ROUGH GUIDE TO DISABILITY INCLUSION IN EYE HEALTH PROGRAMMING

May 2020

What is Disability?

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) defines persons with disabilities as including persons; "***who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.***"

Thus, **Disability = Impairment + Barriers**

Types of **impairments** include:

- **Physical:** performance of body functions e.g. walking, moving arms and legs, using hands, etc. *e.g. spinal cord injury, cerebral palsy, amputation*
- **Sensory:** seeing, hearing or communicating. *e.g. people who are Deaf, hard of hearing, blind or have low vision*
- **Psychosocial:** chronic severe mental health issues or psychosocial distress. *e.g. schizophrenia, depression, bipolar disorder*
- **Intellectual:** language, reasoning, memory, personal care, etc. *e.g. Down's syndrome, cognitive impairments/brain injuries*

Types of **barriers** include:

- **Attitudinal**: stigma, discrimination, negative assumptions, exclusion, teasing
- **Physical**: steps, uneven paths, narrow doorways, open drains, inaccessible buildings/equipment/ vehicles, etc.
- **Communication**: Information only in written or audio format. Lack of interpreters/translation.
- **Institutional/Policy**: Discriminatory laws, policies, practices and procedures

Understanding Disability

Disability is present in all communities.

- People with disabilities report multiple barriers to accessing health services, with these barriers being greater than for people without disabilities.
- 15% of people worldwide are estimated to have a disability (WHO and World Bank 2011), about 80% of whom live in low- and middle-income countries. Disability may be under-reported in many places.
- Identifying and overcoming barriers to accessing eye health is an important and practical way to build disability inclusion in eye health programs.
- Barriers for people with disability, including those with a permanent eye condition, can relate to community attitudes, physical surroundings, financial limitations, communication, and laws and policies.
- Many people with disabilities experience exclusion, stigma and discrimination, especially in relation to false beliefs about causes of impairment and the capacity of people with disabilities.
- At least 20% of people who are blind or have severe vision loss cannot have their sight restored.

What is a DPO/OPD?

A disabled people's organisation (DPO) or organisation of persons with disabilities (OPD) is an organisation **of** and **for** people with disabilities. They can be global, regional, national or local organisations. DPOs comprise a voting membership of people with disabilities and a board, of which a majority percentage (usually 51% or over) is made up of people with disabilities. Most DPOs are primarily involved in advocacy, networking and information sharing amongst their members. DPOs may be focused on representing people with one type of impairment (impairment-specific) or have a broader membership of people with many different impairment types (cross-impairment).

They can also focus on specific groups (e.g. women's DPOs), interests such as sports, or on the provision of disability services. DPOs differ from disability-specific organisations such as CBM, Helen Keller International and Sightsavers in that they are run **by** people with disabilities.

How can engaging with DPOs be useful in eye health programming?

- Helping to locate local people with disabilities for specific outreach
- Advising on accessibility of both facilities and services
- Participating in training or awareness raising sessions
- Participating as research/M&E enumerators, team members or advisors
- Joining project steering committees / stakeholder groups
- Joint advocacy

Why include people with disabilities in eye health programs?

- People with disabilities are people first and have strengths, capacities and abilities to contribute to their communities.
- People with disabilities form the world's largest minority group.
- People with disabilities have a right to health services as outlined in the UNCRPD.
- Eye health staff need to be skilled in responding to the minimum 20% of people with eye conditions whose vision cannot be restored, through linking them with DPOs and disability service providers who can provide appropriate mobility, education, social inclusion, rehabilitation and livelihood opportunities.
- There is a strong correlation between disability and poverty, with poverty leading to higher prevalence of disability and disability increasing the risk of poverty.
- People living in poverty are more likely to acquire a disability due to unsafe living, work and travel environments, and less access to treatment and rehabilitation services.
- People with a disability, such as a physical disability or deafness are very dependent on their vision to support their independent living and therefore should be prioritised in eye health programs.
- Many people with disabilities have not had access to formal education and frequently miss out on livelihood opportunities increasing both their poverty and isolation.
- Women and girls with disabilities face triple discrimination: being female, having a disability and being among the poorest of the poor.
- Women and girls with disabilities are often at greater risk of violence, injury, abuse, neglect, maltreatment or exploitation.

Statement of Approach

Historically, there have been a range of perspectives or models through which disability is viewed, including the charity, medical and social models[1]. Many of the earlier models of disability reinforced negative stereotypes and false beliefs about disability. More recently, and in line with the UNCRPD, a human rights model has been adopted. In 2020, The Fred Hollows Foundation has adopted a human-rights approach as part of our Equity Position Statement which embeds disability as part of the organisation's organising framework (GAPSED+- Gender, Age, Place of Residence, Socio-economic, Ethnicity/Indigeneity/Race, Disability and other context-specific domains impacting social determinants of health).

The rights-based approach to disability takes universal human rights as a starting point, proposing that people with disabilities have the right to full and effective participation in society on an equal basis with others. The rights-based approach incorporates social model thinking, which states that people are disabled by the barriers in society, such as a lack of ramps or accessible toilets, or people's attitudes and assumptions about what people with disabilities can contribute – and that it is society that needs to change.

What is the UNCRPD?

In May 2008, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) entered into force. The Australian government ratified this convention in the same year. As of March 2020, the CRPD has been ratified by 163 countries and signed by 181 countries. This convention requires that people

[1] Further information on the models of disability can be found in CBM's Disability Inclusive Development Toolkit on page 20:

with disabilities have access to mainstream and disability-specific services with an emphasis on full and equitable inclusion. This convention affirms that the obligation for inclusion is placed on society rather than on people with disabilities.

Integrated people-centred eye care

The World Report on Vision (2020) emphasises the importance of *integrated people-centred eye care*. This is defined as services that are managed and delivered so that people receive a continuum of health interventions covering promotion, prevention, treatment and rehabilitation, to address the full spectrum of eye conditions according to their needs, coordinated across the different levels and sites of care within and beyond the health sector, and that recognises people as participants and beneficiaries of these services, throughout their life course. Adopting this Framework requires four strategies:

- Empowering and engaging people and communities
- Reorienting the model of care
- Coordinating services within and across sectors
- Creating an enabling environment

This demonstrates strong synergy with disability-inclusive practices.

