The **Fred Hollows**
Foundation

ROUGH GUIDE TO DISABILITY DATA IN EYE HEALTH

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TABLE OF CONTENTS

INTRODUCTION

The Fred Hollows Foundation (The Foundation) is dedicated to ensuring equitable access to eye health services, leaving no one behind on the journey to eliminating avoidable blindness, including people with disabilities. Despite their equal need for eye health services, people with disabilities often encounter substantial barriers that hinder their access. According to the World Health Organization, approximately 16% of the global population lives with a disability, with 80% of these individuals residing in developing nations. In low-income countries, it's estimated that 22% of people have a disability. Hence, in the contexts where we work, people with disabilities likely constitute a significant portion of the population. Women and girls with disabilities also experience complex and intersecting forms of marginalisation and face increased barriers as a result. However, up until now, we've lacked reliable data to effectively plan, evaluate, monitor, or report on the reach of our programs to people with disabilities. Building on

The Foundation's Rough Guide to Disability Inclusion, this Rough Guide aims to empower country teams with the necessary tools to bridge this critical information gap.

Disability data refers to any type of information relating to disability, including data on people with disabilities and their experiences. Population surveys in many countries consistently show that that people with disabilities – even those with disabilities that are not related to vision – experience higher incidence of vision impairment and eye health problems, but are less likely to access eye health services, compared to people without disabilities. Including this group of people is therefore a key priority for inclusive eye health programs.

Designing, monitoring and evaluating inclusive eye health programs requires different types of data on disability. However, globally, there is a lack of reliable disability data; in many countries, disability data is not routinely collected within the health system. Collecting disability data can be more complicated than collecting other data relating to equity and inclusion, particularly where disability and disability data are relatively new to health systems, partners and personnel.

This rough guide provides a basic introduction to the topic of disability data in eye health, and guidance for how disability data approaches can be designed and implemented at national, partner/facility and project levels. It is based on evidence from the eye health sector, which is summarised in The Foundation's Disability Data Evidence Summary. The guide focuses on the specifics of how disability data relates to the eye health system and eye health programming.

In line with The Foundation's Human Rights, Equity and Inclusion Policy and the GAPSED+ Equity Operating Framework, this guide is founded on a human rights-based approach to disability and data, and informed by the principles and commitments of the UN Convention on the Rights of Persons with Disabilities. Box 1 (below) sets out some key principles which can be followed to guide a human rights-based approach to disability data.

Part A of the rough guide introduces the key topics, principles, methodologies and applications of disability data within the eye health sector. **Part B** provides some practical tools that can be used by country and project teams to help guide their development of disability data approaches that suit their context.

Box 1: Key principles informing work on disability data

The following principles should guide all work on disability data. General ethical data principles and guidance should also be applied (see Part A, Section 3).

- **Autonomy:** People with disabilities should have freedom to make their own choices about data processes. They should be supported to engage and make decisions as independent individuals, rather than relying on any support people or family members. Their responses to questions should always be recorded as provided, and not changed by data collectors or anyone else present.
- **Self-identification:** A person's choice to identify or not identify as a person with disability should be respected, including in the responses they provide to data collectors. This applies regardless of what data collectors may observe or believe about that person.
- **Participation:** People with disabilities should have opportunities to participate throughout the data or research cycle. This includes being engaged as data collectors, researchers, committee members or other such roles – not just as respondents/informants.

- **Accessibility:** All processes, formats and systems relating to data collection, management, use and dissemination should be accessible to all people. This includes use of interpreters or other support people where required.

- **Respect:** People with disabilities should be treated with the same respect and sensitivity as other people within data processes. This means respecting people's differences and seeing disability as a normal part of human diversity.

- **Privacy:** Personal data must be kept private during data collection and management. This includes a person's disability status and any other confidential health information. Once entered, data should be deidentified within systems. A person's data should not be disclosed to other family members or support people without that person's consent.

- **Do No Harm:** A 'do no harm' perspective should be applied to all data collection and use processes. This includes recognising that talking about disability may trigger distressing or sensitive topics, which a person may only want to disclose in a 'safe' space or with/without certain other people being present.

- **Responsiveness:** Disability data should only be collected when it will be responded to, for example by making improvements to services. Information about relevant local disability services should be provided to people who contribute data (even if those services are not connected to the project/service collecting the data).

PART A: APPROACHES TO DISABILITY DATA IN EYE HEALTH PROGRAMMING

1. WHAT DISABILITY DATA IS NEEDED?

Different contexts will require different types of disability data, and different approaches to collect this data. Each eye health institution or catchment area will have its own unique situation in terms of disability and eye health – we need disability data to help understand this situation. And each project will have its own approach to including people with disabilities, based on the local disability context, the institutional and health sector context, the objectives of the project, the priorities of stakeholders, and so on.

It is therefore important to start by identifying how data will be used and what data should be collected, and then designing an approach to disability data that is fit for purpose. This could involve reviewing existing evidence and experiences from inclusive eye health programming, analysing existing disability data, conducting a brief analysis of the local eye health and disability context and identifying the main disability inclusion strategies that a project should take – and then, based on this, deciding on what data is needed.

➔ Use Tool 2: How Do I Integrate Disability Data into the Project Cycle? for more guidance on building an approach to disability data that works for your context.

In order identify what data is needed, a first question that needs to be answered is: ***"Why are we collecting disability data?"*** There are lots of different reasons why a project should collect and use disability data. These include:

- **Understanding the situations of people with disabilities** – e.g., do people with disabilities have the same experiences of vision impairment and healthcare access as people without disabilities? If not, in what ways do they differ? How do they differ for different groups of people with disabilities, for instance, women and girls, men and boys, older people with disabilities, people with disabilities living in rural/remote areas, people with disabilities who are also indigenous persons or members of an ethnic minority group, etc?

- **Designing inclusive programs (identifying barriers and support requirements)** – e.g., what barriers are preventing people with disabilities from accessing eye health services, and what support might be required to ensure they can get the services they need? Do any particular groups, such as women and girls with disabilities, face additional barriers? If so, in what ways?

- **Monitoring programs –** e.g., are people with disabilities within a health service catchment area accessing the eye health services that they require? And how does their access to eye health compare to that of people without disabilities? Are there differences in levels of access based on sex, age, place etc?

- **Evaluating eye health outcomes** – e.g., are people with disabilities experiencing improved eye health outcomes or reduced incidence of vision impairment compared to people without disabilities? Do these results vary based on sex, age, geographical location, etc?

- **Supporting advocacy** – e.g., using data on disability prevalence and the link between disability and eye health problems to advocate for government budget allocation and more inclusive services.

- **Awareness raising** – e.g., involving hospital/clinic staff in collecting disability data from eye health patients to raise their awareness of the diversity of disabilities, the additional barriers faced by women and girls with disabilities, and the need to address barriers to accessing services.

- **Reporting** – e.g., allowing The Foundation to measure the scale of its work on disability inclusion and report to donors.

- **Providing information about disability services** – e.g., identifying patients at an eye hospital or clinic who might benefit from other disability services, and sharing information about those services.

- **Supporting organisations of persons with disabilities (OPDs)** – e.g., helping to build OPDs' technical skills in data, generating data that OPDs can use as evidence in their own advocacy, or helping OPDs identify and share information with local people with disabilities.

- **Monitoring CRPD and national policy implementation –** e.g., helping government hospitals and departments/ministries of health to measure progress against their commitments to disability inclusive healthcare (CRPD Article 25 - Health).

