Query title	Review of ASCEND Lot 1 and 2 Health Systems Strengthening strategies, Leaving No One Behind strategies, and Monitoring and Evaluation information.
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Query	1. Are people with disabilities/DPOs properly engaged in ASCEND programme activities? 2. How do we ensure that people with disabilities get the treatment, surgery, care they need? Are there any opportunities for improvement? 3. Is the Health Systems Strengthening strategy/approach designed to build inclusive health systems – are there any missed opportunities or significant gaps (e.g. DPOs involvement)? 4. Does the data disaggregation/evidence gathering and monitoring go far enough and are there any gaps or missed opportunities? 5. Suggest meaningful indicators for measuring disability inclusion within the logframe 6. Key recommendations
Enquirer	**DFID Health Services Team**

1. Are people with disabilities/DPOs properly engaged in ASCEND programme activities?

Inclusion of people with disabilities is a critical component of this programme and the Sightsavers-led 'Leave No One Behind' (LNOB) strategy is an important recognition of this effort. The country-level LNOB strategies demonstrate that there has been consideration for working with people with disabilities and DPOs, **however it is not clear to what extent and how exactly they will be proactively engaged throughout the programme cycle, and the level of engagement varies significantly across countries.**

There appear to be differing levels of understanding and experience on disability inclusion across the country offices. It would be advisable to **build on what disability-related legal frameworks, established methodologies and training and advocacy efforts already exist in each country** (for example the Nigeria LNOB strategy mentions collaborating with the DFID-funded Inclusion Works Programme to enhance disability inclusion capacity), **and prioritise coordination of monitoring, evaluation and learning across countries on disability inclusion**.

People with disabilities are referred to as a homogenous group in the LNOB plans, but to effectively meet their needs, the diversity of experiences of people of different genders, ages, and with different impairment types need to be analysed and addressed regularly, through for example, conducting barrier analyses, providing accessible feedback mechanisms, and monitoring and evaluating disability inclusion together with DPOs and organisations representing women with disabilities.

Work with a range of different DPOs. There is considerable variation in the disability community, and while most of these countries have a national 'umbrella' DPO that speaks on behalf of people with all disabilities, each country will also have several dozen (and in the case of a larger country like Nigeria, several hundred) smaller DPOs for specific populations – women, refugees, local rural DPOs). Not all must be approached and included, but it is important to know that these exist and especially when working at the local level, to plan on consultation and inclusion with these where appropriate.

Aim to reach people with disabilities who are not represented by DPOs. Probably less than 2% of all people with disabilities are members of DPOs. Moreover, many DPOs are urban-based, male-run and often represent older adults. Compounding this, many people with impairments, especially in societies where there is stigma against disabilities, do not consider themselves disabled, therefore they may not be known to, or receptive of, DPO outreach efforts. ASCEND efforts to reach the hardest to reach must consider how to reach these people as well, for example through house-to-house activities, outreach in general clinics, social mobilisation, accessible communication formats, and questions by community health workers, eg. "Thanks for coming into our clinic to pick up these medications. Is there anyone else in your household who may not have gotten these medications, including young children, older adults, someone with a disability?"

Ensure adequate funding is provided to DPOs to engage throughout the programme cycle. It is often assumed that much of the work that DPOs will do, including reaching out and contacting people with disabilities in their communities, will be done at low cost or no cost. No disability group should be paid less than the women's group or INGO working in the same community.

2. **How do we ensure that people with disabilities get the treatment, surgery and care they need? Are there any opportunities for improvement?**

Recognise that there are two groups with different needs: people with pre-existing disabilities at risk of NTDs and people newly disabled through NTDs. When NTDs and disability are discussed there is often an assumption that efforts to prevent NTDs will prevent disability. In fact, there's two groups involved and responses by the medical community need to be more nuanced:

- **People with pre-existing disabilities:** People with a range of pre-existing disabilities are at least as much at risk from NTDs as all other members of the community and efforts to reach these individuals are part of this project. In some cases health professionals believe that NTD medications are counter-indicated for people with pre-existing disabilities, and more commonly it is believed in many cultures that people with disabilities are not at risk of NTDs. Local traditional beliefs and medical practices regarding the interface between people with pre-existing disabilities and NTDs should be considered and addressed in any outreach programme.

- **People disabled by NTDs:** people disabled by NTDs will need treatment, surgery and clinical care. But where disability is irreversible, they will also need to live successfully with a disability. This is where collaboration with DPOs could be a very important component of ASCEND. People and groups who have lived with disability over time will have a range of ideas, coping strategies and support networks that the newly disabled individual would benefit from. And they would know the national and local laws, programmes and social support mechanisms upon which newly disabled individuals and their families can call.

Provide information materials on disability inclusion to all stakeholders across the programme. Health care workers, community workers, social workers and others involved in ASCEND will need information and training on how to best provide treatment, surgery and care for people with disabilities as well as how to discuss and inform people with disabilities about these services. Working with DPOs and other community groups will be essential. Few clinicians or outreach workers have had much training on *working with* people with disabilities. This is different to knowing about disabling health conditions. In the UK, most medical or public health students will only get one session in their training where a person with a disability teaches them. Working with DPOs to train health care workers has been shown to be a very effective way of ensuring improved inclusion of disability in a wide range of health practice and health promotion efforts.

Conduct assessments on accessibility of health facilities. This is mentioned in a few of the LNOB strategies. There are a number of very good guidelines and checklists regarding accessibility of health care facilities for people with disabilities. ASCEND should choose one of these and make it the 'standard' across the entire project, adapting it to be relevant for NTDs. Wherever possible, DPOs should be asked to participate or lead such assessments of accessibility. Accessibility for health care facilities is needed for people with a range of disabilities. It is not just about putting a ramp into a clinic, it is also about accessible and affordable transportation, attitudes and treatment towards people with disabilities attending the clinic by staff and by other patients, long wait times (especially if there's no place to sit or no place for a disabled person to use the bathroom), and other factors.

3. **Is the Health Systems Strengthening strategy/approach designed to build inclusive health systems – are there any missed opportunities or significant gaps (e.g. DPOs involvement)?**

There is an opportunity to strengthen implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) through the programme, which has not been noted in the programme documents. All countries involved have ratified the CRPD, however there are likely to be opportunities to strengthen its implementation across policies, including universal health policies.

Engage with government to incorporate information on NTDs in existing disability inclusion training. In several country plans there is mention of engaging with government on disability rights and advocacy. There may already be systems in place for training government officials at both national and regional/local levels. NTD related information could be incorporated into these on-going training efforts. Where no disability training is available ASCEND should look into ways it can partner with other health and development initiatives to train government and ministry staff to avoid duplication of efforts.

Review disability inclusion in public health funding and budgets. A contribution that ASCEND could make in some countries is to review budgeting and funding streams for public health in general or NTD related health in particular, to ensure disability inclusion and outreach. Reviewing where and how disability is budgeted (or often not budgeted) in health systems is a practical way of strengthening them.

ASCEND could also **coordinate with other programmes to combine efforts on disability inclusion.** For example, ASCEND is working in the same space as USAID's ACT/East project and it is a missed opportunity not to think about ways in which ASCEND can coordinate disability efforts with USAID.

4. **Does the data disaggregation/evidence gathering, and monitoring go far enough and are there any gaps or missed opportunities?**

The data disaggregation/evidence gathering, and monitoring discussed in the current plans do not go far enough. Only one country is collecting disability-disaggregated data, and several LNOB strategies note the need for further guidance or training on collecting disability-disaggregated data.

All countries need to disaggregate data by disability status using the Washington Ggroup Questions. Support and advice on how to use the WGQs is freely available from the Washington Group, therefore the programme could link to this resource to ensure sustainability. The implementing organisations can also work with government and service providers to integrate the WGQs into data collected by health services, with particular attention to NTDs.
Build on data already available. Currently the Washington Group Short Set is being used by

National Statistics Offices in Chad, Cote d'Ivoire, Guinea, Niger, and Sierra Leone. Data on disability is now routinely collected by UN agencies, academics, development projects and NGO funded applied health efforts and research projects, with most of these groups also using the WGQs These should be reviewed to see what ASCEND can build on. Over the course of this programme, ASCEND should regularly be monitoring both internationally and in-country what new disability data collection efforts are underway (for example for through SDGs reporting) as it may be helpful to use this data rather than duplicating efforts.

Use mixed methods. In the programme documents it is stated that quantitative data on disability will be collected and where quantitative data shows gaps, qualitative data will be used. This is important but qualitative data needs to be integrated with the quantitative data and analysed and then the findings need to be integrated into ongoing outreach efforts in order to provide insight into what ASCEND can do to improve disability inclusion.

5. Suggest meaningful indicators for measuring disability inclusion within the logframe

The following indicators could be used if the WGQs are used to collect disability-disaggregated data, and if DPOs are involved in monitoring and evaluation:

% of people with disabilities (disaggregated by sex and age) who report that they have received information about or are aware of the NTDs addressed in the programme and how to access NTD services **AND** qualitative data on what they know and how they were informed.
OR
% of communications on NTDs and access to health services that are disseminated in accessible formats (a combination of visual and audio formats, using simple language), **AND** qualitative data on whether people with disabilities found these to be accessible.

% of people with disabilities (disaggregated by sex and age) who report that medications/MDA/MMDP/surgery for NTDs is accessible to them, **AND** qualitative data on which barriers were/were not addressed and how.
OR
# of MDA/MMDP/surgeries accessed by people with disabilities through the programme **AND** qualitative data on which barriers were addressed to enable their access.

% of health care workers and CDDs (disaggregated by sex, age and disability) who report that their understanding of disability inclusion has improved **AND** qualitative data on how their knowledge, attitudes and practices have changed.

6. Recommendations

Highly recommended:

- **Disability must be specifically identified and discussed in all 12 national plans.** Few of the national plans provide detailed reference to how disability issues will be approached and included. Several make references to disability but lack specificity and more than half do not mention disability at all. In the LNOB strategies there are broad references to 'marginalised groups', but the programme needs to work with DPOs to analyse and address the specific barriers faced by people with disabilities and how they will address them. Please see Annex A for a mapping of where there are gaps and areas to be strengthened across the national plans.

- **Enhance coordination within and between countries on knowledge and experience on disability inclusion.** The level of knowledge and experience on disability inclusion appears to differ significantly across countries. Both quantitative and qualitative collection of data is

important. A more formal framework of knowledge collection and sharing should be in place now. Sightsavers teams working on this programme should collaborate with colleagues working on disability inclusion advocacy to strengthen their LNOB plans. It is particularly important to make definite and detailed plans for coordination and sharing of knowledge on disability inclusion between countries to ensure consistency across the entire programme. This would be significant not only for NTDs, but also for identification of successful ways to reach people with disabilities on broader public health initiatives.

- **Map existing national disability rights and disability inclusion efforts, information and research.** A review and mapping of existing national disability laws, policies and literature on disability inclusion must be made in each country, if not already available through other Sightsavers programmes. All 12 countries have passed and ratified the CRPD, which requires national laws and policies to be aligned with the CRPD. That doesn't mean that these laws and policies are effectively being implemented in all cases, therefore ASCEND efforts could build sustainable implementation within universal/national health systems. This may also expedite efforts to bring in national Ministries/ DPOs and other components of civil society already working on disability issues.

- **Work with a diverse range of people with disabilities and their representative organisations.** The programme must identify DPOs and advocacy groups that work and speak on behalf of sub-groups within the disability community, as well as umbrella organisations, and adequately fund them to engage throughout the programme cycle. Collaboration between different representative organisations, eg. women's rights organisations (WROs) and DPOs, refugee organisations and DPOs, must also be envisioned and planned for.

- **Strengthen plans for disability data collection and analysis.** Use of the WGQs to disaggregate census/ survey data is strongly recommended for ASCEND. It is an easy to use methodology, with freely available support and guidance available online from the Washington Group. The National Statistics Offices in 5 of the 13 countries involved are already collecting disability data, as are universities, NGOs and UN bodies in many of these countries, therefore existing data could also be drawn upon.

- **Coordinate disability inclusion between ASCEND and USAID ACT/EAST.** This project is being run in tandem with a major USAID NTD project, ACT EAST, (and there appears to be an ACT West project as well). The programmes could develop a coordinated disability framework. Currently USAID ACT/East appears not to have any disability component in their work. I would recommend further discussions with USAID about this.

Advised:

- **Take a twin track approach to disability inclusion.** The twin-track approach in which people with disabilities are both included in general NTD outreach efforts and targeted by disability-specific outreach efforts needs to be more explicitly cited in the LNOB plans. In some of the discussion it is implicit, for example many plans mention house-to-house MDA programmes that might reach people who are unable to get to central locations. But it is helpful to explicitly explain how the programme will proactively seek participation of people with disabilities.

- **Plan accessible communication**. Accessible communication strategies are mentioned for about half the countries. Communications is a key concern with disabled populations and certain subgroups face specific challenges. For example, radio and megaphones will not reach people who are deaf or hard of hearing. Print, billboards, and postcards will not reach many

who have vision impairments. Simple messages that are regularly repeated are also often required for people with intellectual disabilities and people with disabilities who have been excluded from education. A balanced communication strategy that combines different formats would be best, and only about half the countries appear to be using such a combined strategy.

- **Regularly monitor and evaluate how effectively people with disabilities are being reached.** This should not only include quantitative survey data but also qualitative feedback from DPOs and people with disabilities on how they feel ASCEND is including (or excluding) them. Many of the LNOB strategies mentioned that feedback has not been prioritised to date but will be strengthened. It is important that these mechanisms are accessible to people with disabilities and feedback from people with disabilities is regularly and proactively sought.

- **Include DPOs in a range of activities, including social mobilisation**. Only one country, Nigeria, specifically mentions involving DPOs in social mobilisation activities. DPOs are strategically important and they need to be included in the full range of ASCEND activities. Most of the countries reference DPOs but they don't say how they will be involved, and DPOs are increasingly sensitive to major public health projects coming in, mining them for information and then leaving. Open and clear discussions with DPOs is vital to establish a viable working relationship. A cornerstone of the global disability rights movement is 'Nothing about us without us.' For DPOs, this means that any projects need to include them at the outset and throughout the programme cycle – bringing them in later on will be noted and not appreciated.

- **Provide information materials on disability inclusion to health care workers and CDDs.** Less than half of the LNOB plans mention providing information materials on disability to health workers. This may be implied/assumed in other training activities but it would help to make this explicit. This should be coordinated with existing disability inclusion programmes rather than attempting to reinvent the wheel. ASCEND can also bring an NTD perspective to these wider programmes.

- **Train people with disabilities for jobs (CDDs and other roles) in the programme.** Globally, and in the 12 countries in this project, the major issues facing people with disabilities are poverty and unemployment. Access to education and job training is a major concern for people with disabilities. ASCEND should make it a priority to provide qualified local people with disabilities (in both in-country and international project positions) with jobs, which may also facilitate greater inclusion of people with disabilities in programme activities.

- **Increase in-country capacity to address disability and NTDs by strengthening local research and evaluation capacity.** Many of the activities throughout this project have significant evaluation components as well as training and capacity building at the local and national levels. Research, evaluation, and training are important components of Health Systems Strengthening. In-country universities, think tanks and advocacy groups should be called on to partner or lead in many of these activities with the expectation that they are or will become able to undertake this role as independent resources supporting Health Systems in general, and disability-inclusion within health care.

- **Address inclusive WASH for people with disabilities.** Access to WASH is referenced several times in programme documents but not followed up on with any specificity in the LNOB plans. There has been a lot of work on disability and WASH issues including a body of excellent guidelines and check lists from UNICEF, Loughborough University, the London School of Hygiene and Tropical Medicine and especially from WATERAID, which is listed as an implementing organisation in several of the participating countries.

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