



Learning on disability stigma reduction

Concepts of stigma, implementing activities to reduce stigma and demonstrating change in the Disability Inclusive Development – Inclusive Futures programme

27 December 2024



## Contents

1.	Acronyms.....	2
2.	Executive summary.....	3
2.1.	Methodology .....	3
2.2.	Background.....	3
2.3.	Summary of Key Findings.....	4
3.	Background and introduction .....	8
3.1.	Learning questions (LQs) .....	10
4.	Methods .....	10
4.1.	Consortium Validation Group .....	10
4.2.	Theoretical framing .....	11
4.3.	Phase 1: March-May 2024. ....	13
4.4.	Data collection and analysis.....	17
4.5.	Ethics .....	19
4.6.	Participation of people with disabilities .....	19
5.	Findings LQ1 .....	20
5.1.	The language and framing of stigma .....	20
5.2.	Project design.....	22
5.3.	Summary Key Learning Points .....	27
5.4.	Recommendations .....	28
6.	Findings LQ2 .....	29
6.1.	Inclusion Champions .....	29
6.2.	Individual level .....	31
6.3.	Family level .....	33
6.4.	Community level.....	36
6.5.	Structural stigma .....	39
6.6.	Participation of people with disabilities and OPDs.....	41
6.7.	Summary Key learning points .....	43
6.8.	Recommendations .....	45
7.	Findings Cross-cutting issues .....	46
7.1.	Intersectionality.....	46
7.2.	Safeguarding.....	50
8.	Findings – Learning Question 3 .....	54
8.1.	Tools and approaches.....	54

8.2. Key learning points .....	57
8.3. Recommendations .....	58
9. Conclusions .....	59
10. Strengths and Limitations .....	59
11. Appendices .....	60
11.1. Appendix 1: Validation group members .....	60
11.2. Appendix 2: Sample interview guide .....	61
11.3. Appendix 3: Example topic guides: Global, DIFs/inclusions champions/Programme staff .....	64
12. Bibliography .....	69

## List of Figures and Tables

Figure 1: Theoretical model of stigma .....	12
Figure 2: Socio-ecological framework .....	13
Photo 1: Image from an FGD with female DIFs in Kenya, September 2024 .....	15
Photo 2: Flipchart from OPD FGD .....	15
Photo 3: Male ICs in Nigeria discussing their role .....	29
Table 1: Sample of projects for the primary research .....	16
Table 2: Summary characteristics of sample .....	17
Table 3: Overview interview guides .....	18

## Acknowledgements

We are particularly grateful to all the participants who gave their valuable time to make this learning review a success; staff, Organisations of Persons with Disabilities (OPD) members, Inclusion Champions, and beneficiaries.

We would also like to thank the members of the validation group for their invaluable time in commenting on this learning piece at various stages of the process. For the full membership see Appendix 11.1.

## 1. Acronyms

---

ADD	Action on Disability and Development
BRAC	Bangladesh Rural Advancement Committee
DID	Disability Inclusive Development
DIDIF	Disability Inclusive Development and Inclusive Futures
DIFS	Disability Inclusion Facilitators
FGD	Focus Group Discussion
FMT	Fund Management Team
HI	Humanity & Inclusion
IDI	In-Depth Interview
KI	Key Informant
KII	Key Informant Interview
LQ	Learning Question
MEL	Monitoring, Evaluation, and Learning
OPD	Organisations of Persons with Disabilities
SBC	Social and Behaviour Change
SI	Sense International
TO	Task Order
UNICEF	United Nations International Children's Emergency Fund

## 2. Executive summary

---

‘Don’t under-estimate stigma and discrimination. It is putting up barriers and holding back people from accessing services.’ (Key Informant Interview, Global level)

The Disability Inclusive Development - Inclusive Futures (DIDIF) programme is an eight-year, multi-country programme, delivered by a consortium of ten organisations in Bangladesh, Kenya, Nepal, Nigeria, Tanzania, and Uganda. It is funded by UK aid.

In all of these countries, as in many other parts of the world, stigma, and discrimination, including negative attitudes and stereotypes, are significant barriers to disability inclusion, which prevent people with disabilities from accessing health and education services and participating in economic and political spaces. Within the DIDIF programme, stigma was addressed as both a stand-alone theme - a reduction in negative stereotyping and discrimination - and as a cross-cutting issue within health, education, and livelihoods projects.

This learning piece examines disability-related stigma reduction in the DIDIF programme. It aims to explore how development programmes can effectively design, implement, and monitor interventions to reduce disability-related stigma, negative social attitudes, and discrimination. It explores practical learning and experiences about what works, what doesn’t and why. The goal is to provide valuable insights for other development actors and donors based on learning and experience from DIDIF projects.

### 2.1. Methodology

A mixed methods design was adopted, combining a review of programme documentation with qualitative research. This was conducted in two distinct phases. In **Phase 1**: A validation group, composed of representatives from the DIDIF consortium, was established to guide the overall review process. A rapid desk review was conducted of documentation from 14 projects across all thematic areas in all DIDIF countries. This showed that there are a variety of approaches to stigma reduction in the portfolio, but it is not always well-documented and we needed additional information to enrich our learning. In **Phase 2**: Primary qualitative research was conducted in three countries: Nigeria, Bangladesh, and Kenya. In total 22 Key Informant interviews (KIIs) and 7 Focus Group Discussions (FGDs) were conducted, with a total of 64 participants, drawn from consortium partner staff, local project inclusion champions, Organisations of Persons with Disabilities (OPD) members, and beneficiaries.

### 2.2. Background

The concept of stigma is a complex one, and the language and terms used to describe it also varies considerably. For this learning paper, stigma is described as resulting from labelling, stereotyping, and prejudice which together lead to status loss and discrimination for a group or an individual. Put simply, ‘Stigmatisation is a social process that leads to the marginalisation of individuals or groups’ [1].

Key drivers that contribute to stigma include a lack of understanding and awareness about disability, often combined with traditional beliefs, stereotypes and attitudes. Good quality global evidence on what works to reduce disability-related stigma remains scarce [2-4] and Sightsavers' [systematic review](#) [5] also highlighted the significant gaps in research on this topic. This learning review aims to help fill that gap.

### 2.3. Summary of Key Findings

#### LQ1: How can development programmes understand and address disability-related stigma, negative stereotyping, and discrimination, in the design and planning phase?

##### In terms of the language and framing of stigma we found:

- Within DIDIF projects, there was often no unified way to talk about stigma across different types of stakeholders and even within the same organisation. There can be differing perceptions of what stigma is. Our projects found it more useful to illustrate stigma with concrete examples of what it means in practice within that culture and context, using local language and terms.
- There can be inconsistent framing of stigma across stakeholders, with more emphasis on describing social stigma, that is, changing the attitudes and behaviours of others. There is understanding that it is important to address internalised stigma, that is feelings of low confidence, poor self-worth and being isolated, but it is not always given sufficient attention. There also needs to be an examination of the underlying drivers and root causes of stigma.
- Overall feedback was that the proposed framing of stigma, which encompasses social, internalised, structural, and stigma by association, is helpful. But there are also gaps in understanding the role of stigma by association and structural stigma.

*'This categorisation [of stigma] is 'food for thought' – the idea of self-stigma is new to me. We focussed on other people. But it is useful to think about addressing self-stigma and building self-esteem – this could be better incorporated into future programmes.'* (KII partner staff, Nigeria)

##### In terms of project design, we found:

- There needs to be more intentional design of stigma reduction approaches; this can be lost if stigma is a cross-cutting issue. If stigma reduction is not an outcome, and no measures are required, then there is a risk that it is given less attention at the design phase.

*'Stigma was not a primary outcome of this project. We were looking at things more holistically and not specifically looking at stigma. We focussed more on the outcomes.... along the way certain things were dropped unintentionally on stigma.'* (KII partner staff, Nigeria)

- Timely research, which engages with people with disabilities, is identified as key to evidence-based planning for stigma reduction. Ideally it needs to be conducted at an early stage so that it can feed into project design or inception.

- OPDs provide invaluable knowledge and life experience which can be essential for designing stigma reduction approaches, but it should not be assumed that they have all the expertise. They might require stigma reduction technical expertise at the planning stage. And it is also important to ensure that under-represented groups are included, as much as possible.
- Social behaviour change (SBC) can offer a more systematic and evidence-based approach to design for stigma reduction. It emphasises that changing stigma is about understanding norms, changing behaviours (not just attitudes) and goes beyond awareness raising.

### Learning Question 2: How can development programmes deliver effective interventions to reduce disability-related stigma, negative stereotyping, and discrimination?

#### We learnt some broad lessons from DIDIF projects:

- A multi-faceted approach is needed for stigma reduction, with different tactics at different levels of society.
- There is a tendency to focus on ‘educating’ for change, with lots of training courses and awareness raising. These can be valuable, but stigma experienced in a family and community over a lifetime, is unlikely to be impacted by one-off awareness training sessions and short-term interventions.
- The participation of people with disabilities is critical at all stages of project design and implementation. The value of direct engagement between people with and without disabilities in the delivery of stigma work is repeatedly raised as important. People with disabilities bring their lived experience to these dialogues and activities and come from the same communities as the other people participating, so can challenge commonly held stereotypes.

‘Because it was persons with disability that served as facilitators for the training of service providers, it assisted in addressing the community level stigma by showing that persons with disability were also capable [of] impacting knowledge [and] had capacity and potential.’ (FGD male ICs Nigeria)

- Inclusion Champions - most commonly people with disabilities and local leaders - can help address different types of stigma. Their roles are varied and can address different types of stigma through a combination of training and advocacy, as well as engagement with families and peer-to-peer support.
- Advocating for reasonable accommodation<sup>1</sup> is essential to enable people with disabilities to perform their roles effectively. Reasonable accommodation is a key aspect of organisational change initiatives promoted through the DIDIF projects and has potential for further enhancement.

---

<sup>1</sup> Reasonable accommodation is “...necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.” (UNCRPD 2006, Article 2.9)

- There is recognition that changing deep-seated beliefs and social norms takes time and therefore require repeated activities over a prolonged time period.

### **What we found through working with people with disabilities:**

- The empowerment of people with disabilities is both an outcome and a key mechanism to address stigma. People with disabilities, with stronger agency, can contribute to changing the narrative that results from stigma. That said, it is important to understand how social and political power impact empowerment.
- A common approach to support empowerment is providing training for people with disabilities to increase knowledge and skills (for example on self-advocacy or business skills). Increasing knowledge and skills appears to contribute to overall improvement in self-esteem and confidence. Whilst these trainings do not explicitly address stigma, reducing stigma is seen as a by-product. However, training alone is unlikely to shift a lifetime of internalised stigma, and there are calls for ongoing training and support to be more embedded and also to include a mental health component.

'[Self-advocacy training] helps micro entrepreneurs realise who they are, how they can advocate for themselves to build their self-esteem. It [business training] also gives them opportunity to be empowered to do business and thus change the narrative of how the society looks at them. The society portrays persons with disability as people who cannot do business.' (KII partner staff, Kenya)

- Peer support is another valuable tool for addressing internalised stigma and stigma by association. This can be one-to-one support and/or a support group, both of which can provide a trusted environment for sharing of experiences and psychosocial support; this can help to address internalised stigma. Support groups for caregivers can also address the stigma by association experienced.
- People with disabilities participating in the delivery of training to others, such as to health professionals, is also an empowering process. People with disabilities can draw on lived experience, provide concrete culturally relevant examples, and can be role models.

### **What we found through working with families and communities:**

- The family environment is often the starting point for internalised stigma with an early impact on a child's self-belief and self-esteem, as well as a significant barrier to accessing services, like health and education.

'Stigmatisation is strongest at the family level, because if the family does not value the child with disability, the community too would not value him/her.' (FGD Female ICs, Nigeria)

- It is important to identify and engage people with power, for example, traditional and religious leaders, and other people with influence. These people in power will have a voice in the community, can command respect and be listened to, can open doors, and help create an environment where stigma can be talked about and challenged.



‘It also can’t all be left to contact through OPDs. You need to consider power and allies. For example, in the classroom teachers have power, and when they change then the children change.’ (KII partner staff, Global)

- A targeted interpersonal approach, which creates opportunities for dialogue with families, people with disabilities and community leaders is important; this can be about informing, but also answering queries and addressing fears.
- Community and radio drama can operate at different levels, especially reaching a wide range of society to address stigma. It’s important to move beyond awareness raising; creating opportunities for dialogue is key for challenging and changing stigmatising views.

### **What we found through working at a structural level:**

- There were many examples of local advocacy being conducted in DIDIF projects, but direct links to reducing stigma were not always explicit. This may be because it is seen as an indirect approach, with longer term impact.
- Placing people with disabilities in different roles within organisations can play an important role in changing attitudes and shifting organisational culture.
- Engaging in advocacy to ensure disability laws and policies are implemented is pivotal to changing societal attitudes and behaviour towards people with disabilities. Both the public and people with disabilities require more awareness of laws, but awareness alone isn’t sufficient and stronger enforcement of laws is required.

### **Cross-cutting issues – intersectionality and safeguarding:**

- The type of disability a person has, their gender and whether they live in a rural area, are key characteristics which intersect to shape the experience of disability-related stigma. Other factors include socio-economic status, age, ethnicity, and religion. For example, stigma in rural areas is compounded by lack of access to services, including treatment and support, lower levels of awareness on disability issues, with challenges around access to information, long distances, and limited accessible transport. Women with disabilities can experience a double stigma, linked with gender stereotypes and concerns about safeguarding.

‘In urban areas you can access more support, for example for people with intellectual disabilities – but a poor family in a rural area will not get support for a person with intellectual disability. There will be less awareness about disability in the rural areas and less access to assistive devices.’ (KII partner staff, Bangladesh)

- DIDIF projects adopted some tailored approaches to address issues of intersectionality, for example, the provision of a home care education package for people with complex disabilities, including those who are deaf-blind, and their families.
- Stigma and safeguarding are two distinct concepts, but they are intrinsically linked and often must be addressed in tandem to be most effective. Bullying and gender-based violence are still pervasive and social stigma can be a key driver of these behaviours, and at the same time a barrier to reporting abuse. For example, local reporting and

response systems may not be seen as relevant to people with disabilities. Investing in strengthening local reporting and response systems and services so they are disability inclusive, has to go in tandem with mitigating stigma.