A project's approach to disability data should be based on the purposes for which data will be used. For example, if we already know that people with disabilities are missing out from local eye health services and we know what is preventing them from accessing those services, then our approach can focus on making the services more inclusive and monitoring the outcomes of those efforts. But, if we're not sure what the barriers to inclusion are, or if we need some solid evidence to convince stakeholders to start changing policies or practices, then our approach might focus on collecting evidence from the local population.

There are various approaches that eye health projects can take to disability inclusion – e.g., advocacy, policy engagement, health system strengthening, improving service uptake, staff capacity building, implementing accessibility measures, etc. – that will each require different types of information at different stages of the project cycle. These disability inclusion strategies or approaches should be defined at project identification or development phases. They can then also be included as indicators in the MERL framework, to make sure that relevant data is collected and analysed and to help guide decisions about what data should be prioritised. (See also Box 2 below on setting indicator targets.)

Disability data is almost always collected for multiple different purposes. However, with limited resources, it's rarely possible to collect disability data that will achieve everything we would like it to; **we need to prioritise what is most important.**

This can sometimes require balancing competing priorities: for example, donors often request data on the numbers of people with disabilities benefiting from services, but this data can be very difficult and resource-intensive to collect (see Sections 4-7 below). If all our resources are spent on monitoring access to services, we might miss out on other types of data that could be much more useful to support a project's disability inclusion goals. **Approaches to disability data should always be designed based on what we think will result in the best possible outcomes in terms of disability inclusion.**

➔ Use Tool 3: What Data Do I Need? to find examples of data types, sources and collection methods for different uses of disability data.

Box 2: Tips for setting targets and reporting on beneficiaries

Projects often set targets for indicators or beneficiary numbers. It can be challenging to determine the right target for people with disabilities, because data on people with disabilities is often not available, incomplete or inaccurate, or because different approaches to measuring disability are used. The following tips may help:

- **Ideally, indicator targets for people with disabilities should be based on population surveys or baseline data that show both the prevalence of disability and the eye health needs of people with disabilities in the target area**.
- Where baseline data isn't available, many development projects set targets based on disability prevalence estimates – e.g. from statistical surveys or using the WHO's global prevalence estimate of 16%. However, disability and eye health problems are closely related: we would typically expect a much higher rate of disability among persons requiring eye health services. (For instance, in Cameroon, Sightsavers found that 49% of people with vision impairment also had an additional disability of some sort).
- **Where local data on disability and eye health is not available, eye health projects can base targets on studies from other countries** – including RAAB surveys which started reporting disability disaggregated data from 2023. However, since every context is different, these estimates may not be accurate.
- **Targets will depend on the project's disability inclusion approach and monitoring capacity**. If disability inclusion is not deliberately implemented, it is quite likely that fewer people with disabilities will access a service. If an eye health facility or project has limited capacity to disaggregate data by disability, then monitoring data will identify very few people with disabilities.
- **Project reports on the numbers of people with disabilities accessing eye health services should always be based on disability-disaggregated monitoring data.** It is not appropriate to assume that all eye health patients are people with disabilities, or that disability prevalence among eye health patients is the same as disability prevalence in the general population. However, reported numbers can be calculated based on a random sample of patients.

- Limitations on disability data should be noted and explained to donors in project designs and reports.

2. MAKING DATA PROCESSES INCLUSIVE

An inclusive approach to data is not just about collecting disability data; it's also about including people with disabilities in all aspects of the data cycle. This means having people with disabilities themselves involved in different roles in data collection or analysis, as well as contributing as data participants (i.e. informants or respondents who contribute their data). The benefit of this approach is bringing in different perspectives and skills to the data process, help to build awareness of disability and increase the quality of disability data. Collecting data in an inclusive way provides an opportunity for people with disabilities to feel heard and have the space to influence systems and practices. Having accessible data processes is essential for the full diversity of people to be able to contribute and participate.

Eye health projects should follow general guidance for making data processes accessible to and inclusive of people with disabilities. Possible actions include:

- Involving people with disabilities as active participants and decision-makers at all stages, including in design teams, in project/data/research advisory groups, as data collectors, in analysis workshops, and as trainers of data collectors.
- Providing reasonable accommodations if required for any people with disabilities involved in data processes, e.g. changing the venue for consultations, covering transportation costs to attend, hiring interpreters, ensuring support persons can attend alongside a person with disability, allowing someone to contribute their data in a different way/format, etc.
- Adapting data tools and processes (including consent processes) so that they are accessible to diverse groups of people with disabilities, e.g. consent forms and survey questionnaires using plain language and descriptive images/symbols, administered in both written and spoken format, provided in accessible electronic format for users of screen reading software, etc.
- Deliberately targeting or sampling and reaching out to diverse groups of people with disabilities as participants (noting that people from more marginalised groups may not contribute or participate without some additional efforts).
- Collaborating with organisations of persons with disabilities (OPDs) or individual disability advocates to support the data process.
- Creating opportunities for OPDs to build their own capacities in data and to use data to support their own priorities (e.g. advocating for inclusive healthcare).

When starting to engage with OPDs, note that some OPDs or individual disability advocates might be unfamiliar with the eye health sector, or might not consider it to be a priority. **It is important to take the time to build relationships with OPDs and support OPDs to identify how they might want to engage in eye health data processes or whether they want to engage at all.** Although collaboration with OPDs almost always benefits a project or data process, the first consideration should be that the collaboration benefits the OPD themselves and helps them with their agenda. For example, OPDs might want to gain research or data analysis skills, or they might want evidence that can help with their advocacy for inclusive healthcare services.

In locations where OPDs are not operating or have decided not to participate in eye health data processes, there is still an obligation to make data processes inclusive of and accessible to individual people with disabilities.

➔ For general guidance on making data processes inclusive, see Section 3 of Research for All: Making Research Inclusive of People with Disabilities

➔ For guidance on working with OPDs in research or data processes, see Sections 1, 2 and 3 of Research for All: Making Research Inclusive of People with Disabilities

3. ETHICAL DATA COLLECTION

All data collection creates potential ethical issues. **Collecting data from people with disabilities in an eye health context creates some specific ethical issues:**

- Information about disability can be deeply private and sensitive for some people. Disclosure of a person's disability status can have negative impacts on them, for example by exposing them to discrimination, stigma or shame. A person might be comfortable to talk about their experience of disability with a trusted health professional, but they might not want to disclose it to anyone else (even family members).
- Some people with disabilities use family members or other support persons to help them access health services or interpret information. In many cases, health professionals have tended to focus on these support persons – giving them the information and asking them to make decisions – rather than communicating directly with the person with disability themselves.
- People with disabilities may have been denied autonomy to make their own healthcare decisions – for example, having health decisions made for them or against their will, or being given treatment without their consent.
- People with disabilities might have had previous negative experiences of accessing healthcare – for example, receiving discriminatory treatment or being denied access to treatment – which could cause them to feel distressed when responding to questions about disability and health.
- People with disabilities may agree to participate in eye health-related data collection in the hope that they will be provided with some services in response (beyond eye health). This can make people more eager to consent to data collection or to disclose sensitive information.

Most of these issues can also arise in other sectors, but they might be more likely to arise in the context of health research or health service delivery. **Data collection in eye health should follow general ethical guidelines for disability data collection. These should include accessible informed consent processes. Data collection should also follow The Foundation's Research and Evaluation Policy, which outlines our guiding principles and commitments to ethical evidence creation, use and storage.**

➔ For general guidance on ethical disability data collection, see Section 2 of Research for All: Making Research Inclusive of People with Disabilities

In addition to general ethical practices, the following considerations should be applied when collecting disability data relating to eye health:

Informed consent – Ensure that consent processes, forms and all information provided about data collection are accessible. Ensure that people with disabilities themselves understand what they are being asked to consent to, especially when interpreters, family members or support persons are being used. Obtain consent directly from each person whenever possible – the role of a support person is to help facilitate the consent process, but not to make decisions for the person they are supporting.

Privacy and confidentiality – Consider collecting any data that is sensitive in a private place wherever possible – e.g. a treatment room may be more private than a waiting room or registration desk. Note that a person may not wish to discuss some topics in the presence of family members or support persons. Store disability data confidentially. Only disclose data to the person who contributed it, rather than to a family member or other support person. Deidentify all data before sharing it outside of the clinical context.

Referral information – All people with disabilities contributing their data should be provided with information about other services that might be relevant to them. This may require mapping available services in advance and training eye health personnel on their potential relevance. Services may include disability services (such as rehabilitation or hearing services), other health services, OPDs, self-help groups or any other disability-focused groups or networks. Note that this is not a clinical referral (i.e. a referral made by a health professional based on clinical assessment); it is sharing information about local services to someone for whom it *may* be relevant. Explain to all participants that contributing their data or responding in a certain way will not lead to further support/services being offered.

Do No Harm – Train data collectors to deal with potentially distressing topics that may come up during discussions, and to provide information about support services that are available. Where possible, proposed survey or monitoring questions should be reviewed by people with disabilities or other specialists to minimise the risk of causing distress or harm. Do not disclose a person's disability status or any other private information outside of a clinical context.

Inclusive and sensitive communication – Train data collectors on disability inclusive communication, terminology, etiquette, etc. Review and test translations or adaptations of international data tools in different cultural contexts. Clearly explain the purpose of data collection, and why certain questions/topics are being asked – for example, a facility-based data collector could explain that they are asking questions to find out if some people are having difficulty accessing our services and what can be done to make our services more accessible for them.

Financial burden – Ensure that all costs of participating in data collection are covered, especially when data collection requires travel or a substantial time commitment from participants. For example, if participants are travelling to attend a focus group discussion, cover the additional costs that some people with disabilities may incur, such as paying for accessible transport options or for costs relating to any support persons accompanying them.

4. DISABILITY DATA SOURCES AND COLLECTION METHODS

Inclusive eye health programs require disability data from a range of different sources, using various methods. **Data sources and methods should always be selected based on what we think will result in the best possible outcomes in terms of disability inclusion** (see Section 1 above).

➔ Use Tool 3: What Data Do I Need? to find examples of data types, sources and collection methods for different uses of disability data

The **main sources of disability data relating to eye health** are set out in Table 1 below. These are grouped by:

- population-level data: information about disability within a particular health catchment area, including the people with disabilities living there
- facility-level data: information about disability relating to a particular health facility, including the people with disabilities attending that facility
- secondary data sources: information about disability from other organisations, sectors or regions.

Projects will require a mix of different data sources, at different points in the project cycle. In general, population-level data helps to inform the design of disability inclusion efforts (or advocacy for these), and facility-level data is used to monitor disability inclusion approaches.

Table 1: Sources of disability data in eye health

Data source/method	What does it involve?	What can it tell us?
Population-level data		
Rapid Assessment of Avoidable Blindness (RAAB) and other eye health surveys with disability questions	Questions on disability (e.g. Washington Group Short Set of Questions – WG-SS) are added to eye health population surveys and asked to all respondents, to enable disaggregation by disability. RAAB Version 7 now includes an optional disability module incorporating the WG-SS. Can be repeated over time to measure change and/or compared to facility-level data to measure equity.	Key eye health indicators for people with and without disabilities. Rates of eye health problems and service coverage among people with disabilities. Prevalence of disability among the population needing eye health services. Other patterns and gaps relating to access to eye health for people with disabilities.
Other local disability and health surveys with disability questions	Other surveys such as population censuses or demographic and health surveys are increasingly collecting information about disability and/or using tools such as the WG-SS.	Prevalence of disability in the local area (e.g. to inform advocacy or resource planning – note this does not identify the specific population needing eye health services). Experiences of people with disabilities in relation to health or disability services (outside of eye health).

Data source/method	What does it involve?	What can it tell us?
Situation analyses, baseline surveys, research, community consultations, evaluations, etc.	Data is collected, usually by project teams, from people with disabilities and other disability stakeholders in the local area. Often includes qualitative data not collected by surveys. Can be targeted to people with disabilities or to various population groups – including those not represented in population surveys.	Wide range of information: e.g. experiences of people with disabilities in accessing healthcare. Barriers to inclusion. Types of supports or accommodations that may be required. Available support services or networks. Explanation of the causes of inequities picked up through other data sources.
Analytic tools e.g. barrier analysis, stakeholder mapping, power analysis	Disability is integrated into specific tools used as part of situation analysis, and people with disabilities included in the process. Methods are adapted to ensure relevant data on disability inclusion is covered.	Various types of barriers to inclusion, and potential strategies to address these. Types of supports or accommodations that may be required. Available support services or networks.
Facility-level data		
Patient data on disability	Information is collected from eye health patients somewhere in the patient flow, including questions to identify disability (ideally the WG-SS or other standard tools). This may be collected through a health management information system (HMIS) or through separate systems. It may be collected routinely from all patients, or from a sample of patients.	Levels of access to eye health services by people with and without disabilities, alongside other variables such as sex, ethnicity, etc. Information about the population groups (e.g. types of disabilities) accessing services. Support, accommodations or additional services required by patients. Evidence against service standards or indicators relating quality of care and patient outcomes for service users with and without disabilities. Equity of access to eye health services for people with disabilities (if comparable population data is available – see Box 3 below).

Data source/method	What does it involve?	What can it tell us?
Facility audits and self-assessments	Disability inclusion or general inclusion self-assessments are conducted by eye health facility staff, using self-assessment tools and guidance. Accessibility audits are conducted by external stakeholders, such as OPDs, NGOs or health departments (or in joint teams). Often based on international audit tools and/or national standards.	Level of performance against existing policies, standards and processes to support disability inclusion (e.g. staff practices, facility accessibility) – and gaps in implementing these. Identified barriers to inclusion of people with disabilities and recommendations for addressing these.
Feedback mechanisms	Existing feedback mechanisms can be adapted to ensure they are accessible to people with disabilities and include relevant questions/prompts about inclusiveness. Can also involve targeted interviews or focus group discussions with service users with disabilities.	People with disabilities' experiences of engaging with health services. Barriers to inclusion and recommendations to address these.
Administrative data	Data collected and managed by eye health facilities on the scope of their operations and services can potentially include relevant information about disability.	Depends on each facility's system. Examples include number of personnel trained on disability, budget allocation for disability inclusion, accessibility measures budgeted or implemented, etc.
Secondary data		
Organisations of persons with disabilities	Many OPDs maintain databases of local people with disabilities, as well as collating information about key concerns or service needs relating to healthcare for people with disabilities. OPDs may be able to share their data, take part in data processes or introduce individual people with disabilities.	General experiences and priorities of people with disabilities relating to healthcare. Gaps in health and disability services. Available support services.
Disability services	Local disability services collect data on users of their services, and may be able to share or summarise this data. Services could include community-based rehabilitation, assistive technology services, physiotherapy, etc.	Gaps in health and disability services. Available support services. General health and disability support service needs for people with disabilities.

Data source/method	What does it involve?	What can it tell us?
Other comparable secondary data	Data on disability and health may be available at the national level, or from other subnational regions, or from programs or institutions working in other health sectors. These can be assessed for relevance and comparability to a particular eye health context.	Experiences of eye health and disability from other geographic areas or health subsectors. Particularly useful when local population or facility data is not available.

Box 3: Measuring equity in eye health services

An important indicator of inclusive eye health is whether people with disabilities are accessing the services they need on an equal basis to people without disabilities.

Measuring health equity requires:

1. collecting patient data on access to eye health services for people with disabilities for a given eye health facility; AND
2. collecting population-level data on the prevalence of eye health problems among people with disabilities within that facility's catchment area; AND
3. ensuring both of these data sources use the same (or a very similar) approach to disability disaggregation, so that the two datasets can be compared.

If disability-disaggregated facility data is collected without comparable population data, it can still provide information about who is accessing eye health services. However, it cannot tell us whether *all* people with disabilities with eye health problems are accessing services. And it cannot tell us who is still missing out from eye health services, in order to follow up with those groups. Without comparable population data, facility data tells us the numbers of people but it doesn't clearly tell us about the inclusiveness of services.

If disability-disaggregated population data is collected without comparable facility data, it is still possible to assess health equity by measuring changes in eye health outcomes over time for people with and without disabilities (e.g. by repeating RAABs every 5 years). However, this is a longer-term measure and will not provide regular monitoring data on whether disability inclusion efforts are actually resulting in more people with disabilities accessing services.

5. DISAGGREGATING DATA BY DISABILITY

Disaggregation of data is the process of dividing data into subgroups and comparing data from each of these subgroups. It is a core principle of a rights-based approach to data; it allows us to identify which groups are benefiting and which are left behind, so that we can design inclusive services. Disaggregation by disability requires identifying people with disabilities within existing surveys or other data sources. This includes population surveys as well as health facility patient data.

Disability data disaggregation is more complex than other types of disaggregation, such as disaggregation by sex or age. This is because disability is a complex and diverse concept, which has different meanings to different people.

To simplify the process of identifying disability in data collection, **a 'functional approach' is strongly recommended in all eye health contexts**. This means that a person self-reports any difficulties they may have in basic aspects of human functioning (e.g. hearing or communicating). If their responses reach a specified level for risk of disability, then a 'disability identifier' (binary yes/no) is created in the dataset and used for data analysis, including measuring the prevalence of disability within the dataset and disaggregating other datapoints by disability. This identification of disability happens only in data analysis; each person's right to self-identify as a person with or without disability is preserved.

Fortunately, there are simple and standardised tools applying a functional approach that have been developed and tested in many countries, along with guidance and training materials to support these. The most commonly used tool is the **Short Set of Questions (WG-SS)** developed by the **Washington Group on Disability Statistics** (see Table 2 below), which has been adopted in a range of different eye health contexts and is included as an optional module in the RAAB (from Version 7).

The WG-SS is recommended as the preferred tool to be used in all eye health data collection. It is widely used in the sector and can enable comparison of data from different sources.

Table 2: Tools for identifying disability for data disaggregation

Tool	What is it?	When/why to use it?
Washington Group Short Set of Questions (WG-SS)	A set of 6 questions using a functional approach, designed for use in censuses and large surveys, and widely adopted in the development, humanitarian and eye health sector. Translated into many languages and tested internationally. Included in the RAAB disability module.	**Recommended as the preferred tool for use in all eye health data collection, at population and facility level**. It is the shortest and simplest available tool using a functional approach, and is already used in many national statistical surveys.
WG/UNICEF Child Functioning Module (CFM)	Two separate question sets for children ages 2-4 and 5-17 using a functional approach. The only question set designed for children; other tools above are designed for adults (but have been validated with children aged 5 and above).	The recommended tool for any surveys or research studies specifically looking at the eye health needs and experiences of children with disabilities.
WG Short Set of Questions on Functioning – Enhanced (WG-SS Enhanced)	A set of 12 questions using a functional approach, which includes the WG-SS (and therefore can be compared to WG-SS data). Has additional questions on upper body functioning, anxiety and depression.	Consider using in population surveys or research where a more accurate understanding of disability is required. More accurately identifies some people with psychosocial disabilities who may not be picked up by the WG-SS. Increasingly used in humanitarian contexts where psychosocial disability is a priority concern.

Tool	What is it?	When/why to use it?
WG Extended Set of Questions on Functioning (WG-ES)	A set of 24 questions using a functional approach, which includes the WG-SS and WG-SS Enhanced (and therefore can be compared to data using those tools). Has additional questions on pain and fatigue and additional questions on hearing, mobility and cognition.	Consider using in population surveys or research where a more accurate understanding of disability is required. The most detailed/accurate tool developed by the WG.
Other approaches		
Asking direct questions about disability	A person is asked 'Do you have a disability' or whether they have one of several commonly understood/legally defined categories of impairment.	Not recommended, as it identifies only a small proportion of people with disabilities. However, such questions might be needed to align to government definitions, e.g. where a hospital reports on service coverage based on legal categories of disability. Can also be included to enable comparison to other existing datasets that use a direct question about disability.
Formal disability status	In some countries a person's disability status may have been formally determined and recorded in public health insurance, social protection systems, disability registries or disability identification cards. These systems can be used to identify disability within patient health records.	Can be used in contexts where such data is available. However, in many countries these systems have limited definitions or only include a small proportion of people with disabilities. Additional questions (e.g. WG-SS) might be needed to more accurately identify disability or enable comparison to population data.
Clinical assessment of impairment	Clinical tools enable screening for various types of impairments by medical personnel, and may be used alongside eye health assessments in contexts where a broader heath assessment is being conducted.	Used primarily to identify treatment or referral pathways, rather than data disaggregation. Not typically used in eye health services (other than vision screening tools).

Where existing health systems, administrative data or population data use alternative approaches to identifying disability – e.g. a yes/no question about disability – **the WG-SS or other question sets on functioning should be integrated alongside these.** In eye health or any health context, it is important to work with medical and management personnel to ensure they understand the rationale for collecting self-reported functioning data (which might otherwise seem irrelevant to them).

Refer to the Further Reading List for messages to use with stakeholders to explain why other methods of identifying disability – such as asking a yes/no question or using a list of different impairments – are less accurate and not recommended.

The WG-SS (or other more detailed tools) can be integrated into survey questionnaires, patient registration forms, HMISs or any other process where data about individual people is being collected. **The general process for using the WG-SS involves:**

1. **Select** the right question set for your purpose and context (see Table 2 above).
2. **Translate** and test the questions in local languages following the WG guidance, or use existing verified or unofficial translations. (Unofficial translations, which haven't been verified by the WG, are not hosted on the WG website but can be obtain from national OPDs or statistics offices.)
3. **Integrate** all 6 questions and related instructions into the relevant data collection tools (WG questions must be asked before any questions that mention disability).
4. **Train** data collectors on how to ask the questions (e.g. ask all questions to all respondents, don't change the wording, ask questions directly to individuals rather than support persons or family members, etc.), how to record answers and general inclusive data approaches.
5. **Collect** data following the WG guidance,
6. **Provide technical support** and quality control for data collectors on using the WG methodology.
7. **Analyse** WG-SS data using the recommended approaches (see Box 4 below) to measure disability prevalence and disaggregate all indicators/datapoints by disability.

The data is then ready to be used e.g. within the MERL cycle.

➔ For an introduction, training and detailed guidance on the WG-SS, see the Further Reading List on the Washington Group Questions.

Box 4: Analysing WG-SS data in eye health

Most of the general guidance on the use of the WG-SS and analysis of WG-SS data can be followed in the eye health sector. However, the following **specific guidance for analysing WG-SS data in the eye health sector** is provided:

- **All six questions** (including the question on seeing) and all four response categories should be used.
- When analysing data, **the WG's standard recommended 'cut-off point' should be used** – i.e. a person who responds 'a lot of difficulty' or 'cannot do' to one or more of the questions is identified as a person with disability (by calculating a *'person with any disability'* identifier).
- **However, analysis should exclude the seeing domain ("Do you have difficulty seeing?" question).** This is because the focus of data disaggregation in eye health is on people with disabilities other than vision-related disabilities. A *'person with any non-seeing disability'* identifier should be created for each respondent, which can then be used to identify disability for the purpose of disaggregation and reporting.

- Data can also be analysed using all six domains when needed, e.g. to compare data to other datasets using all six WG-SS questions.
- Lower cut-off points can also be used as a basis for identifying people who might benefit from receiving **referral information**. (E.g. data collectors can be trained to offer service information to anyone who responds ‘some difficulty’ or higher to any of the questions other than seeing.)

➔ For an example Excel spreadsheet that uses the approach recommended above to calculate disability identifiers, see Annex 1.

6. WORKING WITH HEALTH SYSTEMS AND FACILITIES TO COLLECT PATIENT DATA

Collecting disability data from eye health patients is an important source of information for inclusive programs. Patient data collection can be **routine**, where disability data is collected from every patient accessing a service, or **targeted**, where disability data is collected from a sample or other subset of patients.

Patient data on disability is essential to be able to monitor the level of access of people with disabilities to eye health services, and to compare these levels of access to those of people without disabilities – which are both key indicators of inclusive outcomes. Patient data can also help identify any barriers to accessing services, supports or accommodations that might be required, and the potential relevance of other local health or disability services. The experience of collecting disability data from patients may also help to raise awareness and change attitudes among frontline staff and serve as a starting point for taking further action towards disability inclusion.

At the same time, however, there are significant challenges to collecting this type of data. Collecting data from every patient, while maintaining quality and ethical standards, requires time, resourcing and technical support (see Section 7 below). Resourcing and institutional capacity in many eye hospitals and clinics are limited, and patient loads and time pressures are even more extreme in many outreach camps/clinics.

Patient data on disability is collected most efficiently and effectively when integrated into the relevant health management information system (HMIS). However, there are few existing HMISs in eye health or general health institutions that are already collecting disability data. And reforming a local or national HMIS requires time, resources and political will.

Because of these challenges, **it is important to consider the approach to collecting patient data on disability that will work best in each context**. The approach will depend on the partner institute and national sector context, management support for reforming data systems, the capacity of partner data systems, the level of control over an HMIS (e.g. is the partner a private hospital that owns its own HMIS, or is it a government provider that uses the Ministry of Health’s HMIS?), the resources available to the project, and other factors. The main options for how patient disability data collection can be approached are shown in Table 3 below.

Table 3: Systems for collecting patient disability data

System	Advantages	Disadvantages
Collecting disability data within the HMIS – Disability data is routinely collected from all patients through the HMIS (e.g. by adding WG questions to the HMIS)	• Integrated into hospital/ sector systems • Efficient: no need for separate systems • Disability data becomes a standard, compulsory part of health information • Disability and other health data are linked and visible to clinical staff	• May require intensive data system strengthening efforts • Individual hospital may not control the HMIS • Limited scope of datapoints can be added • Government HMIS may use limited or specific disability definitions
Collecting disability data through parallel systems – Disability data is routinely collected through a separate system at the facility (e.g. an Excel spreadsheet that is not linked to the HMIS) and sent to eye health NGOs to manage and analyse	• Can be set up in contexts where reforming the HMIS is not feasible • May help model good practice or demonstrate the value of disability data as part of advocacy for HMIS reform	• Disability data and other health data are stored separately and not linked • Hospital staff may not refer to or use disability data • Resource-intensive and inefficient; requires set up of separate systems
Sampling patients – Disability data is collected from a random sample or other subset of patients, through parallel systems (e.g. collecting data only on certain days)	• Can effectively measure access to services • Far less resource intensive than routine data collection • Can be set up in contexts where reforming the HMIS is not feasible • May help model good practice or demonstrate the value of disability data as part of advocacy for HMIS reform	• Unvalidated; requires methodological testing • Limits ability to provide referral information or other supports to all patients with disabilities • Disability data and other health data are stored separately and not linked • Hospital staff may not refer to or use disability data

There are many contexts where it is not feasible to routinely collect disability data from every eye health patient. This could be due to resource constraints, lack of partner or health system support, underdeveloped data systems, or other factors. In these contexts, the following points should be considered:

1. **Collecting disability data from a sample of patients** (see Table 3 above) may be a more cost effective and logistically feasible approach. This will ensure adequate data on access to services for people with disabilities is collected, and can also help build up capacity and momentum or support advocacy efforts for the adoption of disability data measures within HMISs.

2. Projects or country offices could consider resourcing and implementing **advocacy efforts for the reform of facility or health system-level HMISs to include disability data**, and/or collaboration with other eye health organisations to **strengthen the disability data capacity of those systems**.

3. Separate systems or sampling approaches could be set up in selected locations to serve as **pilots or demonstration models to test feasibility, capture learning and demonstrate good practice** on disability data.

4. There are various **other types of facility-level data on disability**, including qualitative data, which can complement data from individual patients or help fill gaps where these are missing (see Section 4 above). Examples include patient satisfaction questionnaires, feedback mechanisms, observation visits to facilities by OPDs, data from inclusion assessments or accessibility audits, and focus group discussions.

5. Even in **contexts where no disability data is being collected relating to eye health patients**, disability inclusion efforts are still essential, and their design can be based on other types of data. For example, accessibility audits, population data on disability and/or health, or consultations with OPDs could all provide adequate evidence to inform the design of accessibility measures within an eye health facility.

Once a decision has been made to collect disability data from patients, there are various **options for collecting disability data at different points in the patient flow**, which each have advantages and disadvantages. These are shown in Table 4 below.

Table 4: Disability data collection options within the patient flow

Patient flow point	Advantages	Disadvantages
Patient registration desk/form – disability data is collected at the point of registration	• First point of contact; can identify any accommodations required • Collected alongside other patient data • Can raise awareness of disability among core staff	• Can create bottlenecks (consider additional staff) • Registration staff might be rushed and not collect data properly • Privacy issues at crowded registrations points
Eye health nurse/ assistant examination – disability data is collected by the ophthalmic nurse/ assistant when first examining the patient	• More privacy (if examination room is private) • Personal/sensitive information collected in clinical/treatment context • Collected alongside other patient data • Can raise awareness of disability among core staff	• Workload and time pressures on nurses/assistants • Nurses may feel that disability questions are inappropriate or not clinically relevant (consider training and support) • May be too late to respond to any required accommodations
Employing additional data collectors – disability data is collected by additional data collectors who survey patients after registration, or after they are seen by an ophthalmic nurse/assistant (i.e. before seeing an optometrist if required or leaving the facility if treatment not required)	• Minimal interruption to patient flow • May be more privacy in waiting rooms than at registration desks • No increase of workload for other staff • More time available for disability data collection • Dedicated staff can be provided training and technical support	• Requires additional personnel resourcing; may not be sustainable • May still be privacy issues in waiting rooms • May be too late to respond to any required accommodations (if collected after initial examination)
Exit/follow-up interview – disability data is collected via	• More time available for disability data collection	• Requires additional resourcing (for exit interviews); may not be sustainable

Patient flow point	Advantages	Disadvantages
exit interviews or post-visit interview/survey	• Dedicated staff can be provided training and technical support • More privacy (in most contexts)	• Follow-up interviews or online/phone surveys may have low response rate • Too late to respond to any required accommodations

7. RESOURCING AND IMPLEMENTING DISABILITY DATA APPROACHES

The ways in which disability data approaches are implemented can have a big impact on how effective those approaches are. If disability data collection is introduced in a hospital or clinic whose staff or management are not fully committed to disability inclusion, or where staff collecting data do not have enough time, training or technical support, then the quality and uptake of data may fall. For example, eye health projects have reported issues with staff collecting disability data only from some patients (i.e. when the clinic is not too busy), questionnaires being abbreviated or filled out directly by enumerators (instead of asking the questions to patients), or data sitting in a hospital system or Excel file and remaining unused.

Some **implementation approaches that can make disability data strengthening efforts more effective**:

- **Embedding disability data within broader approaches to inclusion and/or data systems strengthening** – Disability data should be treated as a component of wider efforts to make services more inclusive or strengthen partner data systems (and not as a separate/standalone initiative or as a donor requirement).

- **Ensuring disability data is valued and understood** – The purpose and value of collecting disability data should be explained and demonstrated, especially to medical personnel and facility management who might consider the WG questions or other disability data tools as not clinically relevant.

- **Raising awareness on disability, inclusion and disability data** – Staff and management at all levels should be involved in training or awareness raising on disability inclusion or inclusive service delivery as a starting point, and then on the need/role for data as part of this. (Noting that the process of disability data collection itself might help to build this awareness.)

- **Training and technical support** – Personnel involved in collecting, managing, analysing and using data should be given basic training and follow-on/refresher training on disability data tools/methods. Ongoing coaching or technical support may also help.

- **Quality control** – Data quality can be strengthened through spot checks on facility data and periodic reviewing or cleaning of data from partners. This should be treated as a process for identifying gaps and strengthening capacity, rather than monitoring for compliance.

- **Adequate resourcing** – Significant resource allocation in terms of budget, staffing and technical input is required to ensure disability data is of an adequate quality, meets ethical standards and actually generates the evidence needed to design inclusive programs. (See Box 5 below for examples of data processes requiring budget allocation, and the discussion below on specific resourcing considerations relating to patient data collection.)

Box 5: Disability data resource allocation

Examples of disability data processes that require budget allocation include:

- Commissioning population studies (e.g. RAAB surveys)
- Funding additional staff roles in eye health facilities (e.g. registration staff or dedicated data collectors)
- Setting up parallel data collection systems (e.g. where The Foundation's staff manage and analyse data)
- Direct disability data collection (e.g. focus groups or surveys as part of regular MERL processes)
- Designing and delivering training to partner staff
- Coordinating and advocating on disability data among government agencies
- Arranging translation and cognitive testing of the WG questions
- Adapting all data systems and processes for accessibility
- Involving OPD representatives or individual people with disabilities (e.g. providing reasonable accommodations and reimbursing for their professional time)

Budgeting and sustainability considerations are particularly important when designing approaches to collecting patient disability data, because of the logistical, resourcing and ethical challenges of collecting this type of data. Some considerations are:

- Do we have enough resources (budget, personnel, technical support) to ensure patient data collection meets minimum ethical and quality standards?
- Should a project fund additional staff to collect disability data, or work with existing partner staff?
- If we invest in collecting patient disability data, will we still have enough resources to collect other types of disability data? Are there alternative types or sources of disability data that are more cost effective?
- How can our eye health partners sustainably adopt disability data approaches and integrate them into their regular systems and processes?
- How should disability data approaches be phased in over time, as part of systems strengthening and/or inclusive service delivery strengthening efforts?

8. AREAS FOR FURTHER RESEARCH AND LEARNING

Disability data in eye health is still an emerging area of practice. There are several topics that are touched on in this rough guide where evidence of good practice and guidance for practitioners is not yet available.

For example:

- Experience from health systems strengthening and HMIS reform relating to disability data in other/general health subsectors may be highly relevant to the eye health sector. There may also be national sector contexts where a common approach to disability data could be explored covering both eye health and other health subsectors. Opportunities to learn from other health sector work or develop common approaches could be built into project designs, sector partnerships/consultations, research projects, evaluations, etc.

- The use of sampling approaches in collecting patient data at eye health facilities is an emerging area of practice. Specific protocols or guidance for sampling methods have not yet been documented in the sector. The advantages and disadvantages of collecting disability data from only a sample of patients compared to routinely collecting data from all patients, has also not been documented. Research, evaluation and technical support could be built into project designs to help pilot and build up knowledge on this topic.

For more examples, refer to The Foundation's Disability Data Evidence Summary.

PART B: DESIGNING A DISABILITY DATA APPROACH FOR A PROJECT OR PARTNER

TOOL 1: WHAT ARE THE KEY APPROACHES TO DISABILITY DATA FOR MY CONTEXT?

The table below summarises the key components of the approach to disability data presented in Part A (above). For each component, key principles or minimum standards are highlighted as a starting point for all contexts. Options for going beyond these, to explore best practice or emerging/innovative approaches, are also noted.

Disability data component/aspect	Where to start? Minimum standards and key principles to follow	What more could be done? Exploring best practice and innovative approaches
Identify disability data priorities and needs	• First identify the purposes for which disability data is needed in your context, before selecting data approaches to fit that purpose • Prioritise data approaches that will result in the best possible outcomes in terms of disability inclusion	• Consider how to strengthen and transform the wider disability data system beyond the scope of The Foundation's programming. E.g., advocating for or supporting HMIS reform, supporting OPDs' capacities to monitor and advocate for inclusive healthcare, or strengthening national disability rights monitoring and reporting.
Set disability inclusive goals and indicators	• Ensure that context-specific disability inclusion objectives and indicators are included within logframes/MERL frameworks • Allocate resources for disability data; prioritise data efforts within available resources • Set indicator targets based on specific eye health and disability data, where available • Reported beneficiary numbers should always be based on disability-disaggregated monitoring data, and not on disability prevalence estimates	• Consider specific goals or indicators relating to strengthening or advocating for improved disability data systems – including at organisational level • Invest in pilot or model projects that set ambitious goals relating to disability inclusion and have robust, well-resourced approaches to data underpinning those • Invest in population surveys or situation analyses to inform evidence-based disability inclusion goals, indicators and targets

Disability data component/aspect	Where to start? Minimum standards and key principles to follow	What more could be done? Exploring best practice and innovative approaches
Make data processes inclusive	• Ensure that data tools and processes (including consent) are accessible to and inclusive of people with disabilities (e.g. using multiple modes of communication, simple language, use of images/icons to support people with low-literacy or cognitive disabilities, sign-language interpretation, etc.) • Consult with OPDs and explore how they might want to engage in eye health data processes • Invite people with disabilities to help design and implement data processes	• Deliberately target and reach out to more marginalised groups of people with disabilities to take part in data processes • Create opportunities for OPDs to build their own capacities in data and use data to support their own priorities
Address data ethics	• Offer referral information about other potentially relevant services to all people with disabilities contributing their data • Maintain privacy and confidentiality throughout the data cycle • Ensure that informed consent processes are fully accessible to all people • Train staff to ask questions sensitively and respond to any issues disclosed • If external ethics review is needed, submit and await approval before starting primary data collection.	• Strengthen health facility systems, processes and practices to meet international standards for data ethics • Consult with people with disabilities or specialists to review data tools and processes
Use a mix of disability data methods	• Use a mix of different types, sources and methods relating to disability data, including qualitative and quantitative data, and data from local populations, health facilities and secondary sources • Integrate disability into existing data tools and processes used throughout the project cycle	• Commission RAABs (with disability module) or other population surveys (with WG-SS) to generate evidence on eye health and disability • Measure equity of access to health services by collecting both population and facility-based data and disaggregating both using the WG-SS • Consider repeat RAABs (with disability module) to measure changes in health outcomes over time

Disability data component/aspect	Where to start? Minimum standards and key principles to follow	What more could be done? Exploring best practice and innovative approaches
Disaggregate data by disability	• Disaggregate all data on individual people by disability • Identify people with disabilities within data collection using a functional approach (e.g. WG-SS) • The WG-SS is recommended as the preferred tool for use in all eye health data collection, at population and facility level. • Also include other tools/questions about disability where required by health systems or to enable comparison to other datasets. • Plan and allocate resources for the full process of using the WG-SS • Exclude the vision domain when analysing WG question data	• Use the WG-ES (or WG-SS Enhanced) in population surveys or research to more accurately understand disability and the eye health situations of more marginalised groups • Explore using the WG-SS Enhanced within population surveys or facility data to more accurately understand disability • Collaborate with others to advocate for and support the adoption of the WG-SS within sector data tools and systems • Test the use of the WG questions (with a lower cut-off point) for providing referral information to eye health patients • Use the CFM in any surveys or research focused on children
Strengthen facility data systems or practices	• Consider the approach to routinely collecting patient data on disability that will work best in each context, including whether parallel systems should be set up or existing systems strengthened over time • Consider how disability data can be best collected within the patient flow • Where disability data cannot feasibly or sustainably be collected from all patients, explore sampling approaches • Collect qualitative data and other data about health facilities to complement and fill gaps in patient data • Lack of facility-level data on disability should not preclude disability inclusion efforts	• Advocate for and collaborate with others to support integrating the WG-SS and other relevant disability questions into government HMISs • Coordinate with stakeholders in other health subsectors around health system reform, sharing lessons learned, sharing data resources and tools, etc.

Disability data component/aspect	Where to start? Minimum standards and key principles to follow	What more could be done? Exploring best practice and innovative approaches
Plan for resourcing, support and quality control	• Allocate adequate resources to ensure data quality and meet ethical standards • Embed disability data within broader approaches to inclusion and/or data systems strengthening • Raise awareness on disability, inclusion and the value of disability data • Provide training, technical support and quality control throughout the data cycle	• Allocate resources for dedicated inclusion and/or data focused roles • Allocate resources to ensure tools, trainings and lessons learnt can be shared externally • Provide financial or technical resources to OPDs to support their capacities to collect and use health sector disability data

TOOL 2: HOW DO I INTEGRATE DISABILITY DATA INTO THE PROJECT CYCLE?

The guide below sets out a step-by-step process for designing and implementing an approach to disability data across the project cycle. Some of the steps set out below may involve separate or standalone processes, while others can be integrated into other project cycle activities (e.g. conducting disability/equity analysis, developing a theory of change and logframe, conducting a baseline survey). The process may look a bit different in different projects; e.g., the order of steps might change.

Identification Phase

Step 1: Understand the disability and data context

➔ Find out what OPDs exist in the project area, what they are doing to collect data and how they use (or could use) disability data

➔ Collate existing data on disability from a range of sources – including general disability data, data on disability and eye health and data on disability and general health

➔ Find out how relevant eye health and general health stakeholders are approaching disability data – from clinic/hospital level through to national level, and both government and non-government stakeholders

Step 2: Engage OPDs and plan for inclusive and ethical data processes

➔ Reach out to OPDs and discuss their interest in disability data in the eye health (or general health) sector

➔ Explore potential roles for OPDs or individual people with disabilities to be involved in disability data processes – noting that there are lots of different options, and an inclusive approach allow OPDs to identify what role (if any) is best aligned to their interests

➔ Find out where you can access technical support and training on how to make data processes accessible and inclusive – this could come from OPDs, consultants, colleagues, etc.

➔ Map what disability services exist in the project area and their referral/eligibility processes, and collate this information to provide to people with disabilities during data collection

Development Phase

Step 3: Decide how to approach disability data disaggregation (DDD)

➔ Start by considering the WG-SS as the recommended tool for disaggregating quantitative data by disability in most contexts.

➔ Analyse existing tools used for DDD within relevant research, surveys and health services at local and national levels, as well as the capacity and willingness of relevant stakeholders to adopt/strengthen DDD tools. For example, the CEEHAT tool includes the Washington Group short set of questions.

➔ Decide on the tools(s) that will be used for disability disaggregation in each planned data collection process (e.g., research, population survey, baseline survey, service monitoring)

Step 4: Conduct disability situation analysis

- ➔ Identify gaps in information that is needed in order to design disability inclusive programming and service-delivery approaches – consider the general experiences of people with disabilities, links between disability and eye health, barriers to accessing eye/general healthcare, support requirements of people with disabilities when accessing healthcare
- ➔ Used mixed methods to collect required information; ensure data collection is accessible and applies ethical principles
- ➔ Integrate the disability module (i.e. WG-SS) into any RAAB surveys being supported
- ➔ Ensure that any quantitative data collection uses the WG-SS or other recommended tools to disaggregate data

Step 5: Define disability inclusion goals, indicators and MERL methods

- ➔ Define disability inclusion goals and strategies for your project, based on situation analysis, and include these in the project theory of change/logframe
- ➔ Set disability-inclusive indicators that relate to each of the project's disability inclusion goals (outcome indicators) and/or strategies (process indicators)
- ➔ Consider specific goals or indicators relating to strengthening or advocating for improved disability data systems
- ➔ Identify potential sources of evidence and tools that will be used to collect data against each indicator
- ➔ Consider the resourcing and practical requirements of each disability data source: ensure that adequate resources are allocated and assess what is feasible for the project – if necessary, reconsider the choice of indicators and prioritise what data is most important to support disability inclusive programming

Implementation Phase

Step 6: Collect baseline data on disability and inclusion

- ➔ Ensure that any baseline surveys address disability inclusion, by including specific survey questions on disability and disaggregating all survey data by disability
- ➔ Capture and record baseline data from any inclusion or accessibility assessment tools that are used in a project
- ➔ Consider consultations or formative research as a potential source of baseline data on disability, to complement survey data
- ➔ Make sure that baseline data on disability is used to help refine inclusive programming approaches (and not just recorded in the MERL system)

Step 7: Support disability data capacity and quality

- ➔ Providing awareness raising or training of all eye health staff and stakeholders (including clinical, administrative and management staff as relevant) on disability inclusion and disability data – including how disability data is essential to effective and inclusive service delivery

- Decide on disability data collection, management and analysis workflows at health service level and identify the staffing, technical or other resources required
- Train data collectors on the proper use of disability data tools, inclusive communication, accessibility and ethics (including providing referral information where relevant)
- Provide refresher training, coaching or other technical support to those collecting, managing and analysing disability data
- Establish quality control measures – e.g. spot checks of facility data or periodic data reviewing/cleaning – to help identify any issues with data during implementation

Step 8: Monitor inclusion and adjust implementation approaches

- Ensure that monitoring tools capture data that can help monitor progress against disability inclusion indicators and identify any gaps or changes required to programming
- Initiate and/or support processes to ensure that eye health partners are able to analyse disability data and use data to identify potential issues or priorities for change in their policies, practices and systems
- Consider annual/periodic processes to review monitoring data on disability inclusion, reflect on successes and challenges, and identify follow-up actions

Evaluation Phase

Step 9: Evaluate disability inclusion outcomes and capture learning

- Ensure that terms of reference for evaluations specify disability inclusion within the evaluative criteria/topics/questions and specify the involvement of people with disabilities and the use of accessible and inclusive methods
- Used mixed methods to collect required information; ensure data collection is accessible and applies ethical principles
- Ensure that any quantitative data collection uses the WG-SS or other recommended tools to disaggregate data
- Consider a dedicated evaluative or learning process focused on disability and/or equity to capture evidence and learning that might be missed in the main evaluation

Step 10: Share data and lessons learnt with others

- Seek out opportunities to share good practices, challenges and lessons learnt in relation to disability inclusion and disability data
- Wherever possible, make population- and facility-level data available to others (in deidentified/summary format) – particularly other eye health stakeholders working in your location or country

TOOL 3: WHAT DATA DO I NEED?

The table below provides examples of the types of data, sources and collection methods that might be needed for different uses of disability data. **These are examples only**; each project or partner's context will be different.

Use of data	Examples of data needed	Examples of data sources
Understand the eye health needs of people with disabilities	• Key eye health measures (e.g. rates of VI and CSC) among people with disabilities in the population	• Population survey in hospital catchment area – e.g. RAAB with disability module • Population research study
Understand the local disability context	• Information on local disability laws/policies, services, programs, OPDs, disability networks, etc. • General priorities/concerns of people with disabilities around access to health • Existing data on disability	Context analysis including: • Key informant interviews/ focus group discussions with OPDs/local people with disabilities • Desk review of policies, data, etc. • Service mapping
Design disability inclusive approaches within a project	• Information on barriers to accessing eye health services for people with disabilities • Information on support requirements/preferences of people with disabilities • Information on the local disability context	• Key informant interviews / focus group discussions with OPDs/local people with disabilities • Eye health facility inclusion self-assessment / accessibility audit • Baseline survey capturing information on barriers and access requirements • Disability context analysis [as above]
Support advocacy for disability inclusive eye health policy or practice	Information to influence eye health sector stakeholders, e.g.: • Prevalence of disability in the general population and/or the population with eye health issues • Key eye health measures (e.g. rates of VI and CSC) among people with disabilities compared to people without disabilities • Information on barriers to accessing eye health services for people with disabilities • General priorities/concerns of people with disabilities around access to health	[All of the above]

Use of data	Examples of data needed	Examples of data sources
Monitor and evaluate equitable access to eye health services by people with disabilities	• Numbers of people with and without disabilities accessing eye health services • Numbers of people with and without disabilities in the population requiring eye health interventions (e.g. rate of VI, refractive error)	• Population survey in hospital catchment area – e.g. RAAB with disability module • Eye health facility patient data – with disability disaggregation using a comparable method to the population survey
Monitor the inclusiveness of eye health services	• Information on actions taken to remove barriers to accessing eye health services • Information on supports provided to people with disabilities accessing services • Change in knowledge, attitudes and practices of eye health personnel • Experiences and perceptions of people with disabilities accessing services	• Eye health facility inclusion self-assessment / accessibility audit • Eye health facility reports on training, budget allocation, service standards, etc. • Survey / interview / focus group discussions with eye health personnel • Key informant interviews / focus group discussions with eye health patients with disabilities • Feedback/user satisfaction surveys from eye health patients with disabilities
Monitor and evaluate meaningful participation of people with disabilities	• Number and % of people with disabilities involved in project management/steering processes, MERL processes, community or hospital committees, or any other participation mechanisms. • Extent to which people with disabilities have contributed to and influenced decisions relating to the project • Extent and nature of OPD engagement with the project or partner	• Project monitoring of participation mechanisms • Eye health facility reports • Key informant interviews / focus group discussions with participating OPDs/ people with disabilities
Evaluate the equity of changes in eye health outcomes over time	• Change in key eye health measures (e.g. rates of VI and CSC) over time among people with disabilities compared to people without disabilities	• Repeated population surveys in health service catchment area – e.g. RAAB with disability module
Generate evidence and learning on disability inclusive eye health practices	• Analysis of disability inclusion interventions and outcomes [as above] • Perceptions of people with disabilities, eye health personnel and project managers on what has enabled or hindered disability inclusion outcomes, lessons learnt, remaining gaps or barriers, etc.	• Analysis of other data [as above] • Key informant interviews / focus group discussions • Facilitated reflection exercise

FURTHER READING

General disability data technical resources:

- Stakeholder Group of People with Disabilities, International Disability Alliance and CBM Global, Disability Data Advocacy Toolkit.
- Plan International Australia & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, Practice note : collecting and using data on disability to inform inclusive development.
- CBM-Nossal Institute Partnership for Disability Inclusive Development and Research for Development Impact Network (2020) Research for all: Making Development Research Inclusive of People with Disabilities
- World Bank, Disability Measurement in Household Surveys: A Guidebook for Designing Household Survey Questionnaires

Guidance on the Washington Group Questions:

- CBM Global Inclusion Advisory Group (2023), Using the Washington Group questions on disability data in development programs: A learning brief
- UNFPA, CBM Global Inclusion Advisory Group, Pacific Disability Forum and ASEAN Disability Forum, Brief Explainer on the Washington Group Questions on Disability
- UNFPA, CBM Global Inclusion Advisory Group, Pacific Disability Forum and ASEAN Disability Forum, Where are we? Questions to aid understanding of disability data and inform advocacy
- Washington Group on Disability Statistics website

E-learning (self-guided) resources:

- World Bank, Collecting Data on Disability Inclusion
- Humanity and Inclusion, Collecting Data for the Inclusion of People with Disabilities in Humanitarian Action (focused on humanitarian programs but includes introduction to the Washington Group Questions)
- UNICEF, Videos on Disability Data Collection
- Center for Inclusive Policy, Videos on the Washington Group Questions

General resources on disability-inclusive health services:

- WHO, Global report on health equity for persons with disabilities
- WHO, Disability-inclusive health services toolkit: a resource for health facilities in the Western Pacific Region

ANNEX 1: SAMPLE WG-SS DATA ANALYSIS SPREADSHEET

Annex 1. Sample
WGQ data entry spr