Sightsavers' vision and approach to inclusive data

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Sightsavers' vision for inclusive data

The inclusion of people with disabilities is at the heart of Sightsavers' mission. **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 Sightsavers' vision and mission. It enables us to better understand the people and communities we work with, how they are marginalised and the factors that create barriers to their inclusion. Using inclusive data, we can work to remove these barriers and improve access to services and opportunities so everyone can enjoy their human rights.

We want the collection, analysis and use of inclusive data to drive a better understanding of whether country programmes are leading to positive change and enabling us, our partners and the communities we work with to hold ourselves to account and to be held accountable. We want to see partnerships and collaboration at a global, national and local level between governments, development actors and partners[1] to strengthen the collection, analysis and use of inclusive data. This will enable us to collectively address the systemic barriers to inclusion, build capacity and invest in strengthening the systems that deliver services.

Ultimately, we want the collection, analysis and use of quality, timely and reliable inclusive data underpinning efforts in the wider development sector to monitor progress, drive better decisions and deliver fairer, equitable outcomes that benefit all so that we can achieve the Sustainable Development Goals' central principle to 'leave no one behind'.

An **easy read version of the vision and approach** to inclusive data is available.

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What is inclusive data?

The development sector recognises inclusive data as data representative of all people, especially those who are marginalised or underrepresented. This includes the disaggregation of data by characteristics such as disability, age, sex, migratory status and other dimensions, where relevant. However, inclusive data goes beyond simply collecting and disaggregating the data. For data to be fully inclusive, we must ensure that the systems, processes and practices around the data are also inclusive. Inclusive data is crucial to ensure that policies and programmes are designed and implemented in a way that responds to the needs and realities of all people. It also monitors how these policies and programmes reach those often left behind.

At Sightsavers, **inclusive data means collecting, analysing and using disability, sex* and age-disaggregated data** while also bringing in other dimensions, such as geography, wealth and poverty, where relevant and valuable. Quantitative data is important for identifying gaps and understanding their scale and scope. Qualitative data deepens our understanding of the process of exclusion and how various factors interact with each other. Using both quantitative and qualitative inclusive data provides a more comprehensive understanding of cross-thematic gaps in our health and inclusion work and drives more targeted programmatic and policy interventions.

In the countries we operate in, Sightsavers works in partnership with governments, civil society organisations, organisations of people with disabilities and international agencies to advocate for inclusive data and strengthen data systems to increase the availability and use of this data.

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* We have used the term sex rather than gender, throughout this document as currently in the quantitative data we 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.

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Why is inclusive data important for Sightsavers?

Sightsavers operates in a global context, and our work is informed by various frameworks that all speak to the importance of inclusive data. The World Health Organization and the World Bank estimate that there are over "one billion people with disabilities globally, and the prevalence is higher in developing countries".[2] However, there is a global lack of accurate and reliable data on disability to allow global, national and local comparisons.

In the countries we work in, the governments are guided by international conventions. The UN Convention on Rights of Persons with Disabilities (UNCRPD) requires States Parties to collect appropriate data and for this information to be "disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights[3]".

The 2030 Sustainable Development Goals have a central commitment to leave no one behind and call for "high-quality, timely and reliable data disaggregated by income, sex, age, race, ethnicity [and] migratory status[4]". Holding governments to account for these commitments and supporting them in collecting, analysing and using disaggregated data is a vital part of our work at a national level.

Often, characteristics such as disability, sex, race and age can overlap to worsen the discrimination and exclusion faced by different people. Intersectional approaches[5] to data enable us to analyse systemic inequality and its root causes better and to understand an individual's or group's experiences of marginalisation.

Our **programme strategy** sets out core principles that underpin the way we work. Inclusive data is intrinsic to bringing these principles to life, particularly those of 'leave no one behind', quality and being evidence-based. Inclusive data allows us to identify where specific barriers and the exclusion of marginalised groups exists. This way, we collect, analyse and use inclusive data to monitor and improve the effectiveness of our programmes in the contexts where we work.

Our **thematic strategies** on health and inclusion all address the importance of inclusive data. The social inclusion and eye health strategies emphasise the importance of inclusive data to help understand the variations between different population groups and their needs to support informed decision-making. The Neglected Tropical Diseases strategy discusses the importance of data in advocating for national-level health system strengthening. In contrast, the education strategy examines why disaggregated data is important in education management and information systems.

Sightsavers Inclusive Data Charter (IDC) Action Plan outlines our inclusive data priorities and key commitments from 2024 to 2027.

We will measure progress towards achieving the goals and objectives within our thematic strategies through our Learning, Accountability and Monitoring Progress (LAMP) framework. The LAMP framework identifies strategic indicators and is supported by thematic learning questions that utilise inclusive data and other sources of evidence. This enables us to

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understand if our programmes reach the most marginalised people and use the data to decide where we need to adapt and make changes.

Without robust data, it is impossible to adequately plan and allocate the necessary resources to ensure our programmes achieve their objectives.

Inclusive data enables us to:

- Better understand the people and communities we work with and identify where specific barriers and the exclusion of marginalised groups exist

- Generate evidence to strengthen the effectiveness of programmes and improve access to services across our health and inclusion work

- Contribute to advancing the 2030 Sustainable Development Goals and 'leave no one behind' agenda

- Hold governments to account on their global commitments, including the UNCRPD

- Support our partners at local and national levels to strengthen their capacity to collect higher quality inclusive data

- Influence governments and encourage them to strengthen systems to facilitate the effective collection, analysis and use of data to drive better decision-making and more inclusive, equitable outcomes for people with disabilities and other population groups

- Contribute to strengthening knowledge and learning with others within the development sector on what works while ensuring the development progress is inclusive

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What is Sightsavers' approach to inclusive data?

Sightsavers' Inclusive Data Charter Action Plan outlines our organisational objectives and key areas of work.

As the programme strategy outlines, our organisational programmatic approach focuses on developing and demonstrating ideas and approaches that work so that governments and other stakeholders can apply these on a wider scale. Our **thematic strategies** outline how we advance implementation, evidence, influencing and collaboration across our work in health and inclusion. Within these organisational strategies, we engage with inclusive data in different ways through **evidence generation, technical expertise, influencing and collaboration.**

Implementation

We work to strengthen the collection of inclusive data as part of project monitoring and evaluation in the countries in which we operate. This includes using the Washington Group's[6] short and extended set of questions on disability and other approaches to disability data collection, where relevant.

We use this learning to strengthen practice in collecting inclusive data across all our thematic areas. This includes examining the intersections between disability, age and sex, particularly in eye health, economic empowerment and education.

We work with local development partners and community-based organisations to strengthen the development of data collection tools and methodologies across the programme cycle that are inclusive of people with disabilities and other population groups.

We provide technical expertise and support the implementation of the Washington Group questions while building the capacity of country partners to strengthen inclusion within management information systems and processes.

Evidence

As outlined in our programme strategy, we generate and use evidence at programmatic, thematic and organisational levels.

We conduct research that incorporates different inclusive data characteristics to identify and address data gaps related to disability and other forms of marginalisation.

We use this data to understand the proportion of people with disabilities who access programmes and services across our thematic areas of work and to see whether this changes over time.

We collect baseline, midline and endline data to generate evidence to understand how marginalised groups access services throughout a project's lifetime.

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We test methods and approaches to collect and analyse inclusive data in response to inclusive data learning questions.

We produce **knowledge and evidence**, including research papers and policy briefs, that promote our work externally and make recommendations on how inclusive data can be collected in different contexts.

We share knowledge internally and externally with the wider development sector through learning seminars and the dissemination of tools and resources to support informed, responsible and ethical data collection practices.

Influencing

We advocate for more effective collection, analysis and use of quality inclusive data to drive better decision-making and to ensure more equitable outcomes for people with disabilities and other population groups at national, regional and global levels. This includes influencing government and development actors to strengthen commitments and action on inclusive data.

We work with civil society, organisations of people with disabilities and other partners to influence governments to commit to collecting, strengthening and using inclusive data within national statistical systems, such as through the adoption of the Washington Group questions.

We work directly with governments, including line ministries and national statistics offices, to provide guidance and support on how disability-inclusive data indicators can be better integrated into health and education management information systems. We support governments to use the data to provide and monitor the improved equity in access and outcomes for people with disabilities and other population groups.

Collaboration

In delivering our work on inclusive data across implementation, evidence and influencing, we collaborate with others to share knowledge, learning and best practice. Internally, we bring together inclusive data stakeholders to advance our collective, cross-cutting organisational goals on inclusive data and share learnings on improving our work.

Externally, we collaborate with others to strengthen inclusive data within systems and service delivery and share knowledge, practice and learning on inclusive data to contribute to the evidence base on what does and doesn't work. Through strategic collaborations and partnerships with others such as UN institutions, the Washington Group, the International Disability Alliance, the Global Partnership for Sustainable Development Data, civil society, donors, the private sector and organisations of people with disabilities, Sightsavers aims to ensure that data and inclusion remain integral to work towards sustainable development.

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Resources

- Inclusive Data Charter: **www.data4sdgs.org/initiatives/inclusive-data-charter**
- Sightsavers' strategies: **www.sightsavers.org/how-were-run/sightsavers-strategies**
- Sightsavers' work on data: **www.sightsavers.org/programmes/inclusive-data**
- UN Convention on the Rights of Persons with Disabilities **social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd**
- Washington Group on Disability Statistics: **www.washingtongroup-disability.com**
- World Report on Vision: **www.who.int/publications/i/item/9789241516570**

Endnotes

[1] Development actors and partners include organisations of people with disabilities, community based organisations, service delivery providers, the private sector, multilaterals, donors and others.

[2] World Bank: **www.worldbank.org/en/topic/disability** and WHO: **www.who.int/news-room/fact-sheets/detail/disability-and-health**

[3] CRPD Article 31 – Statistics and data collection

[4] SDG Target 17.18

[5] Unpacking intersectional approaches to data, Inclusive Data Charter: **www.data4sdgs.org/resources/unpacking-intersectional-approaches-data**

[6] Washington Group questions **www.washingtongroup-disability.com/about/the-washington-group-primer**

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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

Read
Sightsavers Inclusive Data Charter Action Plan

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