help to strengthen the collective voice of OPDs to hold Governments accountable for their commitments and future policies.
- Website design agency Liquid Light, who have designed and created the Disability Data Portal website, including the latest data expansion.

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# Executive summary

Global disability data collection has progressed considerably in recent years. This progress was catalysed by the adoption of the widely ratified United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 and the 2030 Agenda for Sustainable Development in 2015, both of which include requirements for disability data disaggregation.<sup>1</sup> However, in a world increasingly awash with data, too many countries still have poor disability data, and people with disabilities are still hidden because of a lack of existing disability data.<sup>2</sup>

Where disability data does exist, it can often remain unused. While this is happening, people with disabilities will continue to be excluded. Capturing high quality disability data means leaving no one behind, while improving disability data is integral to ensuring that the commitments made in the Sustainable Development Goals (SDGs) are met for everyone. Data is vital for identifying the challenges and solutions that can improve the lives of people with disabilities. If people with disabilities are excluded from data, then governments can't make policies which address their needs.

No one should be invisible. But the voices of people with disabilities are often missing. Until recently, systematic collection and analysis of statistics related to people with disabilities has been largely overlooked, making it much harder for disability rights advocates, governments, international development partners and agencies to highlight inequalities. That is why Leonard Cheshire created the 'Disability Data Portal'<sup>3</sup> in 2018. Through this Portal, people with disabilities can be empowered to use data to monitor and advocate for change within their countries.

The Disability Data Portal leads the way in synthesising high-quality data to reflect the realities of people with disabilities across the world, and to inform future policy and development reforms. While the quantitative data disaggregated by disability on the Portal shows us one side of the story, we also believe that qualitative data<sup>4</sup> such as

stories and experiences generated by Organisations of Persons with Disabilities (OPDs), and through citizen-reporting, is fundamental in understanding the rights of people with disabilities. These stories and experiences are captured on the Disability Data Portal and have informed government and NGO efforts to sustainably improve the lives of people with disabilities.

In February 2022, the governments of Norway and Ghana, along with the International Disability Alliance, will host the second Global Disability Summit. It is vital that policy makers send a strong signal that they are committed to the rights of people with disabilities to be counted<sup>5</sup> – an essential aspect of fulfilling the goals of an inclusive society. Based on this report's findings, Leonard Cheshire urges policy makers to adopt the following meaningful actions and commitments needed to advance inclusive and disaggregated data at the Global Disability Summit:

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**Where disability data does exist, it can often remain unused. While this is happening, people with disabilities will continue to be excluded**

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## Calls to action

### National governments:

- Commit to using Washington Group Questions<sup>6</sup> in all surveys and censuses and increase the availability of internationally comparable data on disability from all key development indicators, including those drawn from the UN SDG framework.
- Strengthen statistical capacity in-country to measure and incorporate disability into national statistical systems.
- Commit to sharing national census microdata to ensure the public availability of datasets disaggregated by disability.

### International development partners and UN agencies:

- Increase funding by bilateral and multilateral development partners, including philanthropic foundations, for the collection, analysis and dissemination of data on disability.
- Increase commitments to and capacity of humanitarian agencies to capture data on people with disabilities, including through adaptations to donor reporting requirements.
- Ensure programmes and policies capture disability data in line with the Washington Group Questions.
- Provide financial and technical support for the development of further Washington Group Question resources for NGOs and promote good practice examples in the use of the data this produces.

## Tips and guidance on holding national governments to account

Leonard Cheshire is keen to work with others to improve the inclusion of disability data in the data revolution for sustainable development data and the SDGs. OPDs, disability activists and NGOs can all play a part in holding their governments to account and lobbying for the collation of disability disaggregated data. Based on Leonard Cheshire's work collecting disability data as an evidence base to advocate for change, we have the following tips to hold decision makers to account:

- Find out what actions your government is taking to collect data as obligated by the UNCRPD.
- Contact your National Statistics Office and ask for data on people with disabilities.
- Inquire what type of data is collected or disaggregated on people with disabilities in line with the UNCRPD and the global SDG indicator framework.
- Check whether the report your government makes to the UNCRPD committee includes disability disaggregated data.

# Introduction

Leonard Cheshire expects the **Global Disability Summit 2022** to lead to **concrete political commitments on data**. These should bring about **genuine change for people with disabilities** and will help to **reduce inequalities and foster inclusive development, and humanitarian action, guided by a human rights approach**.

This report aims to show why it is essential that everyone has access to high-quality disability data. That way, we can improve public knowledge and awareness of the rights of people with disabilities. In this report, Leonard Cheshire highlights new data from the Disability Data Portal and exposes some of the gaps that still need to be closed to make true on Agenda 2030's pledge to 'leave no one behind'.

The report spotlights key data initiatives achieved by Leonard Cheshire within each of the Global Disability Summit

2022 thematic areas. It seeks to highlight the meaningful actions and commitments needed to advance inclusive and disaggregated data at the Global Disability Summit 2022.

Finally, this report showcases best practice examples of youth and OPD-generated data, engagement with government ministries to support the production of disability data, and also the value of high-quality disability data in international development programme settings.



# Section 1: Why disability data matters

## Global state of play

Since 2006, 182 countries have ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>7</sup> This international treaty aims to ensure that people with disabilities access the same human rights as everyone else and that they can participate equally in society by receiving the same opportunities as others.

According to the World Report on Disability, some 1 billion people – amounting to 15% of the world's population – have a disability.<sup>8</sup> Existing data suggests that people with disabilities are more likely to experience adverse socio-economic outcomes than people without disabilities, in relation to access to education, poorer health, lower levels of employment, and higher poverty rates.<sup>9</sup>

However, inconsistent and poor-quality data hampers progress in accordance with the UNCRPD. Although progress is being made, exclusion from surveys and national censuses means people with disabilities continue to be invisible.<sup>10</sup>

## Leonard Cheshire's Disability Data Portal

The Leonard Cheshire Disability Data Portal was launched at the 2018 Global Disability Summit.<sup>11</sup> The Portal is a centralised space for good quality quantitative and qualitative disability data, providing an overview of the current disability data landscape and highlighting where there are current gaps in bodies of data, considering the UNCRPD. The Portal is also '2030 Agenda'<sup>12</sup> centric and considers the International Disability Alliance's list

of Sustainable Development Goal (SDG) indicators prioritised in terms of disaggregated data.

Leonard Cheshire sees the Disability Data Portal as a huge step forward in confronting the reality of disability rights across the world, and for providing a user-friendly resource to access internationally comparable data disaggregated by disability. However, this quantitative data shows just one side of the story. Leonard Cheshire recognises that disability data generated by Organisations of Persons with Disabilities (OPDs) and through citizen reporting are fundamental in understanding the lived experiences of people with disabilities.

This report will explain how critical a data source the direct experience of people with disabilities is for Leonard Cheshire's Disability Data Portal. Through our citizen and OPD-generated data, Leonard Cheshire is connecting a diverse range of people with disabilities to the development of their country. This report provides an important snapshot of the situation for people with disabilities in critical areas such as youth engagement, OPD engagement, inclusive education, inclusive health, economic empowerment, COVID-19 recovery and inclusive climate action.

As the Global Disability Summit 2022 leads a global charge for better data, the Disability Data Portal will be a valuable resource to ensure that all people with disabilities, no matter who they are or where they are, are truly included.

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## Global Disability Summit

The Global Disability Summit offers a concrete mechanism for collecting new, ambitious, and widespread commitments which are critical to achieving real change for people with disabilities. The first Global Disability Summit, held in 2018, was an important event for disability inclusion, co-hosted by the UK Department for International Development (DFID), the Government of Kenya, and the International Disability Alliance (IDA). The 2018 Summit generated commitments to action that will help deliver Agenda 2030's vision to 'Leave No One Behind' as well as existing obligations under the UNCRPD.

The second Global Disability Summit is taking place on 16 and 17 February 2022 and will be hosted by the Governments of Norway and Ghana as well as the International Disability Alliance (IDA). The Summit aims to achieve ground-breaking results for development aid as well as national policy. It will conclude with a declaration on how to work together from here to achieve our common goals.

### Global Disability Summit 2018: disability data commitments

In 2018, national governments and other organisations came together at the Global Disability Summit to make 170 sets of commitments around the four central themes of the Summit. The following commitments were made on disability data:

- 10 additional national governments committed to using the Washington Group Questions on disability status in upcoming national censuses or surveys (Kenya, Kyrgyz Republic, Malawi, Mozambique, Nigeria, Rwanda, Sierra Leone, Tanzania, Uganda, Zambia), of which 7 will include the questions in their national population census in the next five years (Kenya, Kyrgyz Republic, Nigeria, Malawi, Rwanda, Tanzania, Zambia).

- 7 members of the Organisation for Economic Co-operation and Development (OECD) Development Assistance Committee (DAC) committed to using the new DAC disability inclusion marker (Australia, Belgium, Canada, Finland, Italy, Sweden, and the UK).
- The World Bank Group, the Government of Kenya, and the UK Department for International Development (replaced by the Foreign, Commonwealth and Development Office) signed up to the Inclusive Data Charter,<sup>13</sup> adding to the 10 countries that signed up at its launch.

### Global Disability Summit 2022: what needs to happen

The Global Disability Summit 2022 could be a game-changing moment for progress on building a disability inclusive future. But to realise this vision, governments, policy makers and organisations around the world need to demonstrate and realise a commitment to change, to create a more inclusive society. With less than eight years to go before reaching the 2030 target year for the 17 SDGs, the Global Disability Summit 2022 must build on existing commitments, intensify efforts, and strive to ensure that no one is left behind in the drive to reach the SDGs by 2030. The Summit must also promote actions to increase inclusiveness and equality in line with the principle of leaving no one behind and the UNCRPD.

Leonard Cheshire has not only made data focused commitments ahead of the Global Disability Summit 2022 but is also committed to becoming an Inclusive Data Charter Champion, to catalyse broader action on inclusive disability data. Leonard Cheshire will be working closely with the Inclusive Data Charter to fully develop an action plan to achieve this.

# Section 2: Review of Leonard Cheshire's latest disability data and updates on the Disability Data Portal

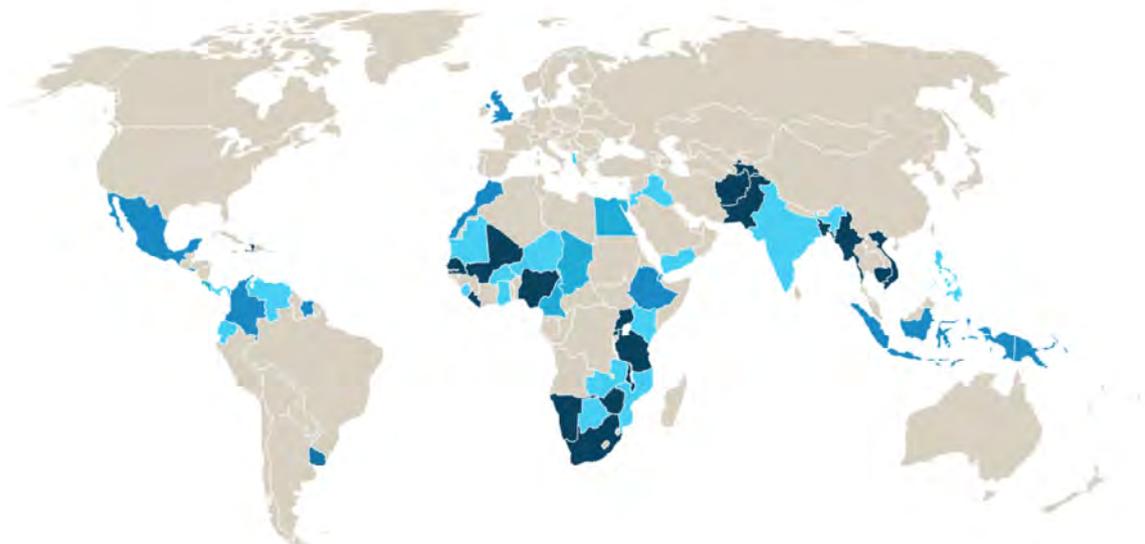
Leonard Cheshire's latest disability data has made significant strides in increasing the understanding of the situation of people with disabilities in low- and middle-income countries, through the collection of existing national and sub-national disability data. As of 2018, Leonard Cheshire's Disability Data Portal has collated quantitative data disaggregated by disability from 48 countries, using key development indicators mostly drawn from the UN SDG framework.<sup>14</sup>

All this, however, is just a starting point. Leonard Cheshire is leading a broad consortium of global, regional, and national organisations to add high quality data for more countries across the world. Ahead of the Global Disability Summit 2022, Leonard Cheshire has committed to sharing over 100 sources of disability data on the Disability Data Portal.

## Data availability by country

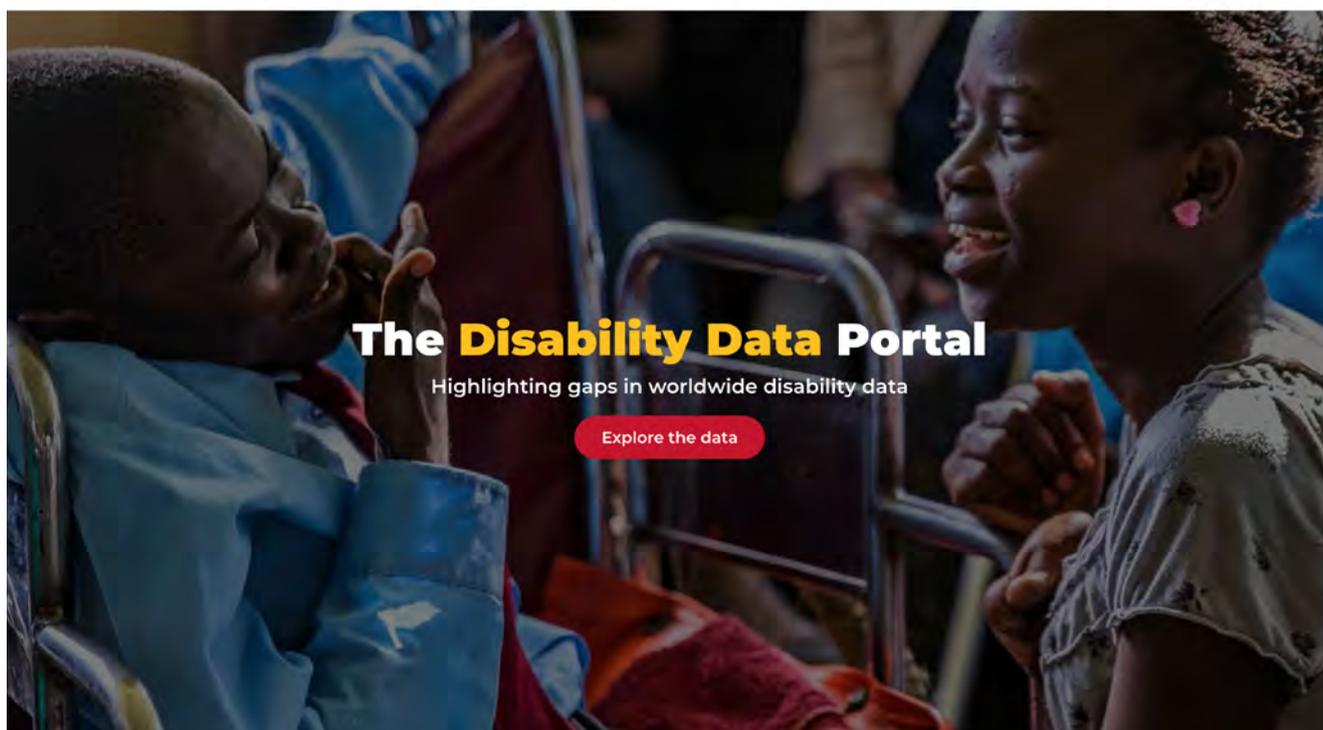
Select Question Type: + Select Country: ▼

Toggle question type + Quick jump to country ▼



## Question type key:

- Uses a question such as 'Do you have a disability?'
- Uses a list of medical questions
- Uses a question on functional limitations, ie what a person can or cannot do
- Uses the Washington Group Questions in some way that is not recommended
- Uses the Washington Group Questions as recommended



## The **Disability Data** Portal

Highlighting gaps in worldwide disability data

[Explore the data](#)

### Expansion of the Disability Data Portal

Leonard Cheshire is working with key data actors to improve the quality and increase the availability of disability disaggregated data on the SDGs, with the aim that this data is used to contribute to ensuring that no one is left behind. This has included working with Fordham University and the United Nations Department of Economic and Social Affairs (UN DESA) to pool together the latest disability data onto the Disability Data Portal, which will feed into and inform the policy guidance in the UN's Disability and Development Report 2023.<sup>15</sup>

Leonard Cheshire has worked closely with researchers at Fordham University, who were responsible for developing the Disability Data Initiative (DDI) and produced their first Disability Data Report in 2021.<sup>16</sup> This report provides a systematic analysis of the disability questions in national censuses and household surveys

globally between 2009 and 2018 and produced indicators disaggregated across disability status for 41 countries with census or household survey data that are based on internationally comparable disability questions on functional difficulties<sup>17</sup> (e.g. seeing, hearing, walking). Their 2022 Disability Data Report will continue this systematic analysis for recent years and provide statistics for more countries.

The Disability Data Portal now highlights some of the findings from this new initiative through data visualisations. They can be accessed on the Portal.<sup>18</sup>

## **National Statistics from the Disability Data Initiative (DDI)**

Data from the DDI's Disability Data Report has found that 'across countries [there is] a disability gap in terms of educational attainment, literacy, food insecurity, exposure to shocks, asset and cell phone ownership, health expenditures and multidimensional poverty'. The data from this report confirms that people with disabilities are at risk of experiencing lower living standards than the rest of the population.<sup>19</sup>

The DDI results also show that "For a majority of countries, there is a disability gap for the employment-population ratio, the youth idle rate, the share of adults in informal work, living conditions (water, sanitation, electricity, clean fuel, adequate housing) and domestic violence."

The DDI results suggest that current economic systems and societies fail to provide ways to include persons with functional difficulties. The results show that disability is a crosscutting, not a specialist, issue. Disability needs to be considered in policies related to aging, gender, health, and poverty. The findings imply that disability should not be seen as a policy issue that is the luxury of high-income and aging economies.

The DDI's Disability Data Report highlights some key findings which demonstrate that measuring disability and making cross-country comparisons is feasible, and provides valuable insights into inequalities. It also shows that more work is needed to analyse data on functional difficulties in general.

While statistics are important, stories and videos are also powerful tools for change. Leonard Cheshire recognises that data generated by OPDs and citizen reporters is fundamental in understanding the experiences of people with disabilities. The next section of this report highlights qualitative and quantitative disability data sources developed by Leonard Cheshire, on the Disability Data Portal and beyond.



Vanessa's story was featured in the Commonwealth Global Youth Development Report

## Youth engagement

Estimates suggest there are around 240 million youth with disabilities worldwide.<sup>20</sup> Nearly 80 per cent live in low- and middle-income countries, and youth with disabilities are still among the poorest and most marginalised of the world's youth.<sup>21</sup> They are routinely excluded from most educational, economic, social, and cultural opportunities.

### Commonwealth Global Youth Development Report 2020

Leonard Cheshire was proud to contribute the first ever disability chapter to the Commonwealth Global Youth Development Report 2020,<sup>22</sup> released in 2021. This data helped Leonard Cheshire to recognise youth with disabilities as key actors in

development and empowered them to raise their voices. The chapter combines government and citizen-generated data, both qualitative and quantitative, bringing to the fore the personal stories behind the statistics and the value of youth-led processes in doing so.

The chapter cited evidence from the Disability Data Portal, which confirmed that youth with disabilities often face the same issues as their peers without disabilities, but often have opportunities denied owing to negative attitudes, discrimination, and barriers to access. The data presented in this chapter also highlighted how youth organisations and youth with disabilities need to be at the heart of the planning and implementation of these policies, and not the mere recipients.<sup>23</sup>

## 2030 and Counting

Youth with disabilities can also play a crucial role in collecting qualitative data through citizen reporting methods. Unlike traditional methods, peer-to-peer models can build greater trust and bring to light the lived experiences of youth with disabilities that often go unheard. Through our 2030 and Counting project, youth with disabilities become agents of social change by leading on citizen-generated data collection and presenting it to policy and decision makers. In doing so they learn how vital data is in building an evidence base to advocate for change.

Our youth engagement programmes train youth with disabilities on leadership and citizen reporting so they can monitor the SDGs in their country by collecting stories – qualitative data – and recording their experiences on their mobile phones. The stories are uploaded onto an online reporting hub and then analysed.

Youth with disabilities, together with OPDs, then share their stories and data trends with policy and decision makers. This has been achieved through social media and global and national advocacy events to ensure youth-appropriate disability inclusive policies are implemented. To date our reporters have spoken at the UN; run national advocacy events in three countries (Kenya, the Philippines and Zambia); and presented draft bills that support disability rights at the Philippines Youth Parliament.<sup>24</sup>



Citizen reporters from the 2030 and Counting project



A meeting at the National Grassroots Disability Organization, an OPD in Bangladesh

## Organisations of Persons with Disabilities (OPD) generated data

Leonard Cheshire considers citizen-generated and OPD-generated data reporting at ground level to have the potential to transform the lives of those with disabilities around the globe.

### New Inclusion Counts tool

Leonard Cheshire has recently worked with OPDs in Bangladesh and Kenya to create OPD-generated disability data, accessed via a new Inclusion Tracker website.<sup>25</sup> The Inclusion Counts assessment tool has been created as a key part of our Disability Data Portal, to help to gather evidence and to look for sources of data to support advocacy efforts for OPDs.

Central to this tool is the meaningful participation of OPDs in implementation and monitoring processes so that the SDGs, and their key principle of leaving no one behind, are fully achieved in line with the UNCRPD.

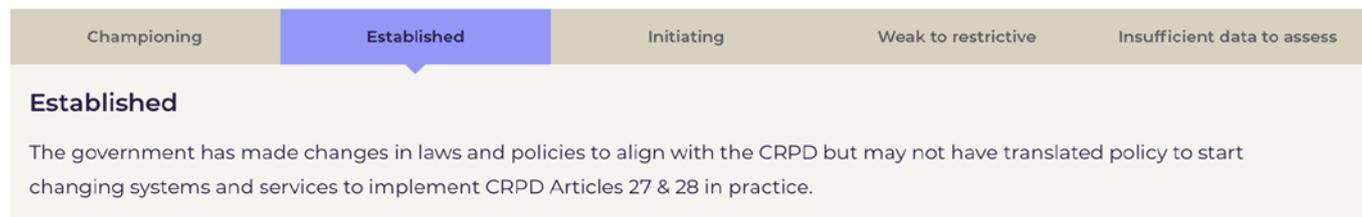
Governments are obligated under both the UNCRPD and the SDG frameworks to ensure that representatives of civil society, in particular people with disabilities and their representative organisations, are involved and participate fully in the development of policies and programmes and the monitoring of their implementation.

The assessment framework within this tool breaks down the framework, measures and safeguards set out under Articles 27 and 28 of the UNCRPD.

### Select Article and Country to explore

Select Article:	Select Country:
Article 27	Kenya

## Article 27



### Kenya Disaggregated Results

#### Assessing your country's legislation on work and employment



[View data source](#)

#### Assessing your country's laws and policies on work and employment



[View data source](#)

#### Assessing your country's national vocational training plan



[View data source](#)

#### Assessing your country's Accessibility standards



[View data source](#)

#### Assessing your country's Equal pay for equal work



[View data source](#)

#### Assessing your country's Reasonable accommodation



[View data source](#)

[Inclusion Counts Tool, Kenya - Article 28](#)

Looking at each measuring key in the disaggregated results on page 15, you can assess where your country is progressing as well as what changes are needed in practice to fully realise the rights enshrined in Articles 27 and 28. Within 'view data source', the measuring keys also detail how OPDs have measured progress within each category, by detailing the legislative sources of data and policy commitments they have found within their respective country.

OPDs can and must play a central role in the decisions that affect their lives, under the slogan of the global disability movement: 'Nothing About Us Without Us'. This tool helps to strengthen the collective voice of OPDs to hold governments accountable for their commitments and shape policies.

### **How OPDs can get involved with the Inclusion Counts tracker**

At present, 21 OPDs from Bangladesh and Kenya have submitted OPD-generated data to the Inclusion Counts website. Leonard Cheshire wants to increase the collective voice of OPDs who have submitted data on the tool, to hold governments accountable for their commitments and shape the policies, development plans and budgets of future generations.

For more information on how you can submit qualitative data onto the Inclusion Counts website, please visit: [inclusiontracker.disabilitydataportal.com](https://inclusiontracker.disabilitydataportal.com)



Children with disabilities remain one of the most likely groups to be excluded from school

## **Inclusive education**

High quality disability data has the potential to transform the lives of those with disabilities around the globe. In the context of inclusive education, disability data can show us how many schools are accessible, how many learners with disabilities are doing well in their education, and how many learners with disabilities are out of school. Disability data is a crucial tool for monitoring the progress of inclusive education policies to create learning environments and ensure no child is left behind.

Globally nearly 240 million children have a disability, yet they remain one of the most likely groups to be excluded from school.<sup>26</sup> Nearly half of all children with disabilities in low- and middle-income countries are out of school, especially those with multiple or severe disabilities or anxiety. Children with disabilities are also less likely to receive support for learning at home and experience difficulties within the school system.

Only when classrooms, schools and education systems are designed to meet the needs of a diversity of learners can the goal of inclusive and equitable quality education for youth with disabilities be realised. The following case study from South Sudan is an example of Leonard Cheshire's work on disability data and the type of programmatic data we want to ensure the Disability Data Portal captures in the future.

## Case study: Improving disability data in national pupil registry in South Sudan

Girls' Education South Sudan (GESS) is a programme funded by UK aid, the Government of Canada, and the U.S. Agency for International Development (USAID), and managed by a consortium led by Cambridge Education/Mott MacDonald.

GESS is an inclusive programme that will transform the lives of a generation of children in South Sudan – especially girls and those in the margins of society – through education by improving school enrolment, reducing barriers to education, and promoting equity of access for all children.

Working in all ten states of South Sudan, the first phase of the programme made huge inroads into improving access to education for girls in South Sudan. However, by the end of the first phase of the

programme, it was realised that children – and especially girls with disabilities – were still largely being marginalised.

To strengthen disability inclusion during the second phase of the programme, Leonard Cheshire came on board as the disability technical advisor within the GESS consortium. The objective is to identify children with disabilities, change negative stereotypes, especially for girls with disabilities, and to target them more systematically – giving them the chance to benefit from a quality education and the opportunity for full participation in society.

Previously, disability data on pupil registration in South Sudan was collected by type of disability, meaning teachers and administrators collecting the data would need to have some knowledge on disability types. As a result, the data collected was scarce. In 2020, when the



A student in South Sudan reads braille

data came, the programme recorded 3,895 children in schools with disabilities, out of a total figure of 2,618,525 children enrolled in primary school (0.15% of children with disabilities enrolled).<sup>27</sup>

In 2020/21, GESS, through technical support from Leonard Cheshire, supported extensive revisions to the Pupil Admission Register (PAR) tool. This update included the Washington Group Questions Short Set to standardise the way disability data was collected. There has been fantastic buy-in and support from the GESS programme and Director General Madam Esther Akumu and her team at the MoGEI, and they underwent extensive training on the Washington Group Questions in preparation for the data collection exercise.

The new PAR tool was rolled out to every school in South Sudan in mid-2021 and has produced some great initial results. Using the recommended Washington Group Questions cut off points, 30,170 children with disabilities have been identified in schools across the country, out of a total enrolment of 2,583,130 children.<sup>28</sup>

While these are more reliable statistics than previously captured, this is still only 1% of the primary school population. This indicates that many children with disabilities are still out of school in South Sudan. More efforts are required to reduce stigma and discrimination and ensure children with disabilities go to school. More work is still required to train teachers on the implementation of the Washington Group Questions as it was found around 15,700 schools were still missing the Washington Group Questions data.

The MoGEI are to be commended on their efforts to improve their national statistics on disability. GESS and Leonard Cheshire are pleased that the 2021 Education Census also included the Washington Group Questions. In 2021, MoGEI also launched their National Policy on Inclusive Education, and it is hoped the new data will help to inform the

development of the inclusive education implementation strategy this year.

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## **We used innovative citizen reporting methods to collect the perspectives of youth with disabilities and those of teachers**

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### **School bullying and violence**

Leonard Cheshire recently led a citizen reporting research collaboration with UNESCO on the theme of school violence and bullying. The report, 'Stories from the Classroom', captured powerful testimonies from over 50 youth with disabilities on their experience of school bullying and violence.

The findings highlighted that the main forms of bullying faced by youth with disabilities were:

- Mocking and teasing
- Dehumanising language
- Dismissive and excluding attitudes
- Intimidating behaviour

Other accounts frequently referenced were:

- Spreading mistruths about disability (e.g. that it is a curse)
- Physical violence

All the testimonials from youth with disabilities within this report contained powerful descriptions of bullying experiences during their school years. Throughout this citizen reporting research, Leonard Cheshire used innovative citizen reporting methods to collect the perspectives of youth with disabilities and those of teachers. We will soon spotlight this qualitative disability data on the Disability Data Portal, to advance efforts to promote safer and inclusive education for all.

## Inclusive health

Since 2018, Leonard Cheshire has been working on the Women's Integrated Sexual Health (WISH) project, led by MSI Reproductive Choices. WISH is funded by the UK FCDO and aims to strengthen support for sexual and reproductive health and rights in African and Asian countries. The programme aims to contribute towards the 'Leave No One Behind' agenda by, amongst other things, reaching women with disabilities whose needs have previously largely been unmet through family planning and Sexual and Reproductive Health (SRH) service provision. Globally, data on disability and SRH remains scarce. While there is a lack of data on SRH in general, data on women with disabilities is particularly hard to come by, partly due to disability stigma. And a lack of data means a lack of information to challenge stigma around disability and sex.

Through our work, we've been able to conduct some research to help shed light on the SRH needs of women with disabilities in West and Central Africa. As part of this research, Leonard Cheshire analysed secondary data taken from demographic and health surveys (DHS) from 11 countries,<sup>29</sup> and explored some key SRH indicators to cover areas where women with disabilities may face disparity in their sexual and reproductive healthcare access, including:

- Accessing healthcare facilities
- Accessing contraceptives and specifically modern, safe methods of contraception
- Assessing the demand for family planning
- Identifying any SRH needs not currently being met



A disability advocate provides advice on contraception to women with disabilities in Sierra Leone through the WISH programme

Considering household and women's health surveys, our first key finding was that not all countries had disability data available that could be analysed with SRH data. This highlights that disability is an area that is not as prioritised within routine national health or household surveys, making it extremely difficult to accurately assess healthcare inequalities.

Looking at the data from these 11 countries<sup>30</sup> we assessed disparities between women of reproductive age (15-49) both with and without disabilities, to paint more of a picture of SRH access. Our analysis revealed that:

- In Mali, there was a greater percentage of women with disabilities who had visited a healthcare facility in the last 12 months (45%) compared to women without disabilities (40%). There was also a higher percentage of women with disabilities using any method of contraception, including traditional and folkloric (19%) compared to women without disabilities (17%).
- Overall, Mali had higher percentages of women with disabilities using modern methods, compared to women without disabilities.
- However, in both Nigeria and Senegal, a lower percentage of women with disabilities reported using modern contraceptive methods, compared to women without disabilities.
- Comparing the three countries, we found that Nigeria had the lowest percentage of women with disabilities using any method of contraception (3.4%), compared to 11.3% of women without disabilities in Nigeria using the same method. Nigeria also had the greatest levels of disparity across all indicators, besides unmet need for family planning, followed by Senegal.

This data provides just a snapshot into how SRH services are accessed by women with disabilities. Available data is just the tip of the iceberg when it comes to identifying the challenges and barriers faced by women with disabilities. It's paramount that more accurate and up-to-date data is gathered to help inform policies and practices around SRH worldwide. That way, the needs of women with disabilities can be better met, and the stigma and misconceptions entrenched in disability and SRH can be broken down.

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**Available data is just the tip of the iceberg when it comes to identifying the challenges and barriers faced by women with disabilities.**

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## Climate and disability

An estimated 20% of people most vulnerable to climate change are people with disabilities. Globally, people with disabilities are more likely to live in disaster-prone areas.<sup>31</sup> Yet, rarely are people with disabilities included in emergency preparedness plans, despite being two to four times more likely to die in a natural disaster than people without disabilities.<sup>32</sup>

Leonard Cheshire is committed to producing disability data that supports inclusive climate action. Many people with disabilities have the expertise and knowledge to make a significant contribution to climate action. Many possess the ability to identify, plan, and implement contextualised climate change risk reduction and adaptation measures.

Leonard Cheshire recently produced a report funded by Elrha's Humanitarian Innovation Fund – Messaging for Inclusion: Identifying relevant factors for disability and age inclusive disaster preparedness.<sup>33</sup> This report looks at just how accessible and inclusive communications around disasters were. Most emergency messaging plans fail to be disability and age inclusive because they do not use the channels these populations use. This leaves large sections of communities uninformed and vulnerable. This report found that existing approaches are not inclusive enough.

Going forwards, the Disability Data Portal will seek to produce innovative disability data on climate action that is inclusive of people with disabilities, and that responds to some of the challenges involved in data generation and reporting during climate emergencies.



People with disabilities find ways to cope with flooding in Bangladesh

## Economic inclusion

One of our most successful citizen-generated data projects has been the Access to Employment (A2E) pilot programme in Thailand.<sup>34</sup> The project aimed to boost awareness of issues faced by youth with disabilities as they sought employment. Youth with disabilities were trained to use mobile phones to document and share experiences online. This created a powerful evidence-base to identify trends and highlight examples of discrimination. This reporting could then be shared with decision makers to influence change.

The volunteers who took part in the A2E programme were asked to share their experience of the job market as youth with disabilities. They were also encouraged to suggest what governments and employers could do to improve the situation. The project received 114 testimonies from 55 youth with disabilities, aged between 18 to 35 years old. Transcripts from these media posts then underwent thematic data analysis to discover patterns and trends, which could be summarised into a report. Several themes were uncovered:

- Lack of accessible recruitment processes and workplaces, including a lack of confidence by youth with disabilities to address inaccessible or discriminatory workplaces
- Stigma from recruiters – a perception of disability as inability
- Lack of employment rights and benefits for youth with disabilities
- Fewer work opportunities for out of work youths due to COVID-19
- More flexibility for those already in work before the pandemic due to the increase in remote working



Lead Youth Advocates from the A2E programme at a group meeting

Through the programme, youth with disabilities put forward strong arguments for improvements and suggested changes, and a webinar was hosted in Thailand to hear first-hand from youth with disabilities on what needs to be done to ensure inclusive employment based on their own lived experience. Stakeholders from UN agencies, governmental bodies, private sector, and civil society joined youth with disabilities to discuss real solutions to the problems they had encountered.

**“This virus has changed the way we live our lives in various aspects. Among people suffering from this pandemic, blind people are facing double challenges.”**

Khim, Missing Voices Youth Reporter – Thailand

**“During the COVID-19 pandemic, my life was even more difficult, as people are wearing face masks which make me hear less and lip reading is not possible.”**

June, Missing Voices Youth Reporter – Thailand

## Case study: JJ

JJ recently took part in our A2E pilot programme. JJ is a person with autism who has been using his experiences in the workplace to advocate for better disability inclusion in Thailand. As a Lead Youth Advocate, JJ has developed his skills and confidence to help empower other youth with disabilities to speak out about the inequalities they're facing.

As part of being a Lead Advocate for the programme, JJ also attended advocacy events with government officials and CEOs. At these events, he shared information on the barriers youth with disabilities face in Thailand. Recently, he took part in an event at the High-Level Political Forum on the SGDs. There he spoke to OPDs and representatives of the Thai Government. He highlighted the importance of inclusive employment pathways, especially in the wake of the pandemic.



JJ at a meeting for Lead Youth Advocates from the Access to Employment programme

## Case study: Working with the Thailand Government to share new disability data on the Portal

Realising the importance of disability-inclusive data, the Department of Empowerment of Persons with Disabilities (DEP) in Thailand has worked in collaboration with Leonard Cheshire to support Thailand's efforts towards quality disability data disaggregation.

Leonard Cheshire facilitated a workshop with the Thailand Ministry in October 2021, to review the existing disability data captured by Thailand and to identify where government departments have data disaggregated by disability. 26 government representatives from the Ministry of Social Development and Human Security, Ministry of Health, Ministry of Education, Ministry of Labour, Ministry of Digital Economy

and Society, Ministry of Justice, and Ministry of Higher Education, Science, Research and Innovation participated in the workshop. Now, the first batch of disability data from Thailand is ready for dissemination on the Disability Data Portal.

Leonard Cheshire will continue to work with the Royal Government of Thailand on disability data. With quality disability disaggregated data in place, Thailand is now able to better understand the specific situation of people with disabilities, resulting in more effective and efficient implementation of the policies that improve the quality of life for people with disabilities.



Ian Banda, one of the lead youth researchers for the Crisis Talks report

## COVID-19 recovery

While pandemics affect everyone, past health emergencies show that the poor and most vulnerable are the hardest hit. In March 2021 we produced *Crisis Talks: Raising the global voice of youth with disabilities on the COVID-19 pandemic*,<sup>35</sup> a report highlighting the realities of youth with disabilities during COVID-19. The project was community-led and raised the voices of youth in India, Indonesia, Kenya, South Sudan and Zambia.

*Crisis Talks* details the views of 545 youth with disabilities (aged 15-35) from Indonesia, India, Kenya, South Sudan and Zambia and their experiences in the pandemic. Responses were kept anonymous to protect those who contributed to the report, but similar themes emerged in every country

where the team conducted the research. The team found evidence of increased discrimination against youth with disabilities arising from the pandemic.

“People are afraid to help us,” said a respondent in South Sudan. “They used to do before the pandemic, but now they fear that we might have COVID-19.”

Across the five countries, youth with disabilities:

- Were often the first to be furloughed or to lose their jobs
- Had little access to healthcare information
- Lost access to medications
- Felt excluded when trying to access remote education

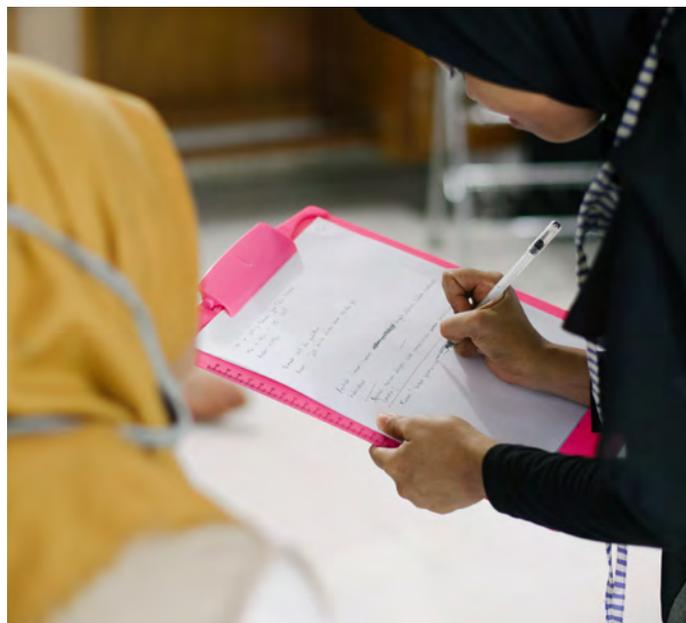
**“People are afraid to help us. They used to do before the pandemic, but now they fear that we might have COVID-19.”**

Research respondent, South Sudan

However, the research also uncovered that these same groups of people had often played leading roles in protecting their communities from the pandemic. Youth with disabilities had helped distribute personal protective equipment (PPE) or spread public health information using local radio stations.

A young person from Indonesia summed up the determination many felt to be part of an inclusive recovery, telling the team: “We, together, must curb and prevent COVID-19.” A young person from South Sudan added: “Since youth with disabilities have got capacity in handling activities like awareness raising, decision making, counselling and sensitization, we need to be better involved in COVID-19 programmes. [But] when programmes are organised, we are often not invited, despite many issues being related to us.”

The report summarises the issues raised by country, and analyses government responses to COVID-19. Urgent action is required to ensure that youth with disabilities are consulted and included in public emergency planning, health response and recovery efforts; and that they are seen as actors who can contribute to the rebuilding of societies. For this to become a reality a multi-sector approach is needed. The recommendations in this report serve as a reminder, not just to governments but a range of duty bearers, that the strongest progress can only be made when acting together.



Crisis Talks research participants from Indonesia

**“Since youth with disabilities have got capacity in handling activities like awareness raising, decision making, counselling and sensitization, we need to be better involved in COVID-19 programmes. [But] when programmes are organised, we are often not invited, despite many issues being related to us.”**

Research respondent, South Sudan

## Section 3: Conclusion and recommendations

As 2030 approaches, commitments to the SDGs are more important than ever. However, when it comes to disability, though increasing amounts of disability data are now being captured, data is still sparse. This makes the task of measuring challenges and impact when it comes to areas like inclusive education, access to jobs and social inclusion, accessible healthcare and inclusive climate action very difficult. Without accurate data, it is marginalised groups – including people with disabilities – who are at risk of being left behind.

World leaders will be present, and the world's population are invited to observe, the Global Disability Summit 2022. This Summit must promote actions to increase inclusiveness and equality in line with the principle of leaving no one behind and the UNCRPD. A menu of suggested commitments has been developed in consultation with the Global Action on Disability Network. Concrete political

commitments on disability data must be achieved, if genuine change for people with disabilities is to be realised.

The following section proposes actions that can be taken now at government, international, and community level, to ensure we have sufficient disability data to assess our progress towards the 2030 SDGs:



## Calls to action

### National governments:

- Commit to using Washington Group Questions in all surveys and censuses and increase the availability of internationally comparable data on disability from all key development indicators, including those drawn from the UN SDG framework.
- Strengthen statistical capacity in-country to measure and incorporate disability into national statistical systems.
- Commit to sharing national census microdata to ensure the public availability of datasets disaggregated by disability.

### International development partners and UN agencies:

- Increase funding by bilateral and multilateral development partners, including philanthropic foundations, for the collection, analysis and dissemination of data on disability.
- Increase commitments to and capacity of humanitarian agencies to capture data on people with disabilities, including through adaptations to donor reporting requirements.
- Ensure programmes and policies capture disability data in line with the Washington Group Questions.
- Provide financial and technical support for the development of further Washington Group Question resources for NGOs, and promote good practice examples in the use of the data this produces.

## Tips and guidance on holding national governments to account

Leonard Cheshire is keen to work with others to improve the inclusion of disability data in the data revolution for sustainable development data and the SDGs. OPDs, disability activists and NGOs can all play a part in holding their governments to account and lobbying for the collation of disability disaggregated data. Based on Leonard Cheshire's work collecting disability data as an evidence base to advocate for change, we have the following tips to hold decision makers to account:

- Find out what actions your government is taking to collect data as obligated by the UNCRPD.
- Contact your National Statistics Office and ask for data on people with disabilities.
- Inquire what type of data is collected or disaggregated on people with disabilities in line with UNCRPD and the global SDG indicator framework.
- Check whether the report your government makes to the UNCRPD committee includes disability disaggregated data.

# Contribute data to the Disability Data Portal – get involved!

In addition to supporting improved quality and increased access to data on disability, Leonard Cheshire is also contributing to the global debate on how to capture data on disability using evidence from our long-term experience in the field of disability data research and policy. Leonard Cheshire is committed to becoming an Inclusive Data Charter Champion, to catalyse broader action on inclusive disability data. Leonard Cheshire will be working closely with the Inclusive Data Charter to fully develop an action plan to achieve this. Recognising that disability data is often difficult to capture consistently at a national level, Leonard Cheshire is also very keen to support National Statistical Offices to develop and implement the most effective data collection techniques to capture information on the extent to which people with disabilities are being included in efforts to achieve the SDGs.

Leonard Cheshire is well placed to undertake this work, with strong experience of gathering data on people with disabilities in both our international and our UK programme work. We are very keen to work with others to improve the inclusion of disability data in the data revolution for sustainable development data and the SDGs.

Visit the Leonard Cheshire Disability Data Portal today:

[www.disabilitydataportal.com](http://www.disabilitydataportal.com)

# Endnotes

1. Disaggregated data is data that has been broken down by detailed sub-categories, for example by marginalised group, gender, region or level of education. Disaggregated data can reveal deprivations and inequalities that may not be fully reflected in aggregated data.
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3. Leonard Cheshire, Disability Data Portal: [www.disabilitydataportal.com](http://www.disabilitydataportal.com)
4. By qualitative data, we mean data that is non-numerical in nature, which approximates and characterises. Qualitative data can be observed and recorded, and can be collected through methods of observation, interviews, questionnaires, focus groups, and participant-observation or reporting.
5. UNCRPD Article 31 states that: ‘States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.’
6. The Washington Group Questions are targeted questions on individual functioning intended to provide a quick and low-cost way to collect data, which allows disaggregation by disability status. Visit [www.washingtongroup-disability.com](http://www.washingtongroup-disability.com)
7. [www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx)
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11. [www.gov.uk/government/topical-events/global-disability-summit-2018/about](http://www.gov.uk/government/topical-events/global-disability-summit-2018/about)
12. The ‘2030 Agenda for Sustainable Development’ was launched by a UN Summit in New York on 25-27 September 2015 and is aimed at ending poverty in all its forms. The UN 2030 Agenda envisages “a world of universal respect for human rights and human dignity, the rule of law, justice, equality and non-discrimination”. Visit: [www.un.org/sustainabledevelopment](http://www.un.org/sustainabledevelopment)
13. The Inclusive Data Charter (IDC) was developed by a task team of Global Partnership for Sustainable Development Data partners to mobilise political commitments and meaningful actions to advance inclusive and disaggregated data.
14. Leonard Cheshire: Disability Data Portal, SDGs explained. Available at: [www.disabilitydataportal.com/about/sdgs-explained/](http://www.disabilitydataportal.com/about/sdgs-explained/)
15. UNDESA (2018). Disability and Development Report 2018. Available at: [www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/10/UN-flagship-report-on-disability-and-development.pdf](http://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/10/UN-flagship-report-on-disability-and-development.pdf)
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