*‘When one woman attempted to discuss her plight with family members, she was met with dismissal. Her relatives asserted that since she had chosen her husband, it was her responsibility to endure the associated hardships. This stance underscores the societal stigma faced by women with disabilities, further entrenching their isolation and suffering.’ (FGD female ICs Nigeria)*

### **Learning Question 3: How can development programmes demonstrate change in disability-related stigma, negative stereotyping, and discrimination?**

#### **What we learnt about assessing and measuring stigma:**

- Most of our projects selected not to measure stigma. At the same time measurement of stigma was seen as challenging. Several tools and approaches were used, but we also received requests for more support and guidance in this area. Research is embedded into some projects, such as Randomised Control Trial (RCTs), alongside mid-term and final evaluations.
- Our projects held regular learning meetings to inform learning about what was working and what wasn't. However, as stigma was not selected as an outcome, the learning here is limited. It was less clear how project learning translated into changes in stigma reduction approaches, and this was beyond the scope of this review. There needs to be a strengthened approach to learning around stigma and ensure projects build in adequate space for measurement and for feedback to be put into practice.
- Given the complexity of stigma, and the fact that shifting social norms and changing beliefs takes time, change should be measured and understood over time.

In conclusion, this review examines three key learning questions on stigma in the DIDIF programme, focussing on the language and framing of stigma, lessons from implementation and approaches to measuring change. Summary key learning points are presented in the executive summary and a broad range of recommendations are provided in the report after each Learning Question.

## **3. Background and introduction**

---

The Disability Inclusive Development Inclusive Futures (DIDIF) programme is an eight-year, multi-country programme, delivered by a consortium. The consortium members are: ADD, BBC Media Action, BRAC, Humanity and Inclusion, International Development Studies (IDS), International Disability Alliance, Light for the World, Sense International, Sightsavers, and Social Development Direct. The consortium is led by Sightsavers and the International Disability Alliance, and hereafter in this learning document it is referred to as ‘The Consortium’. For the purpose of this report, we talk about consortium partners as ‘partners’, who may work at a global or national level. Other organisations that they work with in-country are described as local partners.

DIDIF operates in Bangladesh, Kenya, Nepal, Nigeria, Tanzania, and Uganda. It designs and implements projects to demonstrate what works and what does not work, to improve outcomes for people with disabilities in four thematic areas: increased equity in access to, and outcomes from, health and education services, jobs, and livelihoods activities, as well as a reduction in negative stereotyping and discrimination. See the following website for further detail: <https://inclusivefutures.org/>. Stigma was addressed as both a stand-alone theme (reduction in negative stereotyping and discrimination) and as a cross-cutting issue within health, education, and livelihoods projects. Furthermore, DIDIF's mandate is also to generate research, evidence, and learning, to address gaps in disability inclusion; this was a key motivation for this important learning piece on stigma.

The concept of stigma is a complex one, and the language and terms used to describe it also varies considerably. For the purposes of clarity in this learning paper, stigma is described as resulting from labelling, stereotyping, and prejudice which combine to lead to status loss and discrimination for a group or an individual. Put simply, 'Stigmatisation is a social process that leads to the marginalisation of individuals or groups' [1].

An overview of external evidence on stigma in the DIDIF countries was detailed in the report 'Disability stigma in the Disability Inclusive DID programme countries: an overview of the evidence' [6]. This highlights that stigma, discrimination, exclusion, and neglect of persons with disabilities is still prevalent. Key drivers that contribute to stigma include a lack of understanding and awareness about disability, often combined with traditional beliefs and attitudes. There can also be fear, with a belief that the disability can be contagious, for example to an unborn child; resulting in isolation and exclusion. Stigmatisation can also occur because people with disabilities are seen as a burden, with the stereotype that they are unable to contribute to the community or family. Such low expectations can also be a barrier for parents sending children to school. Stigma can also impact on access to health services, including sexual and reproductive health services. For example, beliefs about the sexuality of persons with disabilities, viewing them as unworthy to be in relationships, or as asexual/hypersexual, often resulting in abuse in various forms. Discriminatory policies and laws can then further reinforce stigma.

Good quality global evidence on what works to reduce disability-related stigma remains scarce [2-4] and Sightsavers [systematic review](#) [5] also highlighted the significant gaps in research on this topic of disability related stigma and discrimination.

The aim of this learning review is therefore to help address that gap, and explore how development programmes can effectively design, implement, and monitor interventions to reduce disability-related stigma, negative social attitudes, and discrimination. This structured learning piece responds to the DIDIF [Theory of Change's](#) cross cutting area: 'Disability-related negative stereotyping and discrimination are effectively challenged at all levels' which contributes to all three domains of change. The collection of good quality evidence on what works to reduce disability-related stigma remains scarce, and this learning piece will contribute to learning and evidence from DIDIF projects.

This is a detailed technical report targeted at a wide range of development actors, including donors, who may be directly or indirectly addressing stigma within their programmes. A learning product summarising the key learning points of the technical report will be developed in early 2025 and be available on the Inclusive Futures website.

### 3.1. Learning questions (LQs)

#### **Learning Question 1: How can development programmes understand and address disability-related stigma, negative stereotyping, and discrimination, in the design and planning phase?**

- How has disability-related stigma, negative stereotyping, and/or discrimination been understood and articulated in the DIDIF programme and projects?
- How understanding of stigma, negative stereotyping, and discrimination affected the design of and planning of approaches in DIDIF projects?
- What recommendations can be given for how development programmes can better understand and articulate disability stigma, negative stereotyping, and discrimination in their context?

#### **Learning Question 2: How can development programmes deliver effective interventions to reduce disability-related stigma, negative stereotyping, and discrimination?**

- What approaches and types of interventions have DIDIF projects delivered to reduce disability-related stigma? What types of stigma have been addressed? What different levels of interventions?
- How have DIDIF projects involved people with disabilities in the design and delivery of interventions to reduce disability-related stigma?
- How have these approaches and interventions been received by project stakeholders? What has been seen to work well/not work well and how does this add value?

#### **Learning Question 3: How can development programmes demonstrate change in disability-related stigma, negative stereotyping, and discrimination?**

- What tools or approaches have DIDIF projects used to demonstrate or measure changes in disability-related stigma, negative stereotyping, and discrimination?
- What do the tools and approaches tell us about journey that DIDIF projects have made in reducing disability-related stigma (if that was their intention)?
- How appropriate, practical, and replicable are those tools at demonstrating change in disability-related stigma, negative stereotyping, and discrimination?

## 4. Methods

---

Mixed methods, combining a desk review and qualitative research, were used for this learning piece. There were two distinct phases to the process, which are further detailed below.

### 4.1. Consortium Validation Group

A validation group was established to inform and guide this learning review. This group consisted of 31 global and national team members. The group met three times during the learning process: 1) to inform the drafting and refinement of LQs, 2) to share and validate

findings from the desk review, and finally 3) to discuss findings from the primary research and inform the learning products.

For full details of the membership of the validation group see [Appendix 11.1](#).

## 4.2. Theoretical framing

There are numerous theoretical frameworks to describe stigma and it is beyond the scope of this review to explore them. We propose a framing of stigma based on the first phase of work, which included a discussion with the consortium validation group. [See Figure 1](#). This framing builds on the work of Brakel [7] Stangl et al [8], Corrigan and Bink [9], Weiss [10], BRAC [11] and UNICEF [12]. In our model a distinction is made between the following different dimensions of stigma:

- **Internalised stigma**, sometimes called self-stigma, which describes the internalised oppression that people with disabilities can feel. This can lead to feelings of low self-esteem and shame, frequently resulting in self-exclusion and isolation which can serve to exacerbate stigma.
- **Social or public stigma** which describes negative attitudes and prejudice held by people in society, including negative stereotypes of people with disabilities. These negative attitudes are often driven by beliefs about disability, shaped by the culture and context. Examples of typical negative stereotypes are that people with disabilities are helpless, cannot work, and are unable to make their own decisions.
- **Structural stigma** refers to systemic issues, such as laws, policies, organisational systems. We include here structural stigma within the media which occurs through the promotion of stigmatising frames of disability.
- **Stigma by association**, which describes when stigma extends to others closely connected to a person with a disability, such as family members. This is sometimes called affiliate stigma [13].
- Discriminatory<sup>2</sup> actions result and contribute to these different types of stigma.

---

<sup>2</sup> Discriminatory actions can be 'enacted' stigma by people who stigmatise and 'experienced stigma' by those experience the action.

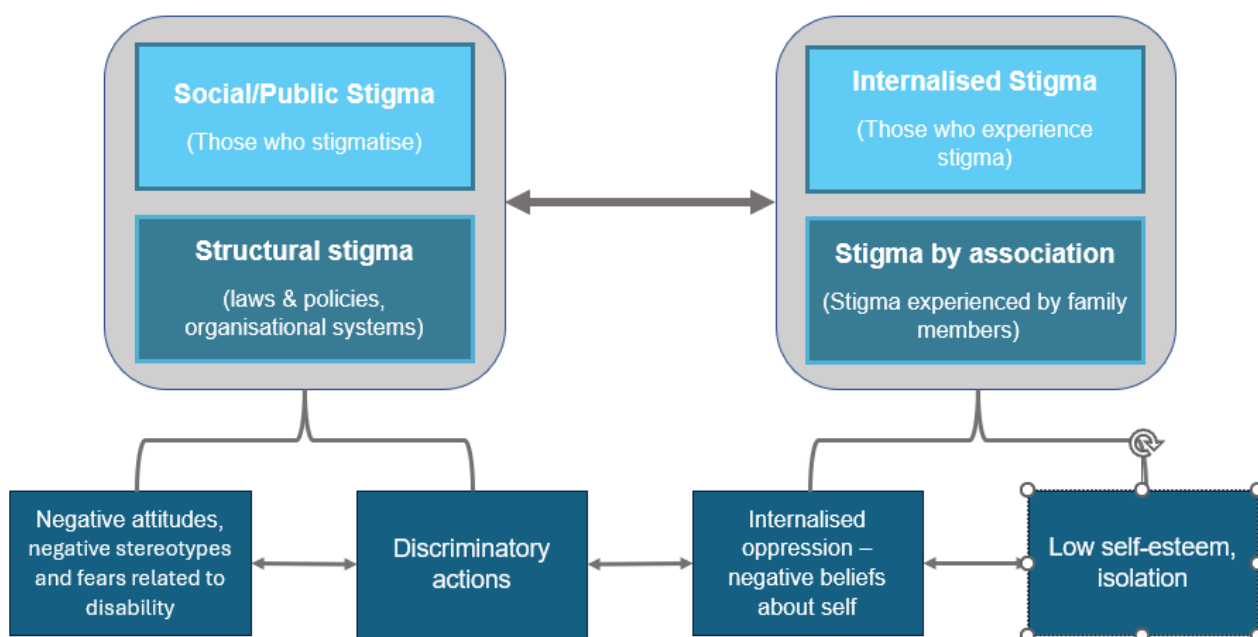


Figure 1: Theoretical model of stigma<sup>3</sup>

The proposed conceptual model illustrates that the different types of stigma interact and can compound or mitigate the level of stigma. It separates out ‘those who stigmatise’ (social stigma), other sources of stigma (structural forms of stigma), and ‘those who experience stigma’ (internalised and stigma by association). It also summarises how these manifest in everyday lives: beliefs and attitudes can result in discriminatory actions, which lead to negative beliefs about self, translating into low self-esteem, isolation, and poor mental health. Whilst we distinguish these ‘types’ of stigma, they are not in silos, reflected by the arrows. Overall, this can then result in limited participation, poorer quality of life and mental health, and reduced access to care and education.

<sup>3</sup> The model has been adapted and modified as we gathered feedback

In addition, we adopted a socio-ecological framework [17] to explore stigma reduction approaches at different levels of individual, family, school, the business sector, community, as well as wider policy-level and institutional change, including reflections on the relationships between those layers. See [Figure 2](#).

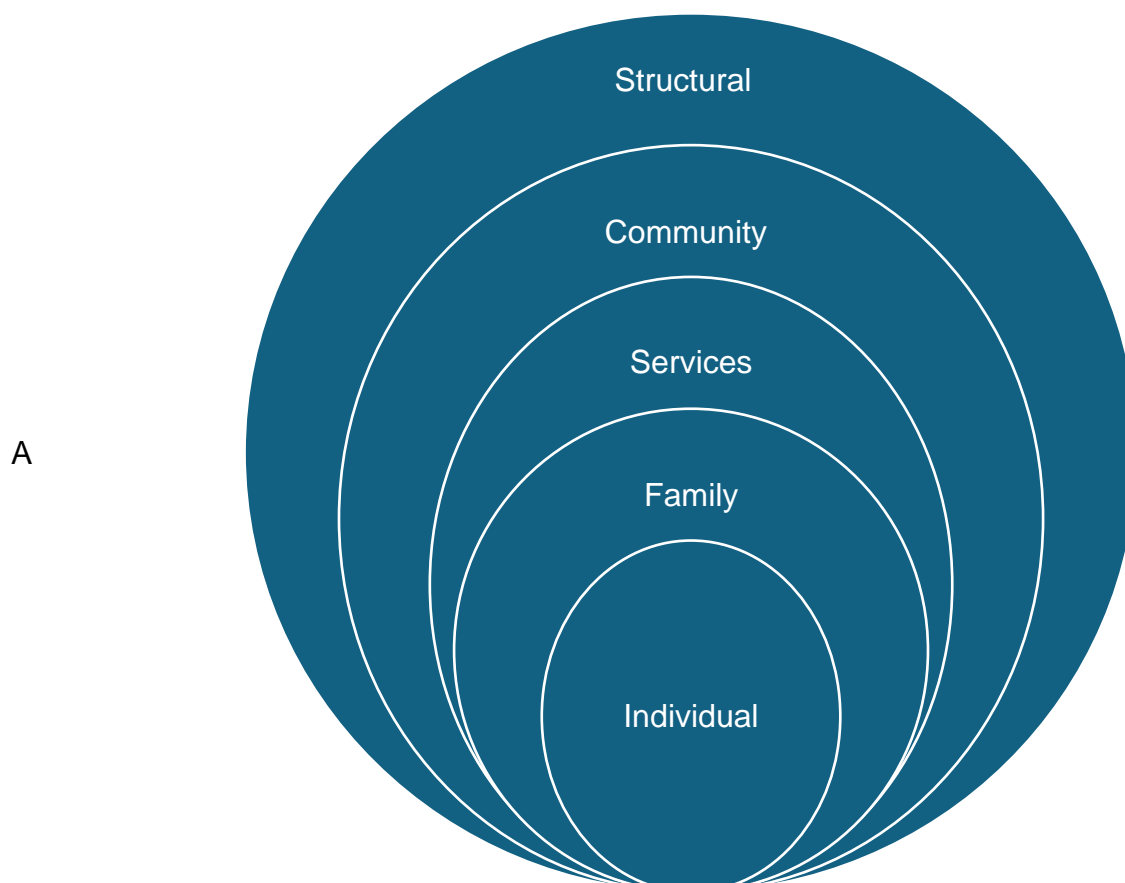


Figure 2: Socio-ecological framework

### 4.3. Phase 1: March-May 2024.

Phase 1 consisted of a rapid desk review and two key meetings with the Consortium Validation Group members. The rapid desk review was conducted on a range of DIDIF project reports, learning documents, and evaluation. The initial selection of documents was made by DIDIF Fund Management team and Sightsavers' Global Technical Lead for Social Behaviour Change.

Criteria for the selection of documentation were:

- Documentation from a DIDIF project (contractually referred to as 'TOs'), covering both those with a direct focus on addressing stigma, and those which may have had an indirect impact on stigma (whilst it was not the original intention) and;
  - The most recent or comprehensive report about project activities.
  - Theory of change guiding project planning and implementation.
  - Learning documents or evaluations with some indication or reference to addressing stigma, negative stereotyping, and discrimination.



- Communication materials with reference to stigma, negative stereotyping, and discrimination.
- Project summaries explaining the background for each project and about the DIDIF programme overall (ToC, most recent annual review, presentation).
- Published programme learning from DIDIF which references approaches and findings to addressing negative stereotyping, stigma, and discrimination.

In total an initial 65 documents were reviewed, covering 14 projects drawn from all thematic areas (livelihoods, health, education, and negative stereotyping and discrimination), across all six countries in the DIDIF programme. In addition, generic documentation relating to the whole DIDIF programme were included. Further documents were then reviewed during phase 2 to provide additional detail and planning for the primary research, as required.

#### **4.3.1. Summary desk review key findings**

In summary, the desk review documented that there were a variety of approaches being conducted to reduce stigma across the portfolio. However, there was commonly no clear articulation and framing of the concept of stigma, and this poses challenges in drawing out learning about stigma reduction approaches across the DIDIF programme. Overall, at the design stage, the approach to stigma reduction appeared fragmented, with some exceptions. Stigma may have been identified as an important barrier, but the pathways of change were less clear. We, therefore, aimed to address lack of data through conducting additional primary research and triangulating the data with the desk review findings. The full desk review findings are available on request at [inclusivefutures@sightsavers.org](mailto:inclusivefutures@sightsavers.org).

#### **4.3.2. Phase 2**

Phase 2 consisted of primary research conducted in three countries, combined with consultation with the Consortium Validation Group. For the primary research a qualitative research approach was adopted, as this was felt to be most suited to capture in-depth detail and facilitate an exploration of issues related to the work conducted on stigma. This included Key informant interview (KIIs) and focus group discussions (FGDs), with a wide range of stakeholders working at various levels: global, national, and local partners.





Photo 1: Image from an FGD with female DIFs in Kenya, September 2024

In addition, our approach allowed for contextual adaptation to the country and project, in order to maximise opportunities for learning at each site. This included:

- Nigeria: 1-2 additional questions on stigma were included into the mid-term review which was being conducted by Sightsavers at the same time as this learning review.
- Kenya: FGDs were expanded to enable a more participatory-style mini-workshop of up to 2-3 hours.
- Bangladesh: Field work was not possible due to the political unrest in July 2024 which coincided with the start of Phase 2; this resulted in a smaller number of KILs conducted online, focused on consortium and local partner staff.
- Written documentation on the LQs was provided where staff were not able to join an interview and/or where global level staff sought additional input from field staff. For example, data provided from the inclusive education project in Tanzania.



Photo 2: Flipchart from OPD FGD

### 4.3.3. Sample

Three countries were selected for the primary research: Kenya, Nigeria, and Bangladesh. The sampling criteria for initial selection of countries and DIDIF projects for the primary research were based on the optimisation of learning potential, identified in the desk review. Additional criteria included:

- A geographic spread, including an urban and rural context.
- Feedback from the validation group.
- Projects which cover different thematic areas of the DIDIF programme (health, education, livelihoods, negative stereotyping, and discrimination).
- An emphasis on current 'live' projects or recently closed projects. We also included a small number of additional KIIs in projects that have recently closed.
- A gender balance and inclusion of people with different types of disabilities.

Learning in each country focused on the following projects detailed in Table 1:

Table 1: Sample of projects for the primary research

Country/Full project title	Project short title used in report	Theme	Dates
<b>Kenya</b>			
Promoting inclusive early childhood development education in Kenya	Inclusive ECDE project Kenya	Education	February 2020 - December 2023
Enhancing the livelihoods of people with disabilities in Kenya	Inclusive Livelihoods project Kenya	Livelihoods	May 2019 – December 2025
<b>Bangladesh</b>			
Strengthening the education system to support children with disabilities in Bangladesh	Inclusive Education project Bangladesh	Education	January 2021 - December 2025
Disability inclusive vocational training and youth employment in Bangladesh (STAR+)	Inclusive livelihoods project Bangladesh	Livelihoods	November 2019- March 2023
<b>Nigeria</b>			
Promoting access to inclusive family planning for people with disabilities in Nigeria (IFPLAN)	Inclusive FP project Nigeria	Health	January 2022- December 2025
<b>Tanzania*</b>			
Promoting inclusive education for girls with disabilities in Tanzania	Inclusive education project Tanzania	Education	January 2022- December 2025

\*Tanzania data was included from a written response from one partner organisation.

In summary, we conducted a comprehensive series of 22 KIIs and 7 FGDs across multiple levels and stakeholder groups reaching a total of 64 participants. Table 2 below details a summary of the sample. This included data from a total of 34 people with disabilities.

Table 2: Summary characteristics of sample

Country	KII	FGD	Participant Category	Participants (M/F)	Male/female with disability
Kenya		4	Beneficiaries, DIFs, OPD members	10 M/13F	10M/13 F
Kenya	7		Partner staff (5) and local partner (1), OPD (1)	5M/4F	2M/1F
Nigeria		2	Inclusion champions	4M/4 F	4M/4F
Nigeria	5		Partner staff (3), digital influencers (2)	2M/4F	*
Bangladesh	5		Partner staff (4), local partner (2)	3M/3F	*
Global		1	DID safeguarding group	1M/6F	*
Global	5		Partner staff	1M/5F	*

\*Data about disability not uniformly collected from staff.

Written responses were also included from an OPD umbrella organisation (Kenya), Safeguarding staff (global), and Tanzania project staff, where these individuals were unavailable for an interview. Data were also added from one additional stigma questions added to 18 KIIs included in the Nigeria mid-term review: OPD members, women with disabilities, and health facility managers.

#### 4.4. Data collection and analysis

Field work was conducted between 20 August-20 October 2024. Data collection in Kenya was conducted by a local senior researcher (JN), supported by a junior research associate (EO). In Bangladesh, KIIs were conducted remotely by the lead consultant (MZ), and in Nigeria most interviews and FGDs were conducted by the Sightsavers Monitoring, Evaluation, and Learning (MEL) officer (MH). The lead consultant conducted global level interviews, additional KIIs in Nigeria, and support to the Kenya team (MZ).

Detailed notes of interviews were taken, interviews were also recorded, and recordings checked as required for additional detail and quotes.

#### 4.4.1. Data collection tools

The different topic guides were tailored to the specific project, see Table 3: Overview interview guides. However, all guides explored six key areas in alignment with the LQs: 1) Understanding and language of stigma 2) Lessons and reflections from the design and planning phase 3) Implementation lessons and reflections 3) Measurement and assessment of stigma change. Cross-cutting issues included: 4) Intersectionality 5) Participation of people with disabilities, and 6) Safeguarding. Recommendations were sought across all key areas. See 11.2 for a selection of interviews and FGD guides.

Table 3: Overview interview guides

Project	Target for guide	KI/FGD
All	Information sheet	Both
<b>Global</b>		
All	Global staff: DIDIF staff and consortium partners, validation group, safeguarding group	KII
<b>Nigeria</b>		
TO 18	Partner staff	KII
TO 49	Partner staff	KII
TO 49	Inclusion champions	FGD
TO 49	Beneficiaries: OPD members, health staff, programme staff (regional)	Additional questions in mid-term review
TO 49	OPDs & social media influencers	KII
<b>Kenya</b>		
TO 50	Disability Inclusion Facilitators	KII
TO 20	Partner staff Kenya	KII
TO 50	OPD members	FGD
TO 50	Beneficiaries	FGD or KII
<b>Bangladesh</b>		
TO 12	Partner staff	KII
TO 45	Partner staff	KII

#### 4.4.2. Data analysis

A thematic analysis was conducted. An initial coding frame was developed based on the key learning questions and desk review, then further themes and sub-themes were developed and modified. There was regular contact and debriefing between the different country research teams to further develop themes in an iterative process. Data analysis was managed using NVivo software and conducted by the lead consultant (MZ). Key findings were then shared with the Validation Group membership and additional feedback sought.

## 4.5. Ethics

Participants were told that participation in the learning review was voluntary. If they agreed to participate, they were informed that they were free to stop the interview at any time. They were provided with an information sheet and verbal consent was recorded. The purpose of the learning study was not to draw on personal experiences of stigma, but to focus on implementation lessons, so it was not anticipated that there would be negative consequences for participants from their involvement.

## 4.6. Participation of people with disabilities

We engaged with people with disabilities throughout the primary data collection process in a variety of ways: 1) OPDs are represented on the validation group 2) OPD members and people with disabilities in specific roles, and/or as beneficiaries were included in KIIs and FGDs 3) We actively encouraged the recruitment of people with disabilities into the research team in Kenya.

## 5. Findings LQ1

---

In this section we document the key themes against each learning question, a summary of key learning points, and a set of recommendations. Recommendations are targeted at a broad audience: donors, mainstream and disability focused development actors, OPDs and local and national governments, that are planning for stigma reduction in their disability inclusive programmes. The recommendations are informed by the participants in the learning review, feedback from the Consortium Validation Group members, and the consultancy team.

Overall, the primary data, alongside the desk review, illustrate that, despite some important gains, disability related stigma remains a key barrier in all of the settings.

### **Learning Question 1: How can development programmes understand and address disability-related stigma, negative stereotyping, and discrimination, in the design and planning phase?**

- How has disability-related stigma, negative stereotyping and/or discrimination been understood and articulated in the DIDIF programme and projects?
- How has the understanding of stigma, negative stereotyping and/or discrimination affected the design of and planning of approaches in DIDIF projects?
- What recommendations can be given for how development programmes can better understand and articulate disability stigma, negative stereotyping, and discrimination in their context?

#### 5.1. The language and framing of stigma

##### 5.1.1. Language

In the DIDIF programme's Theory of Change, stigma is addressed through a thematic pillar on addressing 'Negative stereotyping and Discrimination', and also as a cross-cutting issue in the other three thematic areas (Education, Health, and Livelihoods). Over time, there has been a gradual shift in language towards describing how to address 'stigma and discrimination'. In practice, within the day-to-day running of projects, the language of stigma varies widely, with a wide range of terms used. Across all levels of participants interviewed, they more commonly articulated work on stigma using everyday language, such as feelings and attitudes, addressing myths and taboos, promoting acceptance, addressing self-esteem, and removing barriers to disability inclusion.

One of the challenges identified in all three countries was that terms such as 'stigma' do not necessarily easily translate into local languages. Therefore, the meaning can be lost in translation, and/or there can be confusion around the meaning. The view commonly held was that it is always better to use concrete examples of what this 'stigma' looks like in practice. 'Discrimination', or 'discriminatory practices' were sometimes described as clearer terms, easier to understand, and as something you could follow up on; for example, with consequential legal action.



The terms 'stigma' and 'discrimination' were seen, by a couple of staff members, as negative terms. However, there were mixed views held, even within organisations. For example, a consortium partner staff member reflected that the language of 'stigma and discrimination' could be quite 'affronting' in the Bangladesh and Nepali context; their preferred approach would be a 'softer' way to discuss the issues in the project area. In contrast, another staff member working for the same organisation, but in East Africa, was comfortable about using those terms in the field. In the inclusive livelihoods programme in Kenya, a staff member commented that the term 'stigma' was 'stigmatising' and could be misunderstood in the business sector they work in. Instead, their preference was to talk about 'removing barriers'. In general, in more formal spaces, such as meetings with stakeholders, the language of stigma could be used, but, when discussing it within the community, a richer description of the experience was the default.

In the feedback from the validation group there was also a view expressed that stigma interventions can indicate 'softer interventions'. Whereas the discrimination is the language of the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) and anti-discrimination measures require education but also legal redress and sanctions<sup>4</sup> to combat prejudice, stigma, and stereotypes.

Individuals clearly bring different views and understanding around the language of stigma, so we further explored how participants conceptually understood and framed different types of stigma.

### 5.1.2. Understanding and framing of stigma

The key finding in relation to understanding stigma, across all types of participants in the learning review, was a tendency to explain stigma in terms of 'social stigma', that is, the negative attitudes and beliefs and actions of others.

'It's a superstition of the community. If I give you few examples, I think it will be helpful; a person who is blind have the stigma that they can't do anything.' (KII CDD staff Bangladesh)

'Stigma is being seen as somebody who cannot support herself. Example, one took her papers while looking for a job and they were asked what a deaf person could do. Is to be marked as someone not capable.' (FGD Female microentrepreneurs Kenya)

That said, when probed about stigma at the level of individual, there was recognition of the dimension of 'internalised stigma' that exists. The general feedback was that this was also a very important element of stigma to address. However, it was not commonly described as 'internalised' or 'self-stigma'. Instead, people talked about addressing issues of confidence, a lack of self-belief, feeling not worthy, and being isolated.

'If you took the example of the individual, we would talk about building their confidence and leadership skills and capacity and understanding of their

<sup>4</sup> UNCRPD Article 5 General Comment on Equality and Non-discrimination: 'any non-discrimination and equality measure adopted under article 5 needs to be accompanied by adequate awareness raising measures and measures to change or abolish compounded pejorative disability stereotypes, including those based on gender and age, as well as harmful stereotypes'

rights. That's the way that we would talk about it. We would talk about how we can support the individual to give them the confidence. We wouldn't say that's internal self-discrimination. They may believe that they're not worthy, that they're not capable that they shouldn't be able to do these things. They may believe that initially, and we would try and work with them to say, well actually, these are your rights, you absolutely have a right to have training, and you know they may not believe their work, but that's about building their confidence and self-esteem.' (KII partner staff, Global)

'From what I saw in Kenya, people mainly talked about the attitudes of others towards you. Much less of the reflection on self-stigma elements.' (KII Global research partner 01)

In the inclusive family planning project in Nigeria the Inclusion Champions (ICs) emphasise, in their role, the importance of addressing internalised stigma, highlighted here by a female inclusion champion:

'[Stigma] is something that begins on a personal level. The first origin is actually at the individual level, where you feel it strongest. Since your perception of yourself determines how those around you perceive you.' (FGD female IC, Nigeria).

Overall, examples of 'stigma by association' were not commonly articulated. When it was described, there was not always a good understanding of this dimension of stigma. For example, it was common to reflect on stigmatising behaviour amongst family members towards a child with a disability. This is explored in more detail in section 6.3.3. Structural stigma also was not commonly elaborated upon, although there were good examples provided by some projects of valuable advocacy work as part of a more holistic approach to addressing stigma (see section 7.2.3). There was also the view expressed that in discussing stigma, it focussed on the 'individual' and change for the individual rather than addressing systemic barriers in society and how they can perpetuate stigma. This suggests a narrower understanding of the stigma model.

As already discussed on the language of stigma, feedback from the validation group illustrated that, for some stakeholders, the language and understanding of discrimination is better understood as it relates to the UNCRPD.

When a framing of stigma was discussed (See Figure 1 Theoretical model of stigma), the general feedback was that these different categorisations of stigma were helpful. Many partner organisations commented they were working in those different categories anyway but argued that they would package their work in a different way, not necessarily as work to address stigma.

## 5.2. Project design

Participants who were involved in the project design stage were asked to share learning on what they had found useful to plan for stigma reduction, any challenges, and recommendations.



There was feedback that the proposed framing of stigma (see [Figure 1 Theoretical model of stigma](#)) can be helpful. One Nigeria partner reflected on the fact that the framing of stigma was new to them, but was useful, and would help in planning media work that could also address internalised stigma:

‘This categorisation [of stigma] is ‘food for thought’ – the idea of self-stigma is new to me. We focussed on other people. But it is useful to think about addressing self-stigma and building self-esteem – this could be better incorporated into future programmes.’ (KII partner staff, Nigeria)

Similarly, in discussions with the livelihoods project in Bangladesh, a consortium staff member reflected that their awareness around internal stigma only came later in the project, and there would have been value in addressing it earlier in the project:

‘In my personal opinion I saw internal stigma the most. I saw that when working with other people with disabilities they were constantly thinking about what others think about them and locked themselves in a room. We got to know through the project about this internal stigma, but not at the outset. We saw people had views that they were ‘good for nothing’ and it was difficult to remove this.’ (KII partner staff, Bangladesh)

It emerged that thinking about different types of stigma was generally not built in intentionally at the design stage. The desk review of project documentation also showed that, often, there might be 1-2 references to stigma-related concepts in a theory of change (TOC), commonly highlighting stigma was a barrier, yet the pathways of change were unclear, and often not then further elaborated in planning with defined stigma-reduction focussed activities. In the primary research, a lack of explicit planning on stigma at the design stage was identified as an area which could be improved. Although participatory consultation processes were conducted, global consortium staff expressed views that there was an assumption that OPDs would bring stigma to the table. In practice, there was not an in-depth exploration of stigma. As a cross-cutting issue, whilst a significant issue, there was a tendency for it to not be adequately addressed, albeit unintentionally:

‘The cross-cutting nature of stigma means it can be everybody and nobody’s business’- so it can be lost.’ (KII partner staff, Global\_01)

Partners working across different projects in all three countries explained that as stigma was not a primary outcome in their projects, there was no requirement to measure it, and thus less attention was given to it. Challenges around measurement may also have been a contributing factor and are further explored in [section 8](#).

‘Stigma was not a primary outcome of this project. We were looking at things more holistically and not specifically looking at stigma. We focussed more on the outcomes.... along the way certain things were dropped unintentionally on stigma.’ (KII partner staff, Nigeria)

### 5.2.1. Research

Conducting research, ideally at an early inception phase, was identified as one of the most useful steps to support design and planning appropriate stigma interventions, across all

sites. Research provided important concrete culturally specific examples of stigma, that could then inform the design and messaging. For example, in the Nigeria family planning programme research was identified as key to helping them plan their SBC approach including their media work, so that it also could be closely tailored to the local context and type of disability. For example, specific myths could be targeted and addressed. The key role of research was also summed up by a staff member in the inclusive livelihoods project in Bangladesh:

‘The role of formative research was key to contextualising what we understood by stigma, otherwise it was too abstract and complex. It helped with concrete examples that people could relate to.’ (KII partner staff, Bangladesh)

The IE project in Tanzania also highlighted the importance of research to inform their behaviour change approach. The research was needed to provide a level of detail to tailor their planning, including an understanding of social dynamics and power structures. It was felt this was needed to strengthen their approach and take it beyond awareness raising:

‘The project recognises that adopting a behaviour change approach necessitates further investment in formative research and assessment. This research will help uncover the complexities of existing behaviours within these communities. It is important to note that stigma surrounding children with disabilities varies significantly among communities, which may not be fully addressed by the project. Therefore, the presentation of information can be adapted to reflect the unique social dynamics and power structures present in each area.’ (Partner staff, Tanzania, written response)

The importance of research in contributing to a tailored and more comprehensive stigma approach was similarly raised in the Desk Review. What is less clear from the evidence is the best time for research in order that it translates through to the design, although early in the conceptual project design appears to make most sense.

### 5.2.2. Guidance, resources, and training

Guidance and training during the design and planning phase was valued. In the DIDIF programme, mainstream and disability focused organisations were paired to work on a project and, for example, in Nigeria one mainstream media organisation highlighted the value of this input and training on disability inclusion from one of the other consortium partners, as they needed a foundational understanding of the issues. Disability was a new area of work for them, although this training focused more on disability inclusion more generally rather than stigma.

In terms of specific guidance and resources on stigma, the programme relied on the consortium’s expertise to design projects which made it very much ‘bottom up’. There was no programmatic guidance or resources on addressing stigma. Some global consortium partners interviewed said they assumed their OPD partners would highlight the issue of stigma, and how to address it. In the design stages, consortium partners expressed the need for more technical support and this is discussed below. Project staff did not refer to any particular stigma resources that were useful at the design stage. In the Bangladesh

livelihoods project a toolkit was produced on reducing stigma, *‘Combatting Disability-Related Stigma in Bangladesh: A Behaviour Change Communication Toolkit’* [11] as a project deliverable, but this was a project output and not intended to inform and guide the project. There was a recommendation for improved and wider dissemination of such resources.

In 2022, a programmatic document on ‘Stigma in the DIDIF countries’ ROH 22 was developed, and the intention was for this to help inform programming. In practice it was unclear the extent to which it was disseminated and used. A technical advisory group (TAG) on ‘Negative stereotyping’ was also established at the outset of the DIDIF programme and initially given a role to provide technical support to consortium partners and provide a third layer of review to project design. As a result of COVID and other factors, the TAGs discontinued. The learning about technical support was that there was value in having technical input on stigma, but that it would be better when available at project and country level, as needed. A further related recommendation was that dissemination of technical stigma resources or guidance, is insufficient to strengthen project level design on stigma reduction. Instead, it would be beneficial to have space created for more explicit engagement and exploration of the issues of stigma in the local context:

‘I would aim to get people together, have bigger events to engage on the issues but less frequently. engage with people on the ground. There needs to be more space for people delivering the programme on the ground to engage with the learning’ (KII partner staff, Global)

At the design phase other recommendations were to have strengthened training on the language of disability and also Social and Behaviour Change (SBC) approaches. The latter is explored in the following [section 5.2.3](#).

‘Training of your workplace with people with disability is a pre-requisite. You need to address your own unconscious bias’ (KII partner staff, Nigeria)

Guidance on language to use when discussing disability was valued when provided, and social influencers in the Nigeria programme reflected that it would have been useful to have more guidance on the use of non-stigmatising language:

‘For the next phase, you people will need to train the [social media] influencers on language and choice of words, it’ll be very good. There are words that can be stigmatising especially when it has to do with persons with disabilities. If they could train us on the choice of words and language it will be very important and go a long way. There was no formal training to influencers.’ (KII Social media influencer, Nigeria)

### 5.2.3. Social behaviour change approach

‘Social behaviour change (SBC) is about enabling people to practice healthy and inclusive behaviours – the actions people carry out – that positively influences lives. Social behaviour change can contribute towards understanding and reducing stigmatising behaviours’ (Ref: [Using social behaviour change to promote disability inclusion in](#)

In the wider desk review, there was sometimes confusion about SBC and how that differs from stigma reduction. The use of an SBC approach was adopted by three partners in this

study as a way to strengthen their work to address stigma. Whilst different SBC models were adopted by each partner, key learning identified on the use of SBC included:

- It offers a systematic approach to design and developing of a strategy.
- It is important to bring it into the early stage of project design.
- Research to inform the approach is pivotal.
- It enables a holistic approach.
- Engagement with OPDs in the process is vital.

In Nigeria, the value of using an SBC approach for changing stigma was summed up by a member of partner staff:

‘The use of SBC approach – is the essence of behaviour change – and changing stigma is about changing behaviour. But how to go about it is more complex and different organisations will have different approaches. BBCMA and Sightsavers worked closely together on this. Research was key to the approach. With SBC approach it’s important to take a holistic approach. It’s not about preaching. You need to look at social capital to help people to change their behaviour. You have to include entertainment – there is lots of competition – and you need to make it entertaining to listen to’. (KII partner staff, Nigeria)

The benefit of building this approach into early design was highlighted as important for ensuring a more holistic approach, identified as necessary to address stigma. So, for example, in an inclusive livelihoods project in Bangladesh, a staff member explained that:

‘The Behaviour Change campaign came mid-way through the project – and should have been right at the start – then we could have incorporated the information. We could then have also focussed on internal stigma and built in extra support and training on self-confidence.’ (KII partner staff, Bangladesh)

Similarly, in an IE project in Tanzania, a recent review of the work identified that, in order to further strengthen their work on stigma, they needed to go beyond community awareness raising. They are now planning to implement an SBC approach and strengthen other elements of their work:

‘We also recognise that for change to happen, it often requires a combination of capabilities (knowledge and skills), opportunities (external supporting systems), and motivations.’ (Tanzania partner staff, written contribution).

Training on SBC was also requested, as some smaller partner organisations felt they could not bring this expertise to the table. Additionally, in the wider desk review there was sometimes confusion about what SBC is and how that differs from stigma reduction. It was beyond the scope of this learning paper to explore in any depth learning from SBC approaches, however this is available in a separate learning paper [here](#).

#### **5.2.4. Planning for sustainability**

Planning for a more sustainable approach to stigma reduction was also consistently key feedback from different types of participants, in recognition that reducing stigma takes time. Related to this was the recurring theme that there was often inadequate time to change social norms and deeply rooted beliefs which were key drivers of stigma.

In the Kenya context the main emphasis was the importance of strengthening engagement with government in the co-creation process. This was because government structures are permanent and staff also have '*the mandate and power*'. In Nigeria, similarly, the recommendation was about planning and working with existing institutions, and enhancing their capacity, as highlighted here by the FGD with female inclusion champions (ICs):

'It is essential to understand that confronting stigma is not a singular event; rather, it is an ongoing process that requires sustained efforts over time. This is precisely why the focus should extend beyond transient programmes that may arise and subsequently fade away. Instead, there is a pressing need to enhance the capacity of existing institutions and, where necessary, to establish new ones that can provide a lasting framework for support and engagement.' (FGD female ICs, Nigeria)

The issue of strengthening sustainable approaches was also a recurring issue raised in the next section on lessons from implementation.

### 5.3. Summary Key Learning Points

- There is often no unified way to talk about stigma across projects in the programme, different types of stakeholders and even within the same organisation. There can be differing perceptions of what stigma is. And some staff find the term 'stigma' is a negative term to use.
- The lack of common language and conceptual understanding can pose challenges in drawing out learning about stigma reduction across the DIDIF programme.
- It is most useful to illustrate stigma with concrete examples of what it means in practice within that culture and context, using local language and terms.
- There can be inconsistent framing of stigma across stakeholders, with more emphasis on describing social stigma, that is, changing the attitudes and behaviours of others. There is understanding that it is important to address internalised stigma, but limited emphasis on this. Most common examples improving self-esteem and self-confidence, rather an examination of the underlying drivers and root causes of exclusion.
- There are gaps in understanding the role of stigma by association and structural stigma.
- If stigma reduction is not an outcome, and therefore no measurement required, then there is a risk that there is less attention given to it at the design phase and, subsequently, throughout implementation. This can be a particular challenge when stigma is a cross-cutting issue.
- Good research, which also engages with people with disabilities, enriches design for stigma reduction. However, it also needs to be conducted at an early stage so that it can feed into project design or inception. There also needs to be intentional design of stigma reduction approaches.



- OPDs provide invaluable knowledge and life experience which can be essential for project design, but it should not be assumed that they have all the expertise on approaches to stigma reduction.
- A social behaviour change (SBC) approach is one tool which can offer a more systematic and holistic approach to design for stigma reduction. It emphasises that changing stigma is about understanding norms, changing behaviours (not just attitudes) and goes beyond awareness raising.
- There is recognition that changing deep-seated beliefs and social norms takes time and therefore requires a more sustainable approach.

#### 5.4. Recommendations

Recommendations detailed here would need to be further tailored, depending on the audience. They were informed by findings of the learning review, input from the consultancy team and discussion with the consortium validation group members.

- Addressing stigma in disability-inclusive projects should be required in a consortium programme such as DIDIF. Any programme targeting people with disabilities should recognise stigma as a cross-cutting issue. Projects should have an approach to stigma reduction outlined in the design phase that is reviewed by technical experts at the project and programme level.
- It is essential to have dedicated time and space to conceptually unpack stigma at the design stage and find a common shared language. The language of stigma has to be tailored to the setting.
- A model of stigma which illustrates the different stigma types is useful at the design and planning stage for supporting a more holistic, multi-faceted approach and rights-based approach.
- Research should be conducted as part of the early design or inception phase to understand the drivers and manifestations of stigma, so that any approach can be locally tailored and culturally specific. Research should capture an understanding of power dynamics and key players that can then be harnessed to effect change.
- The participation of OPDs (Organisations of Persons with Disabilities) is crucial in designing and planning stigma reduction initiatives. For programmes targeting children with disabilities, it is equally important to engage with organisations of carers and parents. Check what additional support or training that OPDs and parent support groups may require to effectively implement stigma reduction approaches.
- Create programmatic learning spaces which include a focus on stigma and ensure they meet regularly. Include multiple entry points for cross-learning and cross-pollination on stigma, especially when part of a large consortium. Social behaviour change can be a useful approach for planning stigma reduction but may be new for some partners. Check what capacity strengthening is required and how best to provide technical support.
- Changing stigma is often about changing deep rooted beliefs and social norms which takes time. Any design for stigma reduction requires a sustainable model, and an improved way to measure and understand change.

## 6. Findings LQ2

### Learning Question 2: How can development programmes deliver effective interventions to reduce disability-related stigma, negative stereotyping, and discrimination?

- What approaches and types of interventions have DIDIF projects delivered to reduce disability-related stigma? What types of stigma have been addressed. What different levels of interventions?
- How have DIDIF projects involved people with disabilities in the design and delivery of interventions to reduce disability-related stigma?
- How have these approaches and interventions been received by project stakeholders? What has been seen to work well/not worked well and how does this add value?

Overall, in the primary research, there is a greater emphasis given to approaches to address social stigma, that is, about changing the attitudes (and behaviours) of others. This also aligns with the findings of the desk review.

The perceived changes in stigma, and how those changes came about, are commonly described in terms of which layer of society is targeted; individual, family, community etc. There is a general consensus across interviews that different approaches are required at different levels of the eco-system. That said, there is an emphasis on ‘educating’ others. Participants also reflect on the interactions between layers, for example, that family-level stigma can have a particularly profound impact on the individual, but also interact with the community and vice-versa. We also show the interconnections in the findings.

Overall, the key recurring challenge identified in understanding change is the lack of measurement which is explored in [section 8](#).

### 6.1. Inclusion Champions



*Photo 3: Male ICs in Nigeria discussing their role*

The use of Inclusion Champions (ICs) or Disability inclusion facilitators (DIFs) is an approach adopted by the majority of DIDIF projects. Their role is identified as a key

approach to stigma reduction at different levels of society. This includes; delivering of awareness raising to a variety of audiences in the community, including within the business, health, and education sectors. They also target outreach work to engage with individuals and families and community leaders.

The Nigeria Inclusive Family Planning project uses Inclusion Champions who are local people with disabilities and without disabilities, selected by the local Ward Development Committee. Approximately five are selected per site; three persons with disabilities, a youth leader and female leader. Local leaders are included as they are perceived to ‘have a voice’ in the community and work alongside the person with disabilities to eliminate stigma. All the ICs interviewed were in OPD leadership positions and drew on that wider leadership experience in their role. A total of 90 ICs in Nigeria programme: 55 F of which 17 are women with disabilities and, 35 men, of which 16 have a disability, 18 female youth leaders, and 18 female leaders. They are paid a stipend of 5 USD per month.

The Kenya and Bangladesh (and Nepal) projects all used DIFs who are people with disabilities. In some sites they are selected from local OPDs, but the model varies. They are appointed in consultant-type roles, in that they can be paid a daily rate to deliver activities, when requested. They receive training on disability inclusion, inclusion principles and the ACAP framework (attitude, communication, accessibility, and participation). Whilst stigma is not a specific topic in their training it is addressed within barriers to inclusion.

The DIFs train private and public institutions (PPIs) on disability inclusion and conduct self-advocacy trainings with people with disabilities. As part of the training on disability inclusion, aspects of stigma will be addressed, for example the using of non-stigmatising language, and awareness about disability rights. The DIF will also facilitate the use of Disability inclusion score card (DISC) with organisations. See [section 8.1.2](#) for a more detailed discussion about the use of this tool.

‘The DIF model has really helped us in the program. When it comes to self-advocacy is to empower those undergoing training or those who want to bring change in their institution, we inform them that person with disabilities should be included in decision making. Secondly if they see a person with disabilities like me, they see disability inclusion in action and the value of employment. When one has experience of disability there is so much that they can share with others in the same situation.’ (FGD DIFs Kenya)

DIFs in Inclusive livelihoods project Kenya: 7 M, 4 F. They are all people with disabilities. They are appointed as consultants with an hourly rate for activities of \$5 per hour.

There were several recommendations on how to support DIFs in their role, in both the Bangladesh and Kenya setting. Firstly, the need to strengthen the links between DIFs and OPDs and/or duplicate the role of the DIF within OPDs. The reasons given include the recognition that local OPDs are already working at the local level and are therefore in a strong position to address stigma, and secondly that this is more sustainable model for both the DIF and the OPD. Finally, for the DIFs to be most effective in their role provision of reasonable accommodation is important and could be further strengthened.



## 6.2. Individual level

This section focuses on learning from the targeting of individuals with disabilities, approaches to addressing internalised stigma, and their perceived mechanisms of change.

‘Don’t under-estimate stigma and discrimination. It is putting up barriers and holding back people from accessing services’ (KII Global level-01)

### 6.2.1. Empowerment

The most common feedback on the mechanism for changing internalised stigma was about people with disabilities feeling empowered as a result of their engagement as key actors in various elements of the projects. Most commonly this is articulated in terms of improvements in self-esteem. Empowerment was both identified as an outcome for the individual, but also as an important mechanism for bringing about change. A female Inclusion Champion here reflects on the importance of fostering empowerment within her role providing one-to-one support, and in peer-training sessions:

‘Our primary aim is to build the capacity of these women by fostering their self-esteem, which, in many cases, is alarmingly low. This lack of self-esteem often prevents them from expressing their concerns and advocating for their rights effectively. In our work, we strive to empower these women by instilling a sense of worthiness and confidence within them. Many of the women we assist are unaware of their entitlements and perceive their rights as mere privileges. Our approach involves educating them about their inherent rights, thereby transforming their understanding from a viewpoint of entitlement to one of rightful ownership. This empowerment initiative is crucial for allowing them to articulate their issues and engage in advocacy for their own rights.’ (FGD Female ICs, Nigeria)

Participants with disabilities in an inclusive livelihoods project in Kenya similarly emphasised the role of feeling empowered as a way to mitigate internalised stigma. Building self-esteem was a core component of this; having strengthened business skills allowed them to be ‘independent’, which was seen as key. A recurring theme across both livelihoods projects in Kenya and Bangladesh was the importance of people with disabilities showing that they can contribute to their family and society, shifting the common stereotypes which are held that people with disabilities are always dependent and/or can only work in certain areas.

‘Once you empower a person with disability you build their self-esteem. Through the In- business programme, I have progressed and I can buy things that can help me like the white cane, and medicine’. (FGD OPD Kenya)

‘People with disabilities were known as people who are dependant but through the in-business training they can also cater for their needs because they do business and earn income.’ (FGD OPD, Kenya)

‘My family thought that I could not manage when they bought me a motorbike but through the empowerment I have managed to do well. My

family thought that I will rely on them for help, but I can do my things by myself.' (FGD male microentrepreneurs, Kenya)

### 6.2.2. Training and awareness raising

The main approach identified to support this empowerment process was the provision of training, with varied approaches across projects. Whilst none of the training was explicitly about addressing stigma, it is generally assumed that this would be addressed as a by-product. For example, in the Kenya In-business project the self-advocacy training is a one-day compulsory training, not specifically packaged to address internalised stigma but includes: personal experiences, disability rights, and confidence building. This is delivered by Disability Inclusion Facilitators (see [section 6.2](#)). Project participants then continue receiving other training modules on business skills. Whilst this business training may not specifically address issues of stigma, it is perceived as valuable for individual empowerment, which in turn can 'change the narrative' around stigma. This is summed up by one of the regional partner staff:

'[Self-advocacy training] helps micro entrepreneurs realise who they are, how they can advocate for themselves to build their self-esteem. It [business training] also gives them opportunity to be empowered to do business [and] thus change the narrative of how the society looks at them. The society portrays persons with disability as people who cannot do business.' (KII partner staff, Kenya)

One recommendation in discussing the self-advocacy work was for it to be extended beyond a one-day training, and instead built into a model of ongoing support. Training alone is unlikely to shift a lifetime of internalised stigma. Further, that it should include a mental health component.

### 6.2.3. Peer to peer support

Peer to peer support, either through direct meetings, or in group sessions, is seen as valuable for creating a comfortable environment for sharing experiences. Inclusion Champions (ICs) in Nigeria explained that they 'give others the confidence to open up' and can 'better relate' to other people with disabilities. For example, peer group sessions about family planning are organised in Nigeria, and address different layers of stigma, including the stigma of sexual and reproductive health. A female IC reflects that she brings a unique perspective to the conversation surrounding family planning, child spacing, and sexually transmitted infections. She drew on her own experience and her 'understanding of the mindset' surrounding these issues, which has 'equipped her to convey messages in a manner that resonates with her peers'. She addresses these topics, which are often considered taboo.

The social media element of the Nigeria project also engaged directly with existing WhatsApp groups of people with disabilities to use peer influence and create dialogue, combined with using local micro and nano-influencers on wider social media platforms. It was beyond the scope of this learning review to understand how 'virtual' and 'direct' interpersonal peer support can have a different impact, and there are obviously different budgetary implications, but it is worth further research. In the Bangladesh context, the

validation group members also recommended the importance of harnessing digital spaces to address stigma, and that this should be explored further.

Whilst training is often provided in groups settings, it was not always clear how stigma was addressed, and/or whether more could have been made for opportunities for peer support. This is with the exception of caregiver support groups used as an approach (see section 6.3.3) One OPD leader shared her broader experience from another project which combined both rehabilitation and activities to enhance the well-being of persons with visual impairment. She reflected on the positive impact of a support group, and including sessions for family members to mitigate stigma:

‘The structure of our group includes members who have been part of the community for a considerable time. Many of these individuals have successfully navigated through the challenges associated with their visual impairments, having overcome feelings of isolation and depression. Within this supportive environment, we place a strong emphasis on checking in on one another and fostering encouragement among members. By involving families in our activities, we aim to mitigate instances of discrimination or misunderstanding that may arise within family dynamics.’ (FGD Female ICs, Nigeria)

### 6.3. Family level

This section focuses on learning from the targeting of families, approaches to addressing stigma in the family, including stigma by association, and their perceived mechanisms of change.

A common theme was that addressing stigma within the family is recognised as essential to address. The family environment is often the starting point for internalised stigma with an early impact on a child’s self-belief and self-esteem, as well as a significant barrier to access services. In the Nigeria interviews the crucial role of the family was particularly emphasised, but also an area to be strengthened.

‘The first thing a lady thinks of when she gave birth to a disabled child was that he was useless. I can accomplish nothing with that youngster. The father in particular, but also the mother. He will then enquire, "How did you get this child?". There will be no schooling for the child. He won't receive the same treatment as other children because he will remain at home while his siblings—who may be junior or senior—may be sent to school. As you can see, the child's self-esteem is declining. Thus, stigma in my opinion begins at home and spreads across society.’ (FGD Female ICs, Nigeria)

‘Stigmatisation is strongest at the family level, because if the family does not value the child with disability, the community too would not value him/her.’ (FGD Female ICs, Nigeria)

There was overall general agreement across projects and countries that there have been important changes at the family level in terms of stigma. Several of the approaches adopted at the family level are similar to those for targeting the individual and community. For example, training and awareness raising, but also combined with outreach to families, and

some examples of provision of support groups. One example of a home-education pre-training package is explored in Section 7.1.1 on adapting a programme for children with complex disabilities.

‘At the family level, there has been a gradual transformation in the ways parents and spouses of women with disabilities engage with issues such as family planning. Increasingly, it is these family members who are encouraging the spouses to consider family planning options, a significant shift from earlier attitudes.’ (KII woman with disability, mid-term review, Nigeria)

### 6.3.1. Training

Several projects provide training to parents to increase knowledge, and also to provide skills. For example, skills in parenting (IE project Tanzania) or business skills in Bangladesh and Kenya (Livelihoods projects). This training is not specific to stigma, but the argument is made that addressing stigma is implicitly addressed, as a result of improved knowledge, and also improved skills.

### 6.3.2. A targeted interpersonal approach

Many of the projects adopted an ‘interpersonal approach’ to engage in a targeted way with various stakeholders. This is about providing an opportunity for interaction and dialogue with someone. At the family level there were outreach home visits, for example. This is often the role of an IC and/or an OPD member. For example, in Tanzania there was poor take up of identification of children with disabilities in the IE project. Stigma was identified as a key barrier which had not been sufficiently planned for at the outset of the project. This component was then strengthened through direct outreach to families with a door-to-door campaign in partnership with local the OPD. However, there was limited information available on what that campaign consisted of and it is unlikely that a one-off visit will change deeply ingrained beliefs. It would be useful to have more data to understand what the outreach to families consisted of, and any evidence of the impact. There can be a tendency to assume that better enrolment in school equates with stigma reduction, with a lack of evidence to support this.

The participation of people with a disabilities in direct contact with families is repeatedly emphasised as an important mechanism in changing attitudes and behaviour. The reasons given are that they can draw from real life experience and can be important role models. This was illustrated by a male IC in Nigeria who visited a family where the father was refusing to send two children with visual impairment (VI) to school. The IC spent time with the father to engage him in dialogue, reflect on his own employment status as a person with a VI, whilst at the same time signposting the family to additional support.

‘I met with the father to ask why he does not want his children [with visual impairment] to go to school, and the only reason the father gave was that: “I have never seen a person with visual impairment become a Governor or Minister”. I then asked the father, since he (the father) has no visual impairment, was he a Governor or Minister in the past or currently? The answer was “No”. I also provided another example of a father whose child

was visually impaired and who asked if he could link him up with government or non-governmental organisations to sponsor his visually impaired child's education. I went further to tell the father that I am visually impaired and employed. After much discussion, the father agreed the disability resource foundation would jointly sponsor the children's education'. (FGD Male ICs, Nigeria)

In the Kenya and Bangladesh projects, the use of home-based educators is another approach adopted with families caring for someone who is deaf-blind and/or has multiple and complex disabilities. These home-based educators engage with the whole family to work with their child to gain basic life skills, so they can transition to school wherever possible. This support may also address stigma by association, although that is not a main focus of the support package; it would be helpful to better understand the change processes for the caregiver.

### 6.3.3. Stigma by association

In discussing stigma within the family, the overall emphasis was on the stigma and discrimination towards a child and/or family member in the home. There was very little reflection on stigma experienced by association, the implications of that, and how it was addressed. In the business sector context in Kenya and Bangladesh, it was discussed that other family members or employees in a business can also be stigmatised because they work with a person with a disability. It was less clear how this dimension of stigma was effectively addressed.

In addition to the support by home-based educators, the main approach highlighted to effect stigma by association was the establishment of parent/caregiver support groups (PSGs) in several countries including Kenya, Tanzania, and Nepal. For example, in the Tanzania IE project these PSGs are seen to work by: reducing the isolation that many carers experience, building confidence, learning to advocate collectively, and providing an environment where carers can share experiences. The groups are not specifically established to address stigma, but it is seen as a by-product. The provision of and/or strengthened opportunities for counselling for this target group is identified as an important approach, as well as the suggestion for greater frequency of the support groups. There was some reference to the gendered dimension of caregiving and the experience of stigma by association, which is largely on the female caregiver, captured here:

'The parent networks [in Nepal] that we had were really useful in exchanging between parents. The mothers would come together and would really talk about it [stigma] and having that that group to talk and to discuss that we share the same issues. And it is not only the child that faces discrimination, it is the mother also who faces the discrimination from the family, from the husband. I'm not saying that we had a very comprehensive approach to it, but this is what we found.' (FGD DID Safeguarding Group)

'Through these platforms parents of children with disabilities have shared experiences on disabilities, challenges, and available opportunities that can be used to support their efforts. This cohesion has promoted positive self-help attitudes among the parents and carers, through these groups parents



have planned how to support their children. The PSGs have also increased socialization and experience sharing among the parents/carers that contribute to confidence raising, reduction of stigma, discrimination and inequalities at family and community levels' (Tanzania staff written feedback)

'When we identified caregivers, we organised them into parent support groups to share on their experiences and encourage each other - this improved their self-esteem' (Kenya KII partner)

## 6.4. Community level

In this section we explore how stigma reduction is approached at the community level. Targeting stigma at the community level was addressed across all projects. Most participants commented on a positive shift in attitudes, and behaviour, achieved in a variety of ways.

### 6.4.1. Awareness raising and community dialogue

The most common approach detailed is awareness raising with key community institutions, including governmental and traditional structures. So, for example, using a one-off town hall meetings to sensitise the community. Participants emphasise the importance of 'sensitising' or 'educating' the community on disability issues in order to address stigma. This also reflects what is documented in the desk review.

However, in terms of discussing what works well, there was an emphasis on creating opportunities for dialogue in order to have maximum impact. This could be done through social media, drama in the community meetings and/or on the radio magazine style radio programmes where there is a phone in, and directly engaging with leaders in different ways. Again, the importance of involving people with disabilities in that dialogue was identified as key. For example, this is highlighted in the Nigeria social media programme:

'Our focus is not to tell people how to behave and what to say – we want to create a public discussion about the issues, for example an ad campaign called 'Is it ok?' which discusses various scenarios. With this we wanted to discuss attitudinal and cultural barriers.' (KII Media partner, Nigeria)

Another popular approach highlighted is the use of community drama, for example, it was seen to be useful in Tanzania IE project. It is an approach which attracts people and is a way to bring community members and OPDs together. One KI, an expert on the role of media, detailed that a radio drama can raise certain issues, but a 'magazine model' on the radio allows people to phone in and discuss issues; this is important because 'to get change in society you need to get society to talk'. There is insufficient evidence to compare the evidence of different types of approaches, and this would be worthwhile to explore further.

Social media was used in the Nigeria FP project as a key component to address stigma at all levels; the use of mass media had substantial reach. Fifty-five influencers posted weekly with key messages to debunk stigmatising beliefs as one component of their SBC campaign. A smaller cohort of seven were then engaged in a 'hyper-targeted' campaign with existing WhatsApp groups of people with disabilities. This facilitated 'direct

communication and engagement with the target audience leveraging the power of existing social networks and peer influence to promote family planning inclusivity.’ In a final evaluation of the campaign, these direct on-line discussions were identified as helping to sustain behaviour change even after a campaign had ended. That said, the strength of cultural and religious beliefs around family planning, combined with issues of disability-related stigma were seen as persistent. Other challenges identified here were that people with disabilities often have limited access to the internet and/or limited digital literacy, and the moderation of stigmatising comments on social media can be difficult.

#### 6.4.2. Engagement with opinion leaders and community structures

A recurring theme was the importance of engaging directly with those who have power at the community level. This was seen to have several benefits including: 1) creating an environment where stigma can be actively challenged 2) leaders have a voice in their community, have respect and will be listened to 3) facilitates ‘buy in’ for the project 4) improves accountability 5) has a multiplier effect 6) leaders can bring their knowledge to planning and 7) it can be a more sustainable approach. Some of these influential roles are likely to contribute to shifting social norms towards people with disabilities.

‘Previously we’ve done a lot of work directly in the community [in Tanzania], not just necessarily in the DID program, but in our health programs across the region as well, and we find there that we don’t have as much impact without involving the local leaders. We don’t get that buy in.’ (KII partner staff, Global)

‘It also can’t all be left to contact through OPDs. You need to consider power and allies. For example, in the classroom teachers have power, and when they change then the children change. But I don’t think that issues of power were made explicit in our paper’. (KII partner staff, Global, discussing Kenya IE project)

Training leaders and additionally equipping them with skills and tools to be engaged in stigma-reduction processes is also useful. In Nigeria, for example, local youth and female leaders were also selected and trained to be ICs, working alongside people with disabilities. These leaders can then play a more active role in stigma reduction. This was an area which was identified as requiring further strengthening.

‘We include the [female leaders] as ‘they have a voice’, and if they can work alongside the person with a disability, this will be stronger for eliminating stigma. It can be important in the community for people to see that the female leader is part of the process – she has the respect of the community. [Does she have power?] Yes, she has power which can help address the stigma.’ (FGD ICs, Nigeria)

‘By training individuals within these institutions [particularly religious and traditional structures] and equipping them with the necessary knowledge and tools, they can be motivated to incorporate advocacy for persons with disabilities into their mandate. Often, during their engagements, these leaders inadvertently contribute to discrimination against individuals with

disabilities, manifesting in instances where their decisions lack fairness and equity. It is vital that these systems are assessed and refined to ensure that they do not perpetuate harmful biases but rather support a more just and equitable approach.’ (FGD Female ICs, Nigeria)

‘Through a concerted effort to educate and train those who hold influence within these structures, it is possible to create an environment where stigma is actively challenged, and individuals with disabilities are afforded the respect and dignity they deserve. This multifaceted approach represents a sustainable strategy for combating stigma.’ (FGD ICs, Nigeria)

There were gaps identified in some contexts where it was felt that a better understanding of power dynamics was needed. For example, in the Nigeria context, there was some valuable engagement with religious leaders who were seen to be trusted voices, but the consistent theme was a need to really strengthen this engagement. Similarly, feedback from Bangladesh staff in the VG highlighted the powerful roles and need to strengthen engagement of religious leaders in their context.

‘A preacher claiming that a “a child born with a disability is not a child of God’. Religious organisations must take the initiative. They must be made aware of the fact that this is a part of their duty to educate the public, and they must be made more sensitive to it.’ (FGD female ICs Nigeria)

‘The outreach extended to traditional leaders and community leaders has been instrumental in shaping public perceptions and attitudes towards disability. These leaders hold significant influence within their communities, and their involvement in the campaign ensures that the message resonates at multiple levels. Additionally, the engagement of religious leaders further amplifies the campaign's reach and impact, as these figures often serve as trusted voices within their congregations, capable of fostering acceptance and understanding.’ (KII woman with a disability midterm review Nigeria)

Furthermore, that the entire traditional leadership structure at the community level would benefit from being engaged in the Nigeria context:

‘Currently, the town hall meeting which the project does, are being held with the head of the traditional leaders in the community while ignoring the sub traditional head. By having the town hall meeting with the entire traditional leadership structure disability related stigma would be addressed at the community level.’ (FGD Male ICs Nigeria)

Another approach adopted for engaging with leaders, is to embed people with disabilities into decision-making structures. This can be community structures and in schools and/or health bodies. The argument made is that this can facilitate direct contact and engagement and can support structures in the journey to greater disability inclusion. It is also importantly seen as a more sustainable approach:

‘These organisations [OPDs] play a crucial role in the ongoing battle against stigma by ensuring their presence and accessibility within the community.



Their existence allows for the continuous outreach and sensitisation efforts that are essential for educating the public and promoting inclusivity. By embedding these organisations within various community structures, they can effectively infiltrate diverse associations and gatherings, fostering dialogue and understanding about disabilities and the challenges faced by those affected.' (FGD ICs, Nigeria)

The view was also held that that by having OPD representative in such structures it could make these structures more accountable when issues of discrimination do arise.

Finally, a regularly highlighted key learning, not only when discussing work at the community level, was the importance of having follow up to change attitudes and behaviour. For example, in Bangladesh there were visits to the market committee as part of the inclusive livelihoods project. This is not on a one-off meeting; it was emphasised that regular follow up is required.

## 6.5. Structural stigma

In this section we explore approaches to address the structural stigma, which refers to systemic issues, such as policies and organisational systems and culture which either intentionally or unintentionally limit opportunities for people with a disability and compound stigma. Overall, there was less weight given by informants on their approaches to address structural stigma, and it could be seen as a difficult aspect of stigma to understand. This may be because many of the changes, for example in relation to advocacy, may not have an immediate direct impact on stigma, but are about contributing to longer term change. The role that the media plays in addressing social stigma is also covered in [section 6.4.1](#).

### 6.5.1. Advocacy

In terms of advocacy there were many examples given on how OPDs were engaged in local level advocacy. The direct links to reducing stigma were not always explicit, but it was part of a holistic approach. For example, in Bangladesh, advocacy for securing disability allowances and ID cards for people with disabilities was identified as a component of their stigma reduction work. The implementation of disability laws was a recurring theme, but how that linked to addressing stigma was not always clearly articulated. However, one local OPD member in Nigeria elaborated how the presence and enactment of law is vital in shifting societal attitudes towards people with disabilities:

'One of the foremost issues is the societal perception of individuals with disabilities, which often relegates them to a status akin to that of second-class citizens. This perception manifests in the belief that individuals with disabilities do not truly belong within the fabric of society, leading to an exclusionary mindset. However, there is a glimmer of hope brought about by the enactment of the disability law in Kaduna State, which has undoubtedly marked a significant progress. This legislation has facilitated a crucial step forward in recognising the rights of persons with disabilities.' (KII OPD, mid-term review, Nigeria)

Another recurring issue was the need to educate the broader community, including people with disabilities, about the existence and significance of disability laws. However, one OPD reflected that educating and awareness raising alone was insufficient.

‘Advocacy is inherently about persuasion, where one can only appeal through advocacy, entreaty, and urging; one cannot compel another individual to take action. This established pattern of advocacy, which we have diligently pursued, has reached its limits, and the challenges we encounter remain present. Although it can be acknowledged that the severity of these challenges may have diminished compared to previous circumstances, they have not been entirely eradicated; they continue to exist in a substantial manner.’ (KII OPD mid-term review, Nigeria)

Also in the Nigeria context, there was an identified need, raised by the ICs, to have a stronger mechanisms in place to enforce laws and violations of them:

‘The presence of legislation is not the issue; rather, it is the systemic failure to enforce these laws effectively that must be addressed.’ (FGD, Female ICs, Nigeria)

### 6.5.2. Organisational culture

Changing organisational culture towards disability, that is, shared beliefs, norms, and organisational practices, was also said to be changed, as a result of several DID approaches. The focus was on change in disability inclusive practice, which may also include stigma. The main approaches were training and the placement of people with disabilities into organisations and decision-making bodies.

In the livelihoods project in Bangladesh, a DIF was placed within a mainstream partner district office. There were apparently low expectations from staff at the beginning about the capabilities of the DIF, as explained by one staff member: ‘*Staff were not really trusting for the person with disability to do the work and over time we have seen a change*’. By directly observing the DIF working in his role ‘*it changed the mindset*’ of staff. In the media work conducted in Nigeria, people with disabilities were involved at different levels including as advisors and actors in the dramas, and delivered training to the organisation:

‘If you want to address discrimination you have to address yourself first. Training of your workplace with people with disabilities is a pre-requisite. You need to address your own unconscious bias.’ (KII Partner staff 2, Nigeria)

This latter example also aligns with the desk review finding about the shift in organisational culture when staff with disabilities were appointed into the media organisation in Tanzania.

The training of public and private institutions (PPIs) on disability inclusion, was identified in the Kenya livelihoods project as an important approach for changing the organisational culture, and prevalent negative attitudes towards working with people with disability. For example, with public procurement processes, there is an expectation that people with disabilities will apply for low value tenders, and training is given to help to shift that mindset and challenge negative stereotypes of people with disabilities.

The use of the [Disability Inclusion Score Card \(DISC\)](#) was perceived as a valuable tool used in Kenya and Bangladesh. It is a self-assessment tool which aims to create a dialogue about disability inclusion and explores the different organisational capacities. Whilst it is not explicitly about stigma, elements of stigma might be addressed. Participants who had used it felt that it could illuminate areas to be strengthened and be a 'motivating tool', and arguably contribute to systemic organisational change. One staff member in a mainstream partner organisation that used the tool reflected:

'[The Disability inclusion score card] is a game changer. I really like this tool. Every year we do it and we reflect on it and identify where we need to improve.' (KII partner 03, Bangladesh)

The use of the DISC was discussed as a tool for measuring change, but in practice it is not a tool for stigma measurement. Some of the identified challenges in using it as a measurement tool are briefly explored in [section 8.1.2](#).

Providing people with disabilities with reasonable accommodation to fulfil their different roles in stigma reduction, the provision of reasonable accommodation and support to access assistive devices, is an important structural issues to address. This is a consistent theme across the learning piece, at different levels of the eco-system and referring to different types of stigma.

One further recommendation raised in relation to systemic stigma was the need to strengthen organisational disability policies, for example to have a strengthened code of conduct which is also addresses issues of stigma. Having robust systems in place for address safeguarding are explored in [section 7.2](#).

The findings here align with the desk review where only a small number of projects highlighted their achievements in addressing structural issues, and the links to reducing stigma are not always explicit.

## 6.6. Participation of people with disabilities and OPDs

The role and perceived impact of people with disabilities and OPDs in stigma reduction activities has been explored in earlier sections of the report. In this section we consolidate that learning.

### 6.6.1. Roles

The participation of people with disabilities in approaches to stigma reduction, is a core to the approach across all projects, starting from planning through to implementation. Engagement with people with disabilities includes: 1) at the project planning and design stages 2) the creation of stigma specific products such as radio dramas 3) in formative research 4) as ICs/DIFs 5) in outreach work 6) placement within partner organisations 7) placement within community and national -level decision-making structures (including school and health service structures) 8) working on advocacy 9) actors in drama and community radio 10) delivery of training to various audiences, including health staff and media organisations 11) as advisors embedded within partner organisations, for example, DIFs placed in partner offices in Bangladesh.

### 6.6.2. Mechanisms for change

There are several key reasons given for why the participation of people with disabilities contributes to stigma reduction, and again some of these mechanisms have been touched upon already in terms of their empowerment and agency.

The value of direct engagement is repeatedly raised as important. Firstly, that people with disabilities bring in their lived experience to the dialogue and are in a better position to provide concrete examples, and in-depth knowledge on experiences of stigma, as well as how it should best be addressed. For example, OPDs deliver training to health professionals in the Nigeria inclusive family planning project. This is identified as empowering for the OPD members and also, as one staff member reflected: 'If they lead in these roles then you get more buy in from the health professional in my experience'. The direct contact and being seen as an empowered person with disability was identified as part of the mechanism for changing attitudes.'

'Because it was persons with disability that served as facilitators for the training of service providers, it assisted in addressing the community level stigma by showing that persons with disability were also capable impacting knowledge [and] had capacity and potential. This the first-time persons with disability were given the opportunity to facilitate session in any intervention that I know of. According to one of the service providers "I never knew persons with disability can speak English".' (FGD male ICs, Nigeria)

The importance of having role models of people with disabilities, from the local/national setting, is highlighted in learning from livelihoods project in Bangladesh. A staff member drew on an example of working with a large business, and of the importance of providing concrete examples of people with disabilities from their own cultural setting:

'The retail shop owners didn't want to employ people with disabilities as [they] didn't think they would be seen positively in store – and they wanted concrete examples from Bangladesh, not from other countries – so having those examples is important for changing attitudes.' (KII partner staff, Bangladesh)

Similarly, in working in the home setting with families, having an OPD member visit the home, and being seen by the family members, is also considered important to reducing stigma. The OPD member can be seen as a role model. This was raised as an issue for both projects in Bangladesh (livelihoods and IE), where an OPD member visits the family home as part of the pre-training home package for learners who are deaf-blind. In this particular example the gender of the OPD member was also a factor in changing attitude.

'We found that when the female DIFs went into the household that family members were more encouraged to send their daughter to the training – they can say "If I can work safely then your daughter can work safely".' (KII partner staff, Bangladesh)

One recommendation in Bangladesh was to strengthen the alumni engagement, inviting previous graduates from a business programme to serve as role models. This is an area that could be explored further.

For addressing structural stigma, specifically changing organisational culture, and addressing unconscious bias, it was reflected that having people with disabilities placed within organisations played a role.

### 6.6.3. Capacity strengthening of OPDs and people with disabilities

In this programme there are various types of partnerships and MOUs with OPDs. It was beyond the scope of this learning piece to explore these partnerships in any depth, except where it related to delivery of stigma work. A key theme raised across all countries, was that whilst OPD engagement brought valued expertise, there was still an identified need for capacity strengthening of the OPDs, as well as individuals. This includes more support, including training, on how to deliver awareness on stigma and discrimination reduction. It also extends to capacity strengthening on financial issues, management, and understanding of policies and advocacy.

‘The constraints we experience are exacerbated by the limitation of resources and capacity. Even if there is an intention to implement new initiatives, the absence of adequate support and resources hinders our capacity to act. The knowledge gained through this project has not only benefited service providers but has also enhanced the understanding and capacity of organizations representing persons with disabilities. This ongoing educational journey is crucial; it is imperative to recognise that training should not be viewed as a one-off event that can be easily forgotten. Instead, through consistent training and capacity-building efforts, a far greater level of understanding and responsiveness can be achieved.’ (KII OPD member, Nigeria)

Another recommendation highlighted in relation to capacity strengthening, is the need to provide adequate support and training to OPD members placed in decision-making bodies, combined with clearly defined responsibilities. This was highlighted in the Nigeria inclusive family planning project:

‘It is important to recognise that individuals with disabilities serving on Ward Development Committees should have clearly defined responsibilities that extend beyond mere attendance. Their role should encompass advocating for the needs and rights of persons with disabilities within the facilities where they are involved. Through capacity building, these representatives can better understand the importance of their role and actively contribute to creating a more inclusive and supportive environment within the healthcare system.’ (FGD ICs, Nigeria)

There was also the recommendation for organisations (INGOs, private and public organisations) to build their capacity on reasonable accommodation practices.

## 6.7. Summary Key learning points

### Key approaches and mechanisms of change

- There is understanding that a multi-faceted approach is needed for stigma reduction, and different approaches are needed at different levels.



- In general, there is often not an explicit or intentional focus on stigma. Stigma is not an outcome with a target to demonstrate measurable change, the project's design largely assumes addressing stigma is a by-product of an activity. For example, self-advocacy training will touch on some issues which related to stigma.
- There can be a tendency to emphasise 'educating' for change. However, stigma experienced in a family and community over a lifetime, for example, is unlikely to be impacted by one-off awareness sessions and short- term interventions.

### **Mechanisms at the individual level**

- The empowerment of people with disabilities is both an outcome and a key mechanism to address stigma. People with disabilities can have stronger agency to contribute to changing the narrative around stigma.
- A common approach to support empowerment is engaging people with disabilities as key actors in various elements of the projects. For example, participation in the delivery of training to others, such as to health professionals, is identified as empowering. People with disabilities also benefit from various skills trainings, such as developing business skills, which contributes to improvement in feelings of self-esteem, and confidence. These trainings do not explicitly address stigma, and it is less clear the extent to which underlying drivers of stigma are therefore adequately addressed.
- People with disabilities can draw on lived experience and provide concrete culturally relevant examples, and can be role models
- Peer support is another valuable tool for addressing internalised stigma and stigma by association. This can be one to one or in groups. A support group can provide a trusted environment for sharing of experiences and psychosocial support; this can help to address internalised stigma. Support groups for caregivers can also address the stigma by association experienced.

### **Mechanisms at the family and community level**

- Targeted personal interaction, which creates opportunities for dialogue with families and community leaders is a valued approach. This may be part of outreach activities, such as direct visit to families. It is about creating opportunities for a dialogue around stigma which can be about informing, answering queries, and addressing fears.
- Community and radio drama can operate at different levels of society to address stigma. The importance of moving beyond awareness raising is again highlighted; creating opportunities for dialogue is emphasised as key for changing stigmatising views.
- It is important to identify and engage people with power<sup>5</sup>. This brings many advantages including a voice that will be heard and respected, can directly engage to address

---

<sup>5</sup> We do not explore the concept of 'power' in this learning piece. However, we recognise the complexity of power and the idea of visible, hidden, and invisible power. Visible power is formal rules and structures, hidden power is people and institutions that get to the decision making table, and invisible is more insidious and shaped by social and cultural norms 14. Gaventa, J., *Reflections of the Uses of the "Power Cube" Approach for Analyzing the Spaces, Places and Dynamics of Civil Society Participation and Engagement*" available at <https://www.participatorymethods.org/resource/reflections-uses-power-cube-approach-analysing-spaces-places-and-dynamics-civil-society>, in *CFP Evaluation Series No 4*. 2005: Institute of development studies..



stigma, which can in turn contribute to shifting social norms over time and foster an environment where stigma can be challenged.

- A key approach adopted to maximise engagement with people with disabilities, is engaging them in different ways in decision-making structures and organisations, for example as ICs. It can contribute to shifting organisational culture towards disability, and for example addressing unconscious bias. This is perceived to be a sustainable approach, recognising that changing attitudes and practices is a long- term process.

### **Mechanisms at the structural level**

- Systemic issues can drive and reinforce stigma, however structural stigma is often given less weight in terms of an explicit approach to stigma reduction. This may be because it is seen as an indirect approach, with longer term impact, for example in relation to advocacy work and policy change.
- The lack of provision of reasonable accommodation, including assistive technology can also be a barrier to people with disabilities engaging in their roles to address stigma reduction.
- There were important shifts in organisational culture achieved, for both mainstream partner organisations as well as public and private institutions. The embedding of people within organisations was seen to play a role in changing attitudes. The DISC tool can create dialogue as part of a wider package of training and engagement.
- Advocacy to ensure the local implementation of disability laws, is identified as pivotal to changing societal attitudes and behaviour towards people with disabilities, and thereby contributing to stigma reduction. There was little discussion about how to enforce laws, and for example, steps to address discriminatory practices. This seems to be a gap in the identified approach to reduce stigma.

## **6.8. Recommendations**

Recommendations detailed here include those identified by participants in the learning review, input from the consultancy team and discussion with the validation group.

- A multi-faceted approach is required, working in partnership with a range of actors, tailored to the context. There should be an intentional focus on stigma even if it is a cross-cutting issue.
- Training and education, including skills building can play a role in addressing all forms of stigma, but it needs to be part of a broader approach. One-off training sessions, or one-off home visits, will not address often deep-rooted beliefs and social norms. Any model of training requires refresher sessions, and /or follow up opportunities for mentoring and support, with a sustainable format.
- The participation of people with disabilities in approaches to stigma reduction is core to any approach. Seek specific and detailed feedback from OPD representatives on their capacity strengthening needs, which may include how they can lead on community dialogue on stigma.
- Addressing stigma requires an understanding of the complexity of power at different levels, in partnership with other actors. It should not just be the responsibility of OPDs,

but has to be in partnership with other actors. For example, within a family ecosystem the power to take decisions and actions may be influenced by, for example, kinship structures and gender. At a community level, there will be power over economic and political resources that will shape the intersectional nature of stigma and facilitate or impede approaches adopted.

- Identify wide ranging opportunities to create dialogue, tailoring opportunities to the local context. This can be through targeted 'direct' contact. It can also be through 'virtual/indirect' means, such as media opportunities for creating dialogue, with phone-in radio programmes, social media, and engagement through WhatsApp groups, for example. In some contexts, such as Bangladesh, there is a recommendation to include digital campaigns. The difference in the role of direct and virtual engagement in contributing to stigma reduction is an area which would benefit from further research.
- There is an identified need to strengthen the psychosocial component of addressing internalised stigma, and stigma by association. For example, building in a component of mental health into self-advocacy training, such as integrating mental health 'first aid', and/or providing or referring for opportunities for counselling, as needed. Regular follow up and mentorship might afford opportunities for improved psycho-social support.
- Consider a model of support groups, for both people with disabilities and caregivers. This approach can provide a safe environment for sharing experiences of stigma, as well as valuable for peer support, including psychosocial support.
- Stigma by association in many contexts can have a gendered dimension, for example, it is often mainly experienced by female caregivers in the home environment where there is a child with disabilities.
- Addressing structural stigma at an organisational level should be part of any package of interventions. The engagement of people with disabilities in organisations and decision-making structures can be a valuable approach in changing organisational culture. It is also about the capacity strengthening of members and leaders of a decision-making body to be able to engage meaningfully with OPD representatives
- There needs to be greater understanding of the role that advocacy plays, at a local or national level to address structural stigma. It would be valuable to explore effective ways to uphold laws, in particular how to censure discriminatory practices, as part of any stigma reduction approach.

## 7. Findings Cross-cutting issues

---

### 7.1. Intersectionality

In this section we explore intersectional experiences of disability-related stigma with other characteristics including gender, socio-economic factors, living in urban and rural settings, age, and other attributes. Intersectionality is a cross-cutting issue, and where relevant, has been highlighted in other sections of the report.

The three main attributes repeatedly highlighted were type of disability, gender and living in a rural context, although poverty was also closely interwoven with these.

Intersectionality is defined as the understanding that people are simultaneously situated in multiple social structures and realms. However, when they intersect, identities can produce a multiplication of advantage or disadvantage [15].

### 7.1.1. Type of disability

A key recurring theme was that the type of disability changes the nature of stigma experienced, and therefore may also need a different response. Participants discussed in general the more limited participation of people with some types of disabilities, also reflected within OPD structures, and therefore by extension less participation in project - related activities. This included people who are deaf-blind, those with complex disabilities and those who are deaf. This was not necessarily seen to be directly attributable to stigmatising attitudes, but due to a lack of reasonable accommodation, such as a lack of sign language interpreters. That said, as one staff member argued, it can also be due to a lack of organisational priority to action this provision, arguably a type of structural stigma.

Within the OPD community stigma also exists, reflected in the under-representation of some groups, and stigmatising attitudes which can exist.

In terms of adopting tailored responses, there was some valuable learning. The DIDIF programme included an organisation with expertise in working with people with deaf blindness in the consortium. This partner worked across projects, and also worked with local OPD and national partners with expertise, to improve the inclusion of people with multiple and complex disabilities. For example, in the Bangladesh and Kenya livelihoods projects, a six-month pre-training home-based education package facilitated access. A home-based education facilitator works with individual and family members and also connects them to the local OPD. Whilst addressing stigma is not an explicit component of the pre-training package it is felt that family outreach provides an opportunity to address stigma at the family level. The extent to which that happens would need further exploration.

The media component of the inclusive family planning project in Nigeria ensured that there were stories that reflected the lives of people with different types of disabilities. This enabled them to specifically challenge myths and beliefs that can be associated with different types of disability.

The provision of assistive devices was also key for the inclusion of people with different types of disability in various roles, and this has already been explored in the report.

### 7.1.2. Gender and disability

There was overall widespread recognition in all sites, that stigma was greater for women with a disability who can experience a double layer of stigma, also shaped by cultural beliefs. So, for example, in the Kenya and Nigeria setting, women with disabilities were more likely to be seen as unmarriageable compared to men, and also, if married, more vulnerable to abuse (See [section 7.2](#)) Other attributes, such as age and level of education, also intersected, to shape the experience of stigma.

*'We discovered that the most stigmatised were young women, with a disability.'* (KII partner staff, Nigeria)

In the Bangladesh inclusive livelihoods project, gender and type of disability intersected. If the disability was 'hidden' then parents were particularly concerned about the disability being disclosed, for example through their daughter participating in the project and thus making their daughter unmarriageable:

'A challenge for us was working with parents who still wanted to hide issues of disability in the family. [They were] Concerned that daughter could not get married if open about disability, and we had to convince them to enrol them in the programme – especially if the disability was not that visible, such as hearing impairment, or some partial vision. So, we had to address many layers of issues.' (KII partner staff, Bangladesh)

In adapting to this in Bangladesh setting, safeguarding was a particular issue to address for women with disabilities. This was also tied in with religious and cultural factors. Women with disabilities were therefore always placed in pairs in business settings, and for example were asked to go to the washroom together. Issues of safeguarding, and how that was addressed are explored in more detail in [Section 7.2](#).

'Women with disabilities are more vulnerable and experience different types of stigma and have more risk. Families with girls with disabilities are not confident to send girls out to the marketplace alone. There are concerns for her safety.' (KII partner staff, Bangladesh)

In this cultural setting the gender of the DIF also played a role, and it was seen as preferable for a female DIFs to visit the home when there was a daughter with a disability. The purpose was two-fold; parents saw the female DIF as a role model for their own daughter, but also a young woman would be more likely to talk about their experiences with another female. It was reflected that the programme could be further strengthened with ideally appointing male and female DIFs at each site:

'Women can be more shy sharing in our society, [and are] more likely to share to another female. For example, in one of our locations a woman with autism did not communicate with the DIF or with the master craft person [both male]. If there had been a female DIF, then that would have been better.' (KII partner staff Bangladesh)

Finally, caregiving for a child with a disability, and the experience of stigma by association is also gendered; it is often mothers who experience stigma in the home environment.

### **7.1.3. Living in urban or rural settings**

Living in a rural setting was consistently identified in all three countries to negatively shape the experience of stigma. This operated in a complex number of ways that either directly or indirectly compounded or reinforced stigma. So, for example in the inclusive livelihoods project in Kenya establishing business projects in the rural settings was seen to be harder, stigma was perceived to be greater due to lower levels of education and awareness, compounded by having a narrower customer base, combined with greater distances and yet poorer access to accessible transport.

Also, in rural settings there is less likely to be access to care and treatment, including access to assistive devices. A lack of care and treatment can arguably serve to reinforce traditional beliefs and taboos around causes of disability. A partner staff member in Bangladesh summed these issues up in her reflection on greater stigma in rural areas:

*'In urban areas you can access more support, for example for people with intellectual disabilities – but a poor family in a rural area will not get support for a person with intellectual disability. There will be less awareness about disability in the rural areas and less access to assistive devices.'* (KII partner staff, Bangladesh)

The limited or non-existent internet and social media in rural areas is another factor which can exacerbate isolation. There was some feedback from ICs in the Nigeria setting that there needed to be a greater understanding of the differences in these contexts, and a more nuanced strategy, rather than 'one size fits all' approach.

Other intersecting characteristics raised included poverty, age, ethnicity, and religion. However, even within those characteristics there can be other factors for consideration. So, for example, in the inclusive family planning project in Nigeria, the topic of family planning and sexual and reproductive health also comes with its own stigma, and peer sessions were organised into women were married, unmarried, and men with disabilities. This was with a focus on stigma, but an IC explained that the differentiation of materials and sessions allowed for 'varying social, emotional, and practical support that each group may require'. So, for example, the handbook for young unmarried women with disabilities 'may concentrate on themes such as independence, personal development, and relationship building in a societal context that often marginalises their voices'.

#### 7.1.4. Key learning points

- Overall, type of disability, gender, and living in a rural area, were key characteristics identified which intersect to shape the experience of disability-related stigma. Other characteristics include socio-economic status, age, ethnicity, and religion. For example, Women with disability can experience a double layer of stigma. This is also linked into concerns about safeguarding. Stigma in rural areas is compounded by lack of access to treatment and support, lower levels of awareness on disability issues, with challenges around access to information, long distances, and a lack of accessible transport.
- People with complex disabilities, and those with an intellectual disability are often more marginalised, which can contribute to stigmatisation. The lack of reasonable accommodation can exacerbate this. The lack of priority given to addressing issues such as provision of sign language and assistive devices is arguably a type of structural stigma.
- DIDIF projects adopted some tailored approaches to address issues of intersectionality. For example, the provision of a pre-training home care education package for people with deaf-blindness and their families.

#### 7.1.5. Recommendations

- An intersectional approach to understanding stigma and shaping the response to mitigate stigma is always required.



- Quality research and engagement with people with disabilities is needed to identify important intersectional characteristics, and other local and socio-cultural factors, in order to design and implement tailored responses. Understanding and responding to the particular challenges of living in a rural context is a gap which needs more attention.
- We know that people with disabilities are more likely to be poor, and the stigma of poverty intersects with disability related stigma. It is valuable therefore to recognise the role that approaches to address poverty, which includes improved access to social protection, and support with livelihoods, can play in mitigating stigma.
- As part of a holistic approach, consider how to strengthen approaches for reasonable accommodation and provision of assistive technology. Whilst provision of assistive technology can be outside of the project scope, it is important to connect and facilitate access to government schemes for social protection and to secure technology.

## 7.2. Safeguarding

In its essence, safeguarding is about creating a safe environment that upholds individual human rights and dignity. Under the FCDO Supplier Partner Code of Conduct; Safeguarding, social responsibility and respect for human rights are central expectations. Partners must ensure that robust procedures are adopted and maintained to eliminate the risk of poor human rights practices within complex delivery chains. These practices include sexual exploitation, abuse and harassment, all forms of child abuse and inequality or discrimination on basis of race, gender, age, religion, sexuality, culture, or disability. For more information on DIDIFs safeguarding approach see IDDC Inclusive Safeguarding Report, 2020.

A common view articulated was that stigma and safeguarding are distinct issues, and should be addressed separately, but are closely interlinked. Stigma, most commonly social stigma, was seen to be a driver of safeguarding issues but could also be a barrier to using safeguarding systems.

*‘Safeguarding issues themselves are instances of stigma, harassment and bullying are a form of discrimination.’ (FGD Global safeguarding group)*

At the same time there was a consistent theme that interlinkages between the two concepts could be made more explicit, for example more intentional in the design stage and in safeguarding training.

### 7.2.1. Social stigma and safeguarding

Bullying and abuse in different settings was seen as common safeguarding issue which is often driven by disability-related social stigma.

*‘There were cases of abuse as well because of the disability, and there is also discrimination happening within the house parameter and then when they go to the school. Yes, there is lot of discrimination as well, among the teachers and the students.’ (FGD Safeguarding group)*



‘You need to make it clear that bullying and name calling for example is an offence. You cannot separate safeguarding and stigma. In Bangladesh there is a disability law which states that we cannot bully about disability, but people don’t know that law. In our awareness raising people are often hearing about the law for the first time.’(KII partner staff\_03 Bangladesh)

Another key area of safeguarding commonly raised was in relation to addressing gender-based violence, including sexual abuse, across all the countries. Disability-related stigma was identified as a key driver of violence in the home in various forms. For example, in the Nigeria family planning project gender-based violence, intimate partner violence was identified as a barrier at the start of the project. The link with stigma was articulated by the ICs who stated that within the peer-to-peer sessions, violence was a pervasive issue discussed:

‘One woman described how her spouse belittled her disability, using terms such as "kurma" (offensive word for ‘deaf’) to mock her. This kind of derogatory labelling often becomes a form of emotional and psychological torment. The abusive dynamics extend into their family relationships, as the abuse victim may be subjected to scorn from relatives who blame her for her situation, suggesting that her choice to marry the abusive partner was a personal failing.’ (FGD female ICs Nigeria)

It was also reflected that the Nigeria setting that women often conceal their experience of violence in the home, with societal stigma towards disability exacerbating the experience, combined with the sequelae of stigma; isolation and poor mental health

‘The experience of gender-based violence is a pervasive issue that impacts all women, with particular emphasis on those living with disabilities. This encompasses both married and unmarried women who face unique challenges due to their circumstances. During peer-to-peer sessions aimed at discussing these matters, numerous participants highlighted the alarming prevalence of gender violence’ (FGD female ICs Nigeria)

‘When one woman attempted to discuss her plight with family members, she was met with dismissal. Her relatives asserted that since she had chosen her husband, it was her responsibility to endure the associated hardships. This stance underscores the societal stigma faced by women with disabilities, further entrenching their isolation and suffering. Such narratives reveal a troubling pattern of abuse within domestic settings, illuminating the urgent need for greater awareness and intervention to support these vulnerable individuals.’ (FGD female ICs Nigeria)

Societal stigma which shapes stereotypes about people with disabilities feeds into a cycle of abuse as illustrated here in the example from Nigeria where a woman with a disability was expected to beg:

‘One particularly poignant account came from a woman with a visual impairment. She recounted the grim reality of her husband leaving each morning without providing her with any food or money, he would dismiss her

concerns by reminding her that others, including their friends, were out begging, and earning money. The expectation was that she should follow suit. (FGD ICs Nigeria)

### 7.2.2. Internalised stigma and safeguarding

Whilst it was generally the role of social stigma that was commented on, one IC also reflected on how abuse can contribute to internalised stigma and poorer self-esteem, which is perhaps not surprising. This in turn can reinforce a cycle of stigma and abuse.

‘There are alarming narratives concerning women who, despite entering marital relationships, experience ongoing trauma and abuse. Take, for example, a woman who suffers from a significant mobility impairment; her condition may render her vulnerable to ridicule and neglect, particularly from her husband's family. This perception can lead to emotional distress, causing her to feel as though she is a burden, fundamentally altering her sense of self-worth and agency.’ (FGD female ICs, Nigeria)

### 7.2.3. Structural stigma

The final area that was raised as valuable learning were achievements across projects in addressing structural issues, such as putting in place new and/or strengthened local reporting and response systems and services that are disability inclusive. This is identified as a safeguarding issue but it is also about addressing systemic issues which compound stigma. There is recognition that establishing systems alone are insufficient, and these need to go hand in hand in addressing societal stigma. For example, the attitude of service providers who see people with disability as asexual will need to understand that these mechanisms are also of relevance for people with disabilities. The fact that vulnerability could be heightened by the desire to ‘protect’ children with a disability was another sub-theme raised.

‘[Stigma and safeguarding] are intrinsically linked because ...when we're setting up safeguarding processes and protocols in the community, that kind of education piece around stigma is so important. I've heard from across the DID programmes the perception of disabled children being non-sexual and wouldn't be abused. It is really there. So, it's kind of almost doing that education piece in tandem with setting up the safeguarding systems.’ (FGD Safeguarding Group)

Interestingly there was an example given to explain that safeguarding can be due to other characteristics, such as ethnicity, and not because of disability-related stigma. Of course, with an intersectional lens, these issues are often interconnected.

‘Yes, there is a link. Safeguarding issues can be because of stigma but can also be due to other vulnerabilities or other characteristics e.g., ethnicity. I think it's important to keep the two things separate’ (KII Global FMT)

### 7.2.4. Key points

- Stigma and safeguarding are two distinct concepts but they are intrinsically linked and often have to be addressed in tandem to be most effective.
- Bullying and gender-based violence are still pervasive and stigma and discrimination can be a key driver.
- Stigma can be a barrier to reporting abuse. For example, local reporting and response systems may not be seen as relevant to people with disabilities, for example, if a woman with a disability is seen as asexual. DID projects have invested in strengthening local reporting and response systems and services so they are disability inclusive and this has to go in tandem with mitigating stigma.
- The role of internalised stigma, and the interaction with safeguarding issues, including the agency to report issues, is an area which deserves better understanding and attention.
- Peer to peer support sessions appear to offer a valuable space to discuss issues of stigma and safeguarding.

#### **7.2.5. Recommendations**

- Strengthen the understanding of linkages between stigma and safeguarding. This should be emphasised at the planning and design stage of the programme as well as woven into training and other stages of the programme cycle.
- The application of an intersectional lens can help in understanding the interaction of both stigma and safeguarding vulnerabilities and help tailor the best way to address these.
- Include research on gender-based violence, stigma, and disability, to inform both advocacy and programming. This should also encompass work with female carers who also experience abuse for having a child with disabilities.
- Strengthen the use of peer-to peer support sessions and explore the role they can play in mitigating stigma and approaches to gender-based violence. This should also include addressing issues of internalised stigma.

## 8. Findings – Learning Question 3

---

### Learning Question 3: How can development programmes demonstrate change in disability-related stigma, negative stereotyping, and discrimination?

- What tools or approaches have DID projects used to demonstrate or measure changes in disability-related stigma, negative stereotyping, and discrimination?
- What do the tools and approaches tell us about journey that DID projects have made in reducing disability-related stigma (if that was their intention)?
- How appropriate, practical, and replicable are those tools at demonstrating change in disability-related stigma, negative stereotyping, and discrimination?

Overall, across interviews in all three countries, and at a global level, there is recognition that measuring stigma is a challenge. Whilst recognising that stigma was an important cross-cutting issue most projects chose to not measure stigma.

The main two barriers given for not measuring stigma were a) that it was a concept that was abstract and therefore too difficult to measure, and b) that there were no useful measures and tools that existed. Stigma indicators were not set for the projects reviewed, probably because it was a cross-cutting issues. But as one staff member explained:

‘We have kind of avoided having specific KPI or indicator around stigma and discrimination, because it's very difficult to measure like. How do we measure that?’ (KII Global 02)

This finding also ties in with the findings of the desk review, with projects not selecting to measure stigma; with the exception of projects working towards outcome indicator 2.4 in the Programme Results Framework (Evidence that women, men, girls, and boys, with and without disabilities, reached by behaviour change communication strategies aimed at reducing stigma and discrimination.)

It is also worth noting that whilst we interviewed a wide range of key informants many were not directly involved in MEL activities and therefore information collected was limited for LQ3. There may have been other approaches not captured, although the findings here resonate with the desk review findings which we have incorporated.

### 8.1. Tools and approaches

There were several tools identified as useful in assessing some elements of stigma, although it was limited. In general, they focused on capturing change in social stigma. They included: pre and post-test survey questions, qualitative data, the Wellbeing Checklist [16], and monitoring tools for social media. In addition, the disability inclusion score card (DISC) was referred to by staff; this is not designed for measurement but identified as a useful tool for exploring change qualitatively at an organisational level. This use of this tool is explored in Section 6.5.2. Other approaches adopted which provided some learning on stigma reduction, informed by the desk review, included project mid-term reviews and final evaluations, and pieces of research through the consortium’s research partners (IDS and [The International Centre for Evidence in Disability](#) at the London School of Hygiene and

Tropical Medicine). Whilst the programme's research are extremely important approaches, they were generally not referred to in project staff interviews, which might suggest that further specific probing was required in the learning review, and/or that this research was sometimes seen as quite separate and distinct from everyday project activities.

### **8.1.1. Pre-post-test survey questions**

The most common approach is using pre-post test questions. The mainstream media partner organisation's work in Nigeria is assessed with a mixed approach, combining pre and post campaign surveys and qualitative approaches. The surveys assess reported change in social stigma, that is reported knowledge and attitudinal change. The use of pre-post surveys has value, although weaknesses of this approach include that it looks at change in the short term, is open to social desirability bias, and does not capture a change in behaviour. FGDs are conducted with listener groups, combined with monitoring of social media, all contribute to a more rounded picture of change, although are still assessing short term impact and self-reported change.

In Bangladesh the inclusive livelihoods project used a pre-post survey, and the IE project is using a KAP (Knowledge, Attitude, and Practice) and KAS (Knowledge, Attitude, and Skills) survey. The latter includes questions to measure changes in knowledge and skills of carers and community members, and the argument is made that this will indirectly capture information related to stigma, although it is not clear how. In the Kenya livelihoods project, there were pre-post questions which looked at beneficiary change in confidence in relation to business skills, which could indirectly illuminate changes in internalised stigma.

### **8.1.2. The Wellbeing Checklist**

The Wellbeing Checklist was a product of the Nigerian inclusive education project 'Support Mainstreaming Inclusion to all Learn Equally'. This is a simple question checklist, generated in participation with parents and children with disabilities [16]. It aims to assess different dimensions of the child's life that contribute to overall wellbeing, which includes elements of stigma, both internalised and social stigma. One strength of the tools is that it focuses on the perspective of the person with a disability, in this case a child with a disability. Assessment of wellbeing is arguably a useful proxy measure for understanding stigma reduction and how that relates to overall wellbeing. Stigma is an element of several of the questions, not limited to the following:

- Getting on with other children in school.
- Experiences of teasing /mocking/hurting/bullying.
- Getting on with children at home and in the community.
- Treatment from adults in home and community.

The research partner, IDS, clarified that this tool still requires further testing, and ideally adapted into a pictorial format which is accessible to a wider range of children with disabilities. The participatory nature of the development is also more likely to make a tool which is relevant and appropriate to the target group. The replicability still needs to be tested, as does the robustness of the tool to assess change.

### **8.1.3. Qualitative approach**

A small number of KIIs referred to collecting qualitative data or 'anecdotal' stories from the field about stigma, but this was not done in a regular or systematic way. The usefulness of qualitative data for understanding mechanisms of change was highlighted by a research partner, although budget cuts to the DIDIF programme were identified as a factor which limited more research:

'We know there was a change in attitude in communities around children with disabilities going to school, but we don't know why and what is the mechanism of change. FGDs with the Inclusion Champions would have helped understand that.' (KII Global 04)

Similarly, in the desk review, projects sometimes provide qualitative data which related to stigma in regular project reports, but it is not collected systematically. Qualitative research was most notably conducted for the BBC Media Action work, already described above.

#### **8.1.4. Sentiment analysis**

The social media campaign assessed a shift in social stigma by using online surveys. These looked at reported attitudes and uptake of family planning and also included a 'Sentiment Analