

Sightsavers Inclusive Data Charter Action Plan

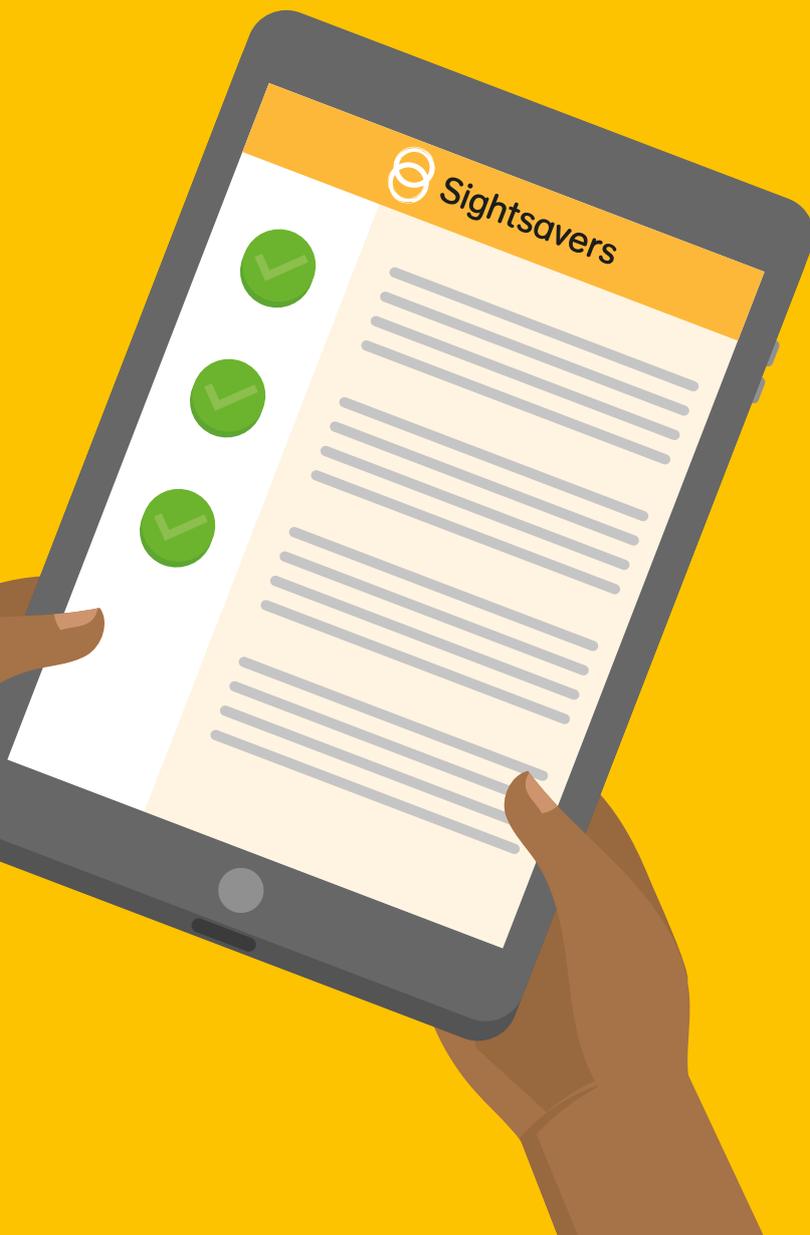
2024-2027



Sightsavers

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Five principles of the Inclusive Data Charter

- 1 All populations must be included in the data
- 2 All data should, wherever possible, be disaggregated to accurately describe all populations
- 3 Data should be drawn from all available sources
- 4 Those responsible for the collection of data and production of statistics must be accountable
- 5 Human and technical capacity to collect, analyse, and use disaggregated data must be improved, including through adequate and sustainable financing

Introduction

Sightsavers is a co-founding champion organisation of the **Inclusive Data Charter (IDC)**, a global initiative to mobilise political commitments and create meaningful actions that advance inclusive and disaggregated data.

This document outlines Sightsavers' renewed commitments to the IDC. It summarises what inclusive data means for our work, our progress and learnings from our first **Inclusive Data Charter Action Plan** and our key commitments on inclusive data for 2024-2027. It complements Sightsavers' vision and approach to inclusive data. Easy read versions of both documents are available. **You can view all documents online.**

Inclusive data is data that is representative of all people, especially those who are marginalised or underrepresented. Collecting inclusive data enables us to better understand who is being left behind and why. This allows us to close the gaps that inadvertently facilitate discrimination and bias in design, monitoring, evaluation and decision-making.

For Sightsavers, inclusive data means collecting data primarily on disability, **sex*** and age while bringing in other dimensions such as geography, wealth and poverty where relevant and valuable. We want to see a world where no one is blind from avoidable causes and where people with disabilities participate equally in society. Inclusive data is critical to advancing our organisation's vision and mission, which enables us to better understand the people and communities we work with, identify where specific barriers

exist and take steps to address them.

We collect inclusive data to strengthen the effectiveness of our programmes and support governments and the partners and communities we work with to collect and use this data. This ensures that data is used to drive better decision-making and more inclusive, equitable outcomes for people with disabilities and other population groups.

***We have used the term sex, rather than gender, throughout this document, as in the quantitative data we currently collect, the characteristic categorisation of male/female (and in some cases prefer not to say) is primarily used in the systems we work in, even where this is termed as gender-disaggregated data. We are continuing to explore ways to collect data on gender, both quantitative and qualitative, and this will be an ongoing area of discussion and work during the period of this action plan, alongside our broader programmatic approach to gender. This work will be informed by the wider current debate on the collection of gender and sex-disaggregated data.**

Front cover image caption: Ayesha (centre) and Jalil (right) are a husband and wife team who conduct mapping surveys to see where people with disabilities live, which is crucial in enabling Sightsavers to provide support. They located Nipa (left) and are supporting her to find work.

Sightsavers' progress on inclusive data

What progress have we made on inclusive data?

In our first IDC Action Plan, published in 2018, Sightsavers made seven commitments to advance our work on inclusive data.

A summary of some of the key progress we have made against each objective is outlined below.¹

Objective 1

Increase the capacity of Sightsavers staff and partners to incorporate data disaggregation into their work

Examples of progress:

- ✔ Created tools and guidance to support data collectors on disability inclusion, the Washington Group questions, data collection and management
- ✔ Embedded data reflection sessions with country project staff as part of routine data collection to identify key trends and issues and inform ongoing learning and improvement



Bencio Mizinho (left) and Micheque Nhambazi (right) survey community members about black fly bites.

Objective 2

Systematic inclusion of disaggregated data in project systems and monitoring

Examples of progress:

- ✓ Expanded the use of the CommCare data collection tool to collect disability data from inclusive eye health projects in five countries (India, Tanzania, Bangladesh, Pakistan and Mozambique), and the successes in disaggregating referral uptake by disability enable us to determine if people with disabilities have equitable access to cataract surgeries
- ✓ CommCare has been used to collect **Child Functioning Module** (developed by the Washington Group and UNICEF) data in education projects in Nigeria and Kenya. The Child Functioning Module is a questionnaire used by teachers to determine if a child has any difficulties that mean they will struggle in the classroom

Objective 3

Continue to collect, report, analyse, and use data on age, disability, sex, economic status and location data where relevant, and contribute to the evidence base

Examples of progress:

- ✓ Completed rapid assessments of avoidable blindness (RAAB) in five countries (Mozambique, Nigeria, Pakistan, Sierra Leone and Senegal), looking at disability data alongside sex, age and location to assess the prevalence of avoidable blindness in the areas we deliver eye health services
- ✓ Shared learning on the use of the Child Functioning Module collection of data at an international level
- ✓ Collected age and sex-disaggregated data to demonstrate how this data can be utilised to improve service delivery in eye health projects in the **Boresha Macho project in Tanzania** and Karamoja, Nigeria

Objective 4

Meet all data disaggregation commitments in new funding streams, such as UK Aid Connect, the Disability Inclusive Development programme and Audacious

Examples of progress:

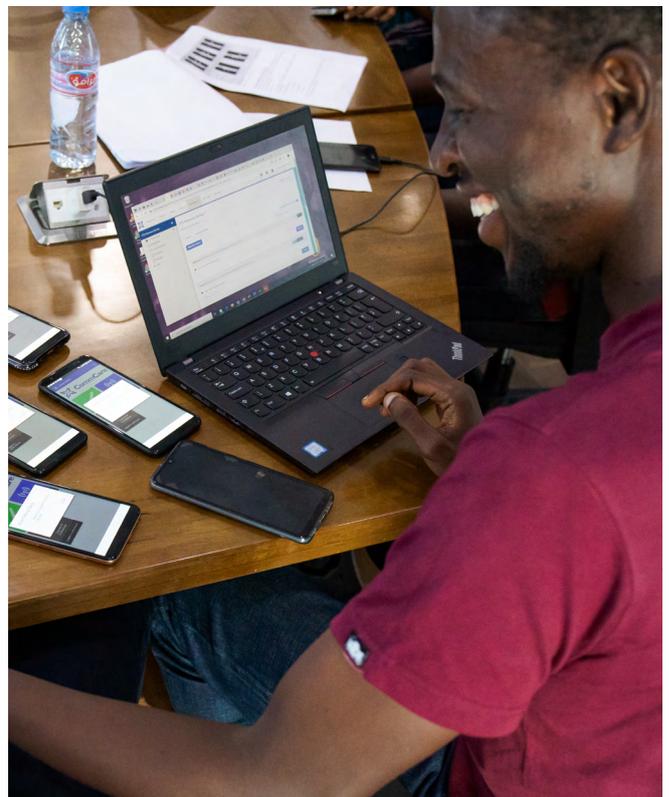
- ✔ Commissioned a **gender synthesis review**, looking at 17 project evaluations that demonstrated improvements in our collection of sex-disaggregated data
- ✔ Successfully piloted the use of the Child Functioning Module in eight schools in Nigeria as part of **Inclusive Futures'** Disability Inclusive Development programme, funded by UK aid
- ✔ Supported the delivery of more than 656,500,000 treatments and more than 161,500 surgeries for trichiasis and hydrocele between 2018 and 2022, and these were all disaggregated by geography, sex and age, as applicable

Objective 5

Develop and share learning with national statistical offices, ministry and civil society partners

Examples of progress:

- ✔ Supported inclusive data learning with ministries and statistical offices in Kenya, Pakistan and Sierra Leone
- ✔ Hosted a global inclusive data knowledge event with UN Women, Development Initiatives and HelpAge International, sharing practices and learnings on collecting and using inclusive data with more than 300 participants



Abakar Gankpala installs the CommCare app for data collection in the field during a training session in Monrovia, Liberia.

Objective 6

Provide evidence to support implementation of the 2030 Agenda

Examples of progress:

- ✔ Published journal articles to contribute to the evidence base on disability data, including a paper on the prevalence of visual impairment, coverage of cataract services based on RAAB surveys and **moving the disability agenda forward with scarce data**



Micheque Nhambazi enters the GPS location for the Magamba community into the mobile phone data collection software used for the Onchocerciasis Elimination Mapping (OEM) project.

Objective 7

Partnerships and working in collaboration

Examples of progress:

- ✔ Advanced strategic collaborations with partners, including the IDC, CBM Global, International Disability Alliance and the Global Disability Summit
- ✔ Successful IDC advocacy strengthened disability-inclusive data in five countries (Cameroon, Kenya, Nigeria, Senegal and Sierra Leone)
- ✔ Partnered with more than 20 civil society organisation (CSO) partners on the **Inclusive COVID-19 Data Unequal Pandemic report** to look at the value of community and CSO data in providing a more accurate picture of the realities experienced by marginalised people

Context

What has changed?

In 2014, Sightsavers set up an internal group to look at disability disaggregated data to strengthen the collection, analysis and use of this data within our programmes. This work was partly driven by our emerging work on data disaggregation piloted in Tanzania and India, the need for us to be doing what we were encouraging the development sector to do, as well as wanting to share our learnings to help strengthen practice within the sector.

Since we started working on data disaggregation, the external landscape and how the development sector engages with inclusive data has changed. We know from our engagement with partners through the Inclusive Data Charter that governments and organisations now have more awareness of the importance of inclusive data.

COVID-19 reinforced social and economic inequalities and excluded marginalised groups, including people with disabilities, and women and girls. With people with disabilities being disproportionately impacted, disability rights advocates came together to launch initiatives² to collect better information on how the pandemic impacted the lives of people with disabilities so they could inform policy interventions.

COVID-19 also increased the prominence of inclusive data and its importance in a targeted pandemic response and post-pandemic recovery. The demand for high-quality, timely and inclusive data to inform policymaking increased. National statistical offices adapted their approaches to data collection, including looking to non-official data sources such as citizen-generated data to complement official data sources.

Since COVID-19, we are seeing more conversations on intersectionality and citizen-generated data to drive more inclusive, equitable outcomes. The key to this work is inclusion and participation in data collection, analysis and use. We must ensure that we do this in partnership with organisations of people with disabilities (OPDs) and think about the people we are collecting the data from, how it is collected and how it benefits them. We are also seeing more conversations on data values, compelling us to take a more values-based, principled approach to our data practice so that the collection, analysis and use of data are seen as being fundamental to societal change.



Trachoma survey team members Kadiatu Thullah, Dr Lloyd Harrison-Williams and Abie Davies speak with community members in Yainkassa community, Sierra Leone.

Internally, Sightsavers has developed its approach to collecting and utilising disability disaggregated data using the Washington Group questions on disability alongside other approaches. We expanded the use of the Washington Group questions in more countries across our work on inclusive eye health. We are now collecting disability data as part of routine monitoring of inclusive eye health and disaggregating data by disability and other characteristics in education and economic empowerment projects.

Since we started our data work in 2014, Sightsavers has increasingly taken a more intersectional approach to data³. We are looking at how disability overlaps with characteristics such as sex and age, and assessing who is being excluded from eye health services.

We've shared our learnings with partners in the development sector and beyond to contribute to best practice and expand our strategic partnerships and collaborations. Alongside our partners, we've successfully influenced governments to strengthen their commitments to the inclusive data agenda in Kenya, Nigeria, Senegal, Cameroon and Sierra Leone.

What is still to be done?

The global community is now at the midpoint of the 2030 Sustainable Development Goals (SDGs). Progress has been made in advancing some SDG indicators, but a significant number of SDGs still lack sufficient data to assess progress. For example, the 2022 SDG report notes that significant gaps still exist in monitoring the progress of vulnerable population groups. When it comes to disability, “out of 10 SDG indicators that require disaggregation by disability status, data is available for only two of them”.⁴

More governments use the Washington Group questions on disability in censuses and surveys. However, in some contexts, challenges have been identified in how the questions are being applied, leading to concerns by OPDs and other actors on the accuracy of the data collected. Work is still needed to build and foster trust, engagement and participation in data processes. We must do more to strengthen the feedback and accountability mechanisms to ensure that OPDs and local-level actors are actively included across the data value chain, from collection, analysis and the use of data.

As an organisation, Sightsavers has gathered knowledge and experience over the last nine years in collecting disability data using the Washington Group questions alongside other inclusive data dimensions such as sex and age, including learnings on what works and what doesn't. Now, we need to build on this intersectional approach to ensure that the data collected is analysed and used to improve programme delivery and outcomes. We need to finalise and embed inclusive data learning questions for each of our thematic areas on health and inclusion and do more to consolidate learnings on what we have trialled. We want to share our learnings and experiences and continue to exchange knowledge with others in the wider global development community on inclusive data approaches.

Externally, we want to see more focused commitments and actions on inclusive data. This includes advocacy alongside partners that will increase investment by decision-makers at global and national levels in the systems and structures needed to close the gaps in inclusive data. Alongside this, we must ensure clarity as part of planning processes on why data is being collected and how it will contribute towards inclusive and fairer outcomes for all.



Jalil (left) and Nipa (right) collect data on where people with disabilities live in their town in Bangladesh.

Sightsavers' updated IDC Action Plan: 2024-2027

Over the next three years, we will advance our commitments to inclusive data in line with our programme and **thematic strategies** on health and inclusion⁵. We will focus more on how we can create change at scale through system strengthening and by looking at the broader enabling environment and the systems and processes needed to support the effective collection, analysis and use of inclusive data.

We will invest resources to strengthen the capacity of our staff and partners on disability-inclusive data.

And we will continue to encourage others, including governments and organisations, to strengthen their commitments to disability-inclusive data.

Sightsavers' inclusive data objectives

Objective 1

We will continue to improve internal knowledge and practice to contribute to strengthening evidence and our learning on the collection, analysis and use of inclusive data.

Key areas of work:

-  Advance our intersectional approach to the collection, analysis and use of data, including age, sex and disability, to improve programme delivery and outcomes for those at the greatest risk of marginalisation
-  Strengthen inclusive data indicators within the learning, accountability and monitoring progress (LAMP) framework for our thematic strategies on health and inclusion
-  Finalise the inclusive data learning questions to complement the learning, accountability and monitoring progress (LAMP) framework, embed them in projects where relevant and feasible to capture and share learnings
-  Continue to explore how to enhance existing and new technologies to collect, monitor and report on inclusive data more consistently, including ways to create better links from local, national and global levels
-  Document, consolidate and share learning on the use of the Washington Group questions and other inclusive data approaches to contribute to sectoral knowledge and practices for highlighting inequality

Objective 2

We will work with local, national and global partners to increase the capacity to collect, analyse and use inclusive data within projects and programmes to improve service delivery.

Key areas of work:

- ✔ Continue to increase the capacity of Sightsavers staff to incorporate inclusive data into their work through guidance, tools and training
- ✔ Increase equity and accountability in our inclusive data approach by exploring how to involve OPDs and other local organisations in all aspects of the data value chain, from collection to analysis and the use of inclusive data
- ✔ Work with OPDs, civil society and other development actors at national and local levels to build awareness, identify gaps and strengthen their capacity on inclusive data collection, analysis and use
- ✔ Pilot and scale up approaches to incorporate inclusive data within health, education and social inclusion systems in-country projects and share learnings on what works to strengthen programmatic interventions and influence decision-makers
- ✔ Build the capacity of partners and governments on effective collection, analysis and use of inclusive data to strengthen health, education and social inclusion systems for improved service delivery



Along with a colleague, Micheque Nhambazi (right) collects participant information during the OEM project.

Objective 3

We will diversify resource mobilisation, engage new supporters and strengthen Sightsavers' reporting and accountability mechanisms to meet our commitments on inclusive data.

Key areas of work:

- ✓ Refine Sightsavers' capacity statement and value proposition on inclusive data for external engagement
- ✓ Engage with institutional donors, corporates and consortia leads to build their knowledge and awareness of the importance of inclusive data while pursuing opportunities for collaboration
- ✓ Strengthen inclusive data reporting, data quality and accountability mechanisms through reviewing and updating information systems and data management tools to provide a consolidated, aggregated view of inclusive data progress across the organisation, enabling us to better report our commitments to others
- ✓ Strengthen decision-making processes on when inclusive data should be collected within programmes to facilitate better cross-organisational linkages and understanding of what inclusive data means for Sightsavers' work

Objective 4

We will continue to advocate for governments and development actors to strengthen their policies, systems and processes to effectively collect, analyse and use inclusive data.

Key areas of work:

- ✓ Influence governments and development actors to collect, analyse and use inclusive data, with a particular focus on the integration of the Washington Group questions into data collection systems
- ✓ Influence governments and development actors to become IDC champions and support the development and implementation of their IDC action plans
- ✓ Engage with governments and relevant agencies to ensure that mechanisms are in place to incorporate disability disaggregated data into SDG reporting
- ✓ Work with OPDs and other partners to increase their understanding of inclusive data and build their capacity to influence and hold governments to account on their commitments to inclusive data
- ✓ Influence the private sector to strengthen their reporting of inclusive data as part of labour force participation, diversity and sustainability monitoring

How will we get there?

We will monitor and report on the progress and delivery of the objectives in the Sightsavers IDC Action Plan through various internal and external mechanisms.

Internally, we will assess progress through our organisation and thematic strategy monitoring mechanisms, which we publish through our **Strategy Implementation Monitoring (SIM) card**.

We will improve internal collaboration mechanisms to strengthen coordination, tools and guidance to facilitate the effective analysis and use of collected inclusive data. To complement the Sightsavers IDC Action Plan, we will develop a detailed internal work plan outlining how to deliver our shared, cross-cutting organisational goals and objectives on inclusive data. The delivery of the action plan and accompanying work plan will be the shared responsibility of an internal inclusive data working group. This forum will bring together stakeholders from across Sightsavers to share learning and practice and collaborate

to advance organisational strategic priorities on inclusive data. Additional progress monitoring will be done through internal management information systems and data management tools to provide a consolidated, aggregated view of inclusive data progress across the organisation.

Externally, we will report on progress towards meeting our IDC action plan objectives through IDC champions monitoring mechanisms, Global Disability Summit progress reviews and ongoing accountability as part of our institutional and donor funding commitments.



Verónica Casmo (centre), a supervisor for the OEM project, talks with Louise Hamill (right) and Jerónimo Langa (left) before the survey teams attend a community-based training day.



The OEM project uses mobile phones to collect data while in the field. Trainees set up their phones and record their location at the start of community-based training day.

Endnotes

- 1 Further details on Sightsavers' progress on IDC commitments can be found in our annual monitoring submission forms: www.data4sdgs.org/initiatives/inclusive-data-charter
- 2 Initiatives included the **COVID-19 Disability Rights Monitor** alongside advocacy campaigns **by disability movement actors**
- 3 Alongside IDC partners, Sightsavers contributed to the series of knowledge products on 'Unpacking intersectional approaches to data'. www.data4sdgs.org/resources/unpacking-intersectional-approaches-data
- 4 The Sustainable Development Goals Report 2022, UN. unstats.un.org/sdgs/report/2022/The-Sustainable-Development-Goals-Report-2022.pdf
- 5 We will review the action plan in 2027. The 2024-27 timeframe enables Sightsavers to assess and consolidate progress and course correct where needed, ahead of the end of the SDG Agenda 2030.

We work with partners in
low and middle income countries
to eliminate avoidable blindness
and promote equal opportunities
for people with disabilities

www.sightsavers.org

Learn more about our inclusive data work at
www.sightsavers.org/programmes/inclusive-data



@Sightsavers

Bumpers Way
Bumpers Farm
Chippenham
SN14 6NG
UK

+44 (0)1444 446 600

info@sightsavers.org