What is disability-inclusive development?

Disability-inclusive development encourages awareness of and active participation by people with disabilities. This development approach respects the diversity in the contribution made by people with disabilities and appreciates that disability is an everyday part of the human experience.

Disability-inclusive development sets out to achieve equality of human rights as well as full participation in, and access to, all aspects of society.

What does disability inclusion in eye health mean?

Disability-inclusive eye health programs are designed to welcome and support all members of a community – whether they do or do not have a disability, and no matter what their disability may be. Programs that plan for disability inclusion will ensure barriers are identified and removed. Inclusive programs also ensure that people with permanent vision loss have access to wider opportunities.

Disability-inclusive eye health programs respond to attitudinal, physical, communication and policy-related barriers. The following points illustrate what disability inclusion can look like in an eye health program:

- Staff with positive perceptions about people with disabilities and attitudes that are welcoming and inclusive.
- Agreements in place with local Disabled People's Organisations (DPOs), people with disabilities who can provide advice on the monitoring of programs and in making them accessible and inclusive of people with disabilities.
- The presence of large contrasting signage for people with vision impairment.
- Good-quality wheelchair access.
- Access to sign language interpreters for people who are deaf.
- A disability policy and a committee to oversee its implementation.
- Financial support to ensure people in poverty with disabilities can access treatment.
- Printed materials that include clear, strong contrast pictures to illustrate key points and use plain language for people with disabilities with low-literacy skills.
- Staff trained in communication skills for people with a range of disabilities, including mental health conditions, vision impairment, acquired brain injury and intellectual disability.
- A disability inclusion committee made up of staff with awareness of access strategies for people with a wide range of disabilities, including knowledge of particular access requirements for women and girls with disabilities.
- A focal person responsible for gender-sensitive disability inclusion.
- Networks, linkages, referrals and access to a low-vision unit.
- Where possible, invite people with a disability to be a member of steering committees, program boards, project design teams and review or evaluation teams.
- Ensure eye health beneficiary data are disaggregated by sex and disability, where possible.

Addressing barriers to access

Universal design

Universal design principles are used in the built environment, education, communication and other areas where it is important to create a setting accessible and useable for all. Ensuring a universal design approach means that as many people as possible can access a program with minimal barriers. Through universal design principles, people with disabilities are consulted to determine their access needs alongside other community members and key stakeholders. Using universal design, features such as access points, doorways and signage are designed with people with disabilities in mind. As a result, entrances have ramps, doorways are uncluttered and wide enough for people in wheelchairs, and signs are at eye level, large with clear text and good colour contrast. This design approach is of benefit to all who access an eye health program, including elderly people, pregnant women and children.[2]

Reasonable Accommodation

Refers to specific support or modifications requested by a person with a disability that are required to address a specific barrier to participation. The support or modification enables people with disabilities to access services on an equal basis with others. An example might be if a deaf person requests a sign language interpreter at their eye health appointment.

Community-Based Inclusive Development (CBID) (previously called Community-based Rehabilitation (CBR))

Over the past 20 years, community based inclusive development (CBID) has matured from a mainly health and rehabilitation focus to a comprehensive rights-based approach based on the principles of the UNCRPD. This evolution is reflected in the increasing use of CBID as a more appropriate title for this field of work. CBID focuses on the creation of inclusive societies where people with disabilities have access to social and development benefits like everyone else in their communities. The rationale is that no one should be excluded from development for any reason, and that the inclusion of marginalised people in development processes reduces poverty, builds community resilience and benefits the whole of society.

FHF country office staff and implementing partners need to be aware of providers of CBID/CBR in their geographical area in order to refer patients to their services, particularly those who will require ongoing rehabilitation in order to achieve independent living.

Do No Harm Approach

'Do No Harm' is a core tenet for health professionals, who have a duty of care to provide quality services[i]. While health interventions carry the potential of further harm, for many, not having access to health interventions can be equally harmful, increasing the risk of illness, morbidity and mortality. Environmental barriers, communication barriers and attitudinal barriers can prevent people with disabilities from getting to a health service, being seen and receiving quality health care. Exclusion from health care or health facilities and increased risk factors for poor health can further increase the risk of secondary conditions and co-morbidities[ii]. Additionally, a lack of training and limited knowledge amongst health workers regarding disability can lead to unsafe experiences for people with disabilities[iii].

Applying disability-inclusive practices in eye health programs

A disability inclusive eye health program may include the following practices:

- Eye health promotion following principles of disability inclusion will enable all community members to access information on health promotion, vision screening and blindness prevention.
- Eye health programs should be aware of approaches to locate, attract and identify women, men, girls and boys with disabilities.
- Screening and patient transfer and transport processes should be aware of and cater for people from a diverse range of disability groups.
- Outreach services should be advertised using a range of formats and networks such as large print, pictorial, radio announcements and community meetings.

[2] For further information see DFAT's accessibility guidelines: https://www.dfat.gov.au/about-us/publications/Pages/accessibility-design-guide-universal-design-principles-for-australia-s-aid-program

- Individual information and counselling should be offered to people with disabilities.
- People with a newly acquired vision impairment should be referred to services that will foster independence such as CBR/CBID, a low-vision clinic, inclusive education and a DPO.
- Reliable follow-up services are essential to ensure all individuals with a disability are monitored for ongoing or additional medical care needs.
- Follow-up is essential with individuals who may have already been to an eye hospital to see if their eye condition has changed or whether other services are required.

More guidance for inclusive eye health programming can be found in Annex 1 and Annex 2.

How to include Disability in a Situation Analysis

When setting up a project, an essential first step for ensuring that it meets equity requirements is to conduct a disability analysis.

A disability analysis should be completed for all projects, however the scope of the analysis will be determined by the project team. This may mean teams making decisions about whether the analysis should be done at a country level, or at the project level, or both. A disability analysis can be done in conjunction with a gender analysis or as part of a wider situational analysis. If, after completing the disability analysis, there are gaps within the information, a more in-depth disability analysis may need to be undertaken.

What does a Disability Analysis involve?

A disability analysis can be a useful process to understand the barriers and enablers present for people with disabilities at a country level. A disability analysis should be conducted either by or in partnership with people with disabilities themselves and as a guide should cover the following questions.

1. What is the situation and number of people with disabilities and their families in the country?
2. What are the social and cultural norms around disability, e.g. perceptions of disability, stigma and discrimination?
3. What is the country's status with regards to ratification of the CRPD and any disability-specific legislation in country?
4. What are the key barriers faced by people with disabilities, particularly in relation to accessing health services?
5. How accessible is the physical, communication and information environment of eye health services in the country?
6. What DPOs and CBID services are available in the project area?

Some baseline information at the country level can be found within the FHF Equity Beneficiary Profiles, found on FredNet here.

For further information on these questions see Annex 3.

Selecting who will be involved

When we are identifying who will be involved in conducting or participating in the analysis, we need to consider the mantra of the disability movement, **'nothing about us, without us'.** People with disabilities themselves are best placed to advise on the barriers they face and the best ways to overcome these barriers. Where possible it is best to have a person with a disability conduct the disability analysis either alone or with the project team.

It is also vital to ensure that interviews and focus group discussions to collect information to inform the analysis are accessible:

- Who is asking the questions? Women might be more comfortable talking to other women or men talking with other men.
- What language are you going to use? Does everyone speak the same language in the focus groups? Do you need a sign language interpreter?
- Where and when are you going to conduct interviews and focus group discussions? Make sure the physical location and transport to and from the location are accessible.

Determining an approach

There are different ways of collecting information for a disability analysis. The most appropriate approach is the one that best suits the purpose of the analysis. The options include:

- Desk top review;
- Surveys;
- Interviews;
- Focus groups;
- Observational investigations, such as an accessibility audit; or
- Participatory approaches.

See FHF's general guidance on conducting a Situational Analysis for details of these approaches.

Annexes 4 and 5 provide tips for inclusive communication, and for running inclusive meetings and events.

Development of a detailed plan

At this point in the process, a detailed disability analysis plan needs to be developed, including a budget, which must include provision for accessibility[3] and reasonable accommodation[4]. Who is being consulted with and participating in the analysis (partners, health works, community volunteers, beneficiaries, children with disabilities, people with psychosocial or intellectual impairments) will determine if ethics approval needs to be sought before data collection can start. This may also vary from country to country. If unsure if ethics approval is required it is best to consult with the Research Team.

Optional: Engaging a consultant

If appropriate a consultant can be contracted to undertake all or part of the disability analysis. Key recommendations for selecting a consultant for a disability analysis include:

- A person with a disability[5]
- Expertise on eye health, health systems and disability
- Demonstrated experience in disability analysis implementation; expertise on survey design and analysis; and qualitative research (if relevant)
- Knowledge of the local context (especially the local eye health system)
- High level of communication with The Foundation and strong understanding of the analysis requirements (as shown by the quality of the submission).

If a consultant is going to be contracted to do all or part of the disability analysis please consult with the Development Effectiveness team who can support with ToR, contract etc.

A Disability analysis ToR template can be found at Annex 6.

Development of materials for the analysis

Given the scope of a disability analysis can vary and the approach needs to be tailored for the country or community context, there may be a need to develop (or source) materials. There are however survey templates and guides, standard survey questions, and template interview schedules that are available and provide a good starting point. Examples of guiding questions can be found in Annex 3.

Undertake the analysis

Once the plan and tools have been developed, data collection can be undertaken. Once all data and information has been collected, it needs to be analysed. It is good to set aside time for the analysis of the information. If can be helpful to include someone with disability analysis expertise to assist with the analysis of the data.

In some circumstances further information may be required to ensure a robust analysis.

Prepare Report

Once the desk top review and field work is completed a report should be prepared. This report will include recommendations on what should be included in the project design. Consider sharing the draft with participants for feedback on analysis of themes and recommendations. Incorporate feedback and finalise report.

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[3] **Accessibility** is the removal of barriers and obstacles which make it easier for everyone to participate, e.g. providing ramps, clear large print signs.

[4] **Reasonable accommodation** is the provision of additional 'reasonable' modifications or support to enable certain individuals to participate fully, e.g. sign language interpretation.

[5] Whether or not a person with a disability is contracted to undertake the disability assessment (which is preferred) it is also vital to engage with the local DPO as a key stakeholder.

Share Findings

The findings from a disability analysis should be shared widely and to all stakeholders involved. Options for sharing findings include:

- Workshop with partners
- Sharing findings with participants who have been involved in the analysis
- Sharing across The Foundation (through the disability equity learning network)
- Publishing findings (this may require ethics approval)

The findings from the disability analysis will form part of the project situation analysis and will be included in project design workshops and discussions.

Monitoring and Evaluation of Disability Inclusion

What our projects should be able to tell us:

- How barriers affect beneficiaries' ability to participate in/benefit from the project
- How the project has affected the different beneficiary groups in the project (men, women, children with and without disabilities)
- To see whether project benefits are equitably distributed among all participants

In order for our projects to tell us the above, we need to ensure a robust M&E plan, consisting of Key Evaluation Questions that can be used to answer the above questions. Suggestions of disability inclusive indicators are in Annex 7.

ANCP has some specific indicators around disability inclusion, and these should be used where possible:

- Number of DPOs actively engaged with a project
- Number of people who received training in disability awareness and/or inclusion
- Number of health workers who received training and development
- Number of people who received disability support services specific to their needs, including referrals for rehabilitation services, etc.

The Washington Group Short Set of Questions on Disability (WGQS) is a set of six questions developed for use in censuses and surveys to capture disability disaggregated and can be used to ascertain if persons with disabilities are participating equally in program. To date, the questions have been used in over 60 countries and their use has been adopted by many government and UN agencies globally. Information on how to use the Washington Group Questions in surveys can be found in Annex 8.

How disability inclusive is your project?

It is important to remember that the extent to which projects consider disability inclusion falls along a continuum. All of our projects should be classified in the following way:

1. **Mainstream Approach**—actively including people with disabilities as participants and beneficiaries of development efforts across all sectors
2. **Targeted Approach**—targeting people with disabilities in development initiatives designed specifically to benefit people with disabilities.
3. **Twin Track**— applying both a mainstream and targeted approach.
4. **Not Targeted**—The activity is not targeted to promoting disability inclusion, however, disability inclusion could be addressed by ensuing participation of people with disability or a disability analysis will be/ has been undertaken as part of the activity's design.

If your project is classified as Mainstream, Targeted or Twin Track, in the project design document you will be asked to specify the focus of the activity as:

- The project actively involves people with disabilities and their representative organisations (such as DPOs) in planning, implementation & M&E

  and/or:

- The project activity identified & addressed barriers to inclusion & opportunities for participation for people with disabilities to enable them to benefit equally from project.

Further Support

Please contact Anita Afford, Senior Equity & Inclusion Advisor for additional support.

Resources relating to disability inclusion can be found on FredNet here.

ANNEXES

Annex 1 – Improving disability access to eye health programs

Annex 2 – Project level self-assessment checklist

Annex 3 – Disability Analysis guiding questions

Annex 4 – Tips for inclusive communication

Annex 5 – Tips for holding inclusive meetings

Annex 6 – Disability Analysis terms of reference

Annex 7 – Sample M&E indicators

Annex 8 – Use of the Washington Group Questions in eye health programs

ANNEX 1

Improving disability access in eye health programs

PHYSICAL BARRIERS ACCESS STRATEGIES

People with disabilities may experience difficulties entering and moving around the eye health building.

- Review physical access to the building, checking for ramps, hand-rails, wide doorways and clear markings on the floor.
- Ask people with disabilities through a local DPO to audit the accessibility of the building.
- Ensure at least one obvious, signposted ramp entrance is available with a gradient, preferably 1:20, and never steeper than 1:12.
- Ensure colour contrast at top edge of all steps and place high-contrast, raised markings (tactile indicators on the floor) at points of surface change.
- Refer to national and local laws and policies that require disability access compliance for hospitals and other public buildings. Rooms and other facilities such as toilets may not be accessible to people with physical disabilities.
- Ensure each building includes separate accessible toilets for men and women, with wide entrances, door pull straps, 'grab' rails, and a low-level wash basin.
- Ensure wide, unobstructed corridors and doorways throughout the building.
- Make sure consultation rooms have enough space for a wheelchair to freely turn around.
- Ensure equipment such as slit lamps allow full access for a wheelchair user.
- Health services may be in capital cities where people with disabilities from remote locations may find them hard to reach.
- Create opportunities for mobile health facilities to remote communities.
- During mobile outreach, proactively seek out people from a diverse range of disability groups in need of eye consultations.
- Identify free or affordable accessible transportation to major eye clinics.
- Create opportunities for referral through primary health care facilities or CBR/CBID programs.
- Ensure access to health services is financially affordable to the poorest people in a community, who often include people with disabilities.
- Network with existing services for referral processes.

COMMUNICATION BARRIERS ACCESS STRATEGIES

People with a vision impairment may not be able to see all signs to locate and navigate around buildings.

- Check the building to ensure that all signs are preferably between 1m and 1.5m from floor, of good colour contrast and in a large, clear print.
- Use clear images with good colour contrast on signs to ensure people with disabilities and others with low literacy skills are able to interpret information.

- Use tactile cues such as raised tiles or tactile indicators to assist people who are blind or vision impaired to orientate around the environment. Promotional information including community posters may not be accessible to people with specific learning disabilities, intellectual disabilities or a vision impairment.
- Use large, clear print with good colour contrast to improve access for people with a vision impairment.
- Use pictures and plain language as many people with disabilities have had limited education opportunities and may not be able to read all information.
- Use other methods such as radio announcements and community meetings to inform people with disabilities about the eye health program.
- Raise awareness about the eye service with a range of community groups such as village health workers, CBR/CBID workers, DPOs and religious leaders.
- Raise information about the eye health program by sending accessible brochures home with patients to share with their community.

COMMUNICATION BARRIERS ACCESS STRATEGIES

People who are deaf will have difficulty understanding spoken communication in meetings and consultations.

- In consultation with people who are deaf or hard of hearing, determine the preferred forms of communication to be used. It is useful to present information in a range of modes such as in posters and print handouts.
- Identify local sign interpreters and possibly select a particular day each month where consultations are scheduled for people who are deaf[6]. Important information printed on medicine packets and brochures may be inaccessible to people who cannot access print.
- Ensure vital information is provided in an alternative format such as large print or Braille for someone with a vision impairment.
- Clarify that spoken information such as that read from medicine packets is understood.

ATTITUDINAL BARRIERS ACCESS STRATEGIES

Negative community attitudes and myths about disability – including for women, girls and elderly people with disabilities – may lead to a sense of reduced acceptance.

- Address negative attitudes about disability, especially those based on false beliefs about how impairments are acquired.
- Engage with local DPOs to run staff disability awareness training to encourage positive perceptions.
- Employ men and women with disabilities to reinforce the valuable contributions people with disabilities can make to the workforce, ensuring relevant supports are in place.

POLICY/FINANCIAL BARRIERS ACCESS STRATEGIES

Eye health program fees may be prohibitive for people with disabilities and their family members, especially when 22% of the world's poorest people have a disability.

[6] Warning that this should only be done– if this day has been decided in consultation with the deaf/hoh communities and promoted well in advance. But there should be opportunities and room to move for those who are unable to make this date – reasonable accommodation should be adhered to in those situations (i.e. don't limit access/services to those who came on the "wrong days".

- Be mindful of how family money is allocated regarding people with disabilities accessing health care, especially for women and girls.
- Reduce or remove costs, including travel costs, for people with disabilities and other people in poverty accessing eye health services. People who present with a vision impairment may feel discouraged if there are no relevant services or supports to be referred to.
- Identify community supports for counselling.
- Ensure referrals are made to CBR/CBID, education and other relevant services.
- Ensure referrals are made to low-vision rehabilitation services, including prescription of low-vision devices.
- Connect people who are identified with a permanent eye condition with a local DPO and CBR/CBID program or relevant personnel where available.
- Reinforce capacity, potential and supports which mean that people with a vision impairment and other disabilities are viewed as valued members of their community.

For more information about how to ensure accessibility in programming, you can also refer to the Australian government ‘s ‘Accessibility Design Guide: Universal design principles for Australia’s aid program’: https://www.dfat.gov.au/sites/default/files/accessibility-design-guide.pdf

ANNEX 2

Disability Inclusion in Projects / Programs – Self-Assessment

This checklist is an optional tool which can be used to assess disability inclusion at a project level. It can be completed by country office or implementing project staff to conduct a self-assessment of how they are doing in relation to disability inclusion before creating an action plan to improve their practice. The three different sections can be used separately depending on the phase of the project: design, implementation or monitoring and evaluation.

Part A: Design and Planning

Questions	Comments / Evidence / Actions
Are diverse people with disabilities and their representative organisations actively engaged in analysis, design and planning?	
Do situation analyses clearly identify under-represented groups and analyse social roles, relations, norms and inequalities in relation to disability and gender?	
Does community mobilisation include accessible and participatory processes so that diverse people from under-represented groups are actively engaged?	
Do program designs have objectives and result areas that contribute to achieving both disability and gender equality?	
Does the design include specific measures with budget to address equality and non-discrimination in line with the CRPD? E.g. providing reasonable accommodation.	
Are programs designed comprehensively to address accessibility, availability, affordability, acceptability and quality?	
Are there budgeted activities that challenge attitudes, stigma, stereotypes and discrimination faced by all people with disabilities?	
Are there budgeted activities that contribute to participation and decision-making of all people with disabilities in services and government-led initiatives?	
Are there budgeted activities that target those who may face barriers or stigma on other grounds, including more isolated or under-represented groups?	
Are there budgeted activities that address intersectional or multiple discrimination?	
Is there budget for partners to develop capacity on disability inclusion?	
Is there budget for accessibility, participatory processes, reasonable accommodation and other specific measures to ensure non-discrimination, such as sign language interpreters, braille, easy read documents?	

Do indicators or data systems include disaggregation (at minimum by sex, impairment and age) to monitor progress and equality of outcomes?	
Is there budget and technical capacity to identify, monitor and mitigate potential risks so that no person is harmed by our work?	

Part B: Implementation, Monitoring and Learning

Questions	**Comments / Evidence / Actions**
Do programs have staff with disabilities and a proactive approach to ensure inclusive recruitment?	
Are accountability mechanisms in place and regularly reviewed using accessible community consultation processes?	
Is disability inclusion expertise available within teams and/or through consultancies with people with disabilities and/or DPOs?	
Are information and feedback mechanisms provided in a range of accessible formats, including local languages?	
Do activities create safe and accessible spaces for all to participate equally including, where necessary, separate spaces to ensure diverse and marginalised voices are heard?	
Is disaggregated data consistently collected and analysed following Office of the High Commissioner for Human Rights (OHCHR) Principles of participation, self-identification, transparency, privacy and accountability?	
Are all incidences of discrimination, including denial of reasonable accommodation, raised with managements and formally addressed through organisational complaints systems?	
Does the programme regularly take time to listen to diverse voices to reflect on how implementation may need to be adjusted?	

Part C: Evaluation

Questions	**Comments / Evidence / Actions**
Do evaluation teams include women and men with disabilities and diverse lived experience?	
Do evaluation teams use local expertise, languages and participatory processes that enable diverse and marginalised voices to be heard?	

Are evaluation initial findings and recommendations shared back with end users/local communities and partners in accessible formats and diverse communications modes to ensure feedback and validation?	
Do evaluation reports reflect the views of women, men, girls and boys with disabilities on the program outcomes?	
Is learning on disability and gender equality form evaluations consistently used to inform future programmes and strategies?	
Do programs contribute to outcomes relating to increased participation and decision making for women, men girls and boys with disabilities?	
Do programs contribute to outcomes relating to mainstreaming of disability and gender specific issues in national strategies/policies/plans?	
Do programs contribute to outcomes relating to the realisation of the rights of women, men, boys and girls with disabilities in line with the CRPD?	

ANNEX 3

Guiding Questions for Disability Analysis

In order to identify disability inclusion issues in project design there are a number of questions to consider. It is recommended that disability analysis be conducted at the country level, for example when developing a country strategy, rather than at the individual project level, however this information can then be used to inform individual project design. The first four questions are macro level questions relating to the country as a whole, the final question is specific to a facility or project site.

1. **What is the situation and number of people with disabilities and their families in the country? Ensure information covers all impairment types (physical, visual, sensory, intellectual, psycho-social)**

   It can be very hard to ascertain the actual number of people with disabilities in a country or program area, as disability data is often not collected and/or under-reported. The global prevalence of people with disabilities is 15% of the population and it is estimated that 80% of people with disabilities live in low and middle income countries (WHO, World Bank, 2011). If the national census figures do not show a prevalence rate close to 15% it can be assumed the number is under represented and programs should assume a prevalence rate of 15%.

2. **What are the social and cultural norms around disability, e.g. perceptions of disability, stigma and discrimination?**

   Is there a word in the local language for disability and is it a derogatory term? Does it refer to all impairment types or only to people with physical disabilities for example? Are there religious or cultural beliefs about disability? Are people with disabilities hidden? Are some people with disabilities more marginalised than others, e.g. deaf people, people with psychosocial or intellectual disabilities? It is also worth considering the intersectional issues in this space - are women and girls with disabilities discriminated against more than men and boys with disabilities? What about people with disabilities from a sexual and gender minority?

3. **What is the country's status with regards to ratification of the CRPD and any disability-specific legislation in country?**

   Country ratification status can be found here: https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4 DPOs can be a good source of information on disability specific legislation. Bear in mind that disability specific legislation often does not meet a country's obligations under the CRPD.

4. **What are the key barriers faced by people with disabilities, particularly in relation to accessing health services?**

   Consider environmental or physical barriers e.g. inaccessible buildings, lack of transportation; communication barriers e.g. information that is not accessible or inclusive; attitudinal barriers e.g. stigma, discrimination, people with disabilities being seen as less capable; institutional or systemic barriers e.g. laws or policies which discriminate or prevent people from disabilities form participating.

5. **How accessible is the physical, communication and information environment? (Although the disability analysis should be conducted at the country level this aspect can be done per facility).**

   Ensure you consider all impairment types, for instance the space may be accessible for a person with a physical disability, and for blind people, but inaccessible for a deaf person or a person with intellectual disability. Consider contracting a local DPO to conduct this accessibility audit, or at a minimum jointly conduct it with a DPO, consultant who is a person with a disability.

ANNEX 4

Tips for inclusive communication with people with disabilities

These tips can be used when dealing with people with disabilities who access eye health programs and also when conducting needs assessments, community outreach, working with DPOs and M&E activities such as focus group discussions.

General tips

- Talk directly to people with disabilities rather than people who might be assisting them (e.g. interpreters, family members, personal assistants)
- Ask people with disabilities how they prefer to communicate, where they prefer to meet, where they prefer to sit in meetings, etc.
- Try to sit or stand so that you are talking at eye level (rather than looking down at someone)
- When communicating with a whole community or a group of people with different types of impairments, use more than one type of communication – both visual and verbal.

Tips to include people with vision impairments

- Ask how people prefer to access written material (e.g. Braille, large print or electronic format) and provide materials in this format as much as possible
- Read out loud descriptions of written material or pictures that are used in any meeting
- In a group meeting or event, introduce yourself every time you speak (so that a person with vision impairment knows who is speaking).
- Try to make sure only one person speaks at a time in meetings.
- Tell the person if you are leaving the conversation or room

Tips to include deaf people and people who are hard of hearing

- Ask a person what type of communication is best for them – for example, sign language, lip reading, using help of a family member
- If a person uses sign language it is important to use a sign language interpreter
- When there are no sign language interpreters, close family members might be able to interpret for the person – ensure you seek consent from the deaf person.
- If a person can lip read, look directly at them, make sure they can see your lips and speak clearly
- Use multiple different types of communication – pictures, writing, demonstrations, etc.
- Make sure only one person speaks at a time in meetings and encourage people to raise their hands before speaking so the person (or interpreter) can follow the conversation (particularly if they are lip reading).
- Ask people where they would like to sit so they can follow the conversation better.

Tips to include people with intellectual disabilities

- Use pictures and photos instead of lots of words
- Do not speak to adults or teenagers/youths like they are children
- Repeat information and demonstrations to help understanding
- Use hands-on (practical) activities and give examples
- Give people lots of time to understand and think about what is being said
- Be accepting of behaviours that are different to what you are used to as long as they don't harm others or prevent the outcomes of the meeting being achieved. It is important to lead by example in this respect and to not allow bullying or teasing.
- Be accepting of different ways of communicating and make reasonable adaptations to maintain communication when needed. For example, you may need to give extra time for people to respond to questions, or you may need to provide information in smaller pieces so they are more easily understood.
- Some people may require more notice of events/activities in order to prepare themselves, and they may benefit from reminders of upcoming events.
- If it is a new activity for a person, check with them if they prefer to have a support person attend with them.
- If a person appears distressed, ensure you assist them in the same way you would people without disabilities (e.g. listening to their concerns or asking if they are ok if they look worried, asking if there is someone you can link them to for help, etc).

- Be flexible and give opportunities for people to make choices - don't assume that people cannot make their own decisions because they have a disability. Some people may also need support or extra time to make decisions.

Tips for including people with psychosocial disabilities

- People with psychosocial disabilities include those with long term difficulties or impairments related to mental health or emotional conditions. This can include changes in mood, such as experiencing depression or mania; people who experience seeing, hearing or feeling things that others do not (eg hearing voices); may think things differently to how everyone else understands them; may be very nervous or fearful (for example, may think that people are talking about them, when others do not agree). These experiences usually don't happen all the time, and when they do people may become confused and/or it may affect communication. However, often the biggest barrier that people with psychosocial disabilities face is negative attitudes from others. Their experience of disability is as much about discrimination and exclusion as it is about the persons' difficulties. Be accepting of different ways of communicating and make reasonable adaptations to maintain communication when needed. For example, you may need to give extra time for people to respond to questions, or you may need to provide information in smaller pieces so they are more easily understood. Some people may require more notice of events/activities in order to prepare themselves, and they may benefit from reminders of upcoming events.
- If it is a new activity for a person, check with them if they prefer to have a support person attend with them.
- Be accepting of behaviours that are different to what you are used to - it is important to lead by example and not allow bullying or teasing.
- Some people might feel uncomfortable being in big groups, so make available smaller group activities and individual activities as well when required.
- Ensure that there are frequent rest breaks throughout activities as people may get tired or lose concentration more quickly
- Some people may feel restless and need to walk around to feel calm - you can help by leaving the meeting door open and allowing people to come and go when needed.
- Sometimes medication for mental health conditions can make people gain weight quickly - be aware that people may be sensitive to their changed body image and may need some extra support to join in sport activities
- If a person appears distressed, ensure you assist them in the same way you would people without disabilities (e.g. listening to their concerns or asking if they are ok if they look worried, asking if there is someone you can link them to for help, etc).
- Be flexible and give opportunities for people to make choices - don't assume that people cannot make their own decisions because they have a disability. Some people may also need support or extra time to make decisions.
- Some people may experience changing energy levels from day to day. Be understanding that people may need to take breaks from programs/activities at times, but ensure that you still remain in contact with the person if they are away from the activity for a long time - this can help people to feel welcome to return when they recover.

ANNEX 5

Six tips for planning and running inclusive meetings and events

Ensuring meetings and events are inclusive – not just of people with disabilities, but of a diverse range of people – benefits all attendees and ensures everyone can participate. This document offers six tips to guide you in making community level events and meetings inclusive. These provide a starting-point: given that local contexts and individual needs will vary widely, it is best to ask people with disabilities what supports they require to fully participate.

These tips can be used when conducting any kind of community meeting but are also useful for conducting community outreach or focus group discussions as part of monitoring and evaluation.

1. Identify and specifically invite people with disabilities:

- Ask a local Disabled People's Organisation1 (DPO) or self help group for advice on how to get the message out to people with disabilities in the community and invite them to participate.
- Ensure that all invitations and material used to advertise events show that people with disabilities, the elderly etc are welcome and that the event is accessible.
- Use a variety of methods to advertise the event: for instance, radio as well as newspaper; or contacting the women's group as well as the village head.

2. Find out whether particular assistance or support is required to enable attendance and active participation in your meeting/event:

- Ensure written and verbal invitations ask questions such as the following:
  Do you require any additional support to enable you to participate (like sign language interpreters or accessible transport)? If yes, please let the organisers know so that we can best meet your needs.
- Ensure that it is clear who participants should contact.

3. Ensure promotional and meeting material is accessible:

- Ask how people prefer to access written material (eg: Braille, large print or electronic format) and provide materials in this format wherever possible
- Try and present information in both visual and audio formats. For example if you are showing a picture or a chart, also explain what is in the chart, Likewise, if you are talking, make notes of the key points or show pictures/charts.
- Use signs in large print and clear font to guide people to the venue

4. Choose an accessible venue:

- Check that the venue is physically accessible and includes accessible toilets, wheelchair access (ramps and wide doorways) and good lighting.
- Ask DPO/self help group contacts for local venues which are known to be accessible and easy to get to
- If no accessible venue is available, ask people with disabilities what assistance you can offer to enable them to attend
- Provide transport to meetings if people have difficulty walking and/or local transport options are inaccessible (which is common)
- Reserve seating or space for people with disabilities and the elderly, particularly in crowded venues. Ensure there is space for wheelchair users

5. Use inclusive communication:

- Ask a person what type of communication is best for them – for example, sign language, lip reading, help from a family member. If a person uses sign language it is important to have a sign interpreter.
- Open the meeting by asking participants to speak slowly and use clear language to facilitate translation, interpretation and understanding for people with intellectual disabilities, and those for whom the language spoken is not their native language.
- Encourage participants and translators/interpreters to ask questions as the meeting progresses to ensure discussions are being clearly understood/translated.
- Use clear and non-offensive language. Only refer to someone's disability or impairment where this is directly relevant.
- Repeat key concepts and use practical demonstrations to help understanding.
- Talk directly to people with disabilities rather than to people who might be assisting them.
- Introduce yourself to a person with vision impairment each time before you speak.
- Make sure that only one person speaks at a time in meetings. Encourage people to raise their hands before speaking so it is easier to follow the conversation.

- If a person can lip read, look directly at them, speak clearly and make sure they can see your lips.

6. Facilitate active participation during the meeting/event:

- Ask participants where they would like to be seated, to assist with accessing the area, lip-reading, and the use of sign interpreters or language translation services.
- Ask people with disabilities if they would like to be paired with another person who could help in individual or group activities.
- Some people – with or without disabilities – might feel uncomfortable being in a very big group, so make time for smaller group activities.
- If a person seems like they are not interested or quiet, give them encouragement to participate.
- Treat the person with respect at all times and ask their opinion in discussions.
- Be flexible and give opportunities for people to make a choice - some people might feel worried in situations where they do not have any control

ANNEX 6

Disability Analysis Terms of Reference

1. Project Title:

2. Rationale for conducting the Disability Analysis: *(Please explain the rationale for the Disability Analysis and the reason for conducting it at this particular point in time).*

3. Project Overview and Scope: *(Please identify the high-level problems/disease areas/context and target locations the disability analysis will specifically focus on).*

4. Findings Audience and utilization: *(Who are the various audiences for this disability analysis and who will use the findings and how?).*

5. Information Needs: *(Use the disability analysis framework to identify information needs required to complete the disability analysis).*

6. Data Collection Methodologies: *(Please provide details regarding the available data sources and the proposed methods for data collection and the overall data collection plan).*

- **Data Sources** *(primary and secondary)*
- **Methods for data collection**
- **Data Collection Plan**

7. Data Analysis: *(Please detail the types of data analyses that will be conducted and specify if a consultant will be contracted for this.)*

8. Participants: (*Please list the participants that will need to engage as part of the Disability Analysis and the nature of their involvement, if a person with a disability will not be undertaking the disability analysis please explain why not).*

9. Timeframes, Activities and Deliverables: (*Please detail the timeline for all the activities and deliverables required for this disability analysis).*

Timeline	Activities	Deliverables

10. Budget: *(Please include a detailed budget of activities required to complete the disability analysis, including a specific budget line of between 3-5% for accessibility and reasonable accommodation.)*

11. Reporting and Dissemination of Findings: (*Please detail the plan for dissemination and discussion of findings, for instance in briefings with country teams or discussions with stakeholders. How are the findings going to be implemented into project design).*

12. Consultant Key Selection Criteria: *(If a consultant is going to be engaged please detail the key selection criteria against which you will assess consultant proposals, one key criteria should be that the consultant is a person with a disability).*

ANNEX 7:

Sample indicators for Monitoring and Evaluation of Disability Inclusion

Outcome	Indicator	Target	Means of verification
General Disability inclusion			
People with disabilities are benefiting from project achievements	Number of project beneficiaries that are people with disabilities (broken down by sex and age) % of project beneficiaries that are people with disabilities (broken down by sex and age)	10% of beneficiaries are people with disability	Preferably HMIS but may need to be assessed during baseline as WGSS should be used to determine number of people with disabilities.
People with disabilities are meaningfully participating in community decision making processes	Examples of meaningful participation as reported by people with disabilities		Interview/focus group discussion with people with disabilities during evaluation
Referral mechanisms established to refer people who cannot have their vision corrected to disability specific programs such as CBID/CBR, vocational training, education services.	Examples of partnerships with disability specific organisations Number of referrals to disability specific organisations.		Referral records
Effective working relationships established and nurtured with DPOs	Examples of partnerships with DPOs that have facilitated increased disability inclusion in project activities Examples of outreach to people with disabilities via DPOs. Number of DPOs actively engaged with a project		Interviews with DPOs during evaluation
Country office staff and implementing partners are aware of disability and how to include people with disabilities in eye health programs	Number of awareness sessions or disability inclusion training sessions delivered Number of people who received training in disability awareness and/or inclusion Number of health workers who received training in disability awareness and/or inclusion Number of staff who display increased awareness of disability inclusion		Training records KAP surveys

ANNEX 8

Use of the Washington Group Questions in eye health programs

What is the Washington Group Short Set of Questions on Disability?
The Washington Group Short Set of Questions on Disability (WGSS) is a set of six questions developed by the Washington City Group on Disability Statistics for use in national censuses and other surveys. The questions were designed to identify people who are at greater risk than the general population of participation restrictions because of difficulties in six core domains of functioning. The questions ask how much difficulty a person has performing basic actions (walking, seeing, hearing, cognition, self-care and communication). They were originally designed for use with the general population (over 5 years of age). The Washington Group and UNICEF have prepared a separate module on child functioning for use with children aged 2-17 years.[7]

The questions are not designed to measure all aspects of functional difficulties that people may experience, but rather those domains of functioning which are likely to identify a large majority of people with disabilities. The WGSS also does not aim to identify particular health conditions or diagnostic categories. International testing has shown that the questions are well understood across cultures and produce internationally comparable results.

Box 1: Washington Group Short Set of Questions on Disability

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?

2. Do you have difficulty hearing, even if using a hearing aid?

3. Do you have difficulty walking of climbing steps?

4. Do you have difficulty remembering or concentrating?

5. Do you have difficulty with self care such as washing all over or dressing?

6. Using you usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response categories: no – no difficulty; yes – some difficulty; yes – a lot of difficulty; cannot do at all
For further information, visit http://www.washingtongroup-disability.com/ or view this video.

Why not directly ask if people have a disability?

Asking questions such as “Do you have a disability?” or “Do any family members have a disability?” has been shown to identify relatively low numbers of people with disabilities. In particular, people with mild impairments or people with impairments such as those associated with old age may not self-identify with the term ‘disability’. Stigma and discrimination towards people with disabilities and different cultural understandings of disability also influence self-disclosure of disability.

Key factors to consider in using the WGSS questions

When to use the WGSS in eye health programs

It is not intended that the WGSS would be used routinely for all eye health screening or treatment. Some key places where the use of WGSS is recommended are:

- Advocate for their inclusion in government HMIS with ministries of health

[7] See https://data.unicef.org/topic/child-disability/module-on-child-functioning/

- Use at key stages of the program cycle such as when conducting a baseline, midterm review or end of program evaluation
- Use when conducting a disability analysis or household survey to understand other needs assessment data as it is disaggregated by disability.

Translating and testing the WGSS in a particular country context

It is important that the WGSS questions are translated into the appropriate local language/s for the context. Enumerators should not translate the questions while they are administering the survey: this needs to be done prior to using the WGSS so that translation can be tested. Translations should focus on communicating the meaning, rather than a literal translation of the questions.

Following translation, the questions should be tested to ensure that they are understood and the meaning is conveyed as intended. Cognitive testing is a good method to determine if the questions are understood as intended and if the translation is appropriate.

Guidelines on protocols for translation and testing are available on the Washington Group website: http://www.washingtongroup-disability.com/publications/implementing/

Providing training to survey enumerators

It is important to provide training to people that will be asking the WGSS questions. This training should cover:

- The reasons why the WGSS focuses on 'functioning' as opposed to 'disability', noting that the questions are not focused on recording health conditions or causes of disability, but instead are looking at difficulties that everyone might experience.
- How to appropriately introduce the WGSS questions.
- How to ask the WGSS questions and record participant responses.

Introducing the WGSS questions

You do not need to provide any particular introduction to the WGSS questions before you ask them. However, it is important that you do not introduce them as being questions about disability. Instead, if you need to introduce the questions, use the phrase "The next questions ask about difficulties you may have doing certain activities because of a health problem." Do not include any other screening questions such as "Do you have a disability?" in the survey before asking the WGSS, as this will interfere with (and possibly contaminate) the results.

Asking the WGSS questions

The WGSS questions should be asked at an individual level, rather than a household level as difficulties in functioning are an individual experience. Ideally each individual would be asked the questions directly, however if a single respondent is being asked about household or family members then this is acceptable, as long as they provide responses about each individual. It is important to read out each question one at a time exactly as it is written and provide the response categories. Do not assume you know the answer to a question through observation (e.g. because a person is a wheelchair user) or skip any questions.

If people are not sure what a question means then you can briefly explain further, or provide a picture to assist. Avoid explanations which may have negative connotations, imply disability or change the meaning of the question. Standard responses to questions and aids for administering the questions should be developed prior to doing any interviewing. All responses and materials should be evaluated to be sure that they reflect the question's intent.

Interpreting survey results

Identifying people at risk of disability

The Washington Group recommends that if people answer “Yes – a lot of difficulty” or “Cannot do at all” to at least one question, then they can be recorded as a person with a disability. If the intent is to identify a broader range of people with difficulties functioning (including those with minor functional difficulties) then you can change this cut-off to people that answer “Yes – some difficulty” to at least one (or two) question(s), however this is likely to significantly increase the number of people identified.

Disaggregating other survey data by disability status

If the WGSS questions are included as part of a broader data collection, they can be used as demographic information to disaggregate other survey results (in a similar way to data being disaggregated by gender or geographic location). For example, if a survey also asked about employment status, the WGSS questions can be used to determine the proportion of people with and without disabilities who are currently employed. The questions can also be used with measures of participation in development programs to determine if those with a disability (difficulties functioning) are participating to the same extent as those without disability.

Changing the WGSS

The WGSS questions have been extensively tested in a broad range of countries and should not be changed, unless this is done as the result of cognitive and field testing in a particular country context and is done to clarify the intent of the original question. This should occur very rarely. If there is additional information you would like to investigate through a survey, then it is preferable to add additional questions rather than change the WGSS questions.

Using the WGSS questions in registration processes

Although originally designed for use in large scale surveys, many organisations are now considering using the WGSS in registration processes at services or events, to track participation of people with disabilities or identify people who may require additional follow up or support. It is suggested to apply the WGSS using the same principles as in survey settings.

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[i] Government of South Australia. (2015). *Safeguarding people with disability overarching policy*. Government of South Australia, Department for Communities and Social Inclusion.

[ii] Mactaggart, I., Banks, L. M., Kuper, H., Murthy, G. V. S., Sagar, J., Oye, J., & Polack, S. (2018). Livelihood opportunities amongst adults with and without disabilities in Cameroon and India: A case control study. *PloS one,* 13(4).

[iii] World Health Organization & World Bank. (2011). Chapter 3: General health care In *World report on disability*. Geneva, Switzerland: World Health Organization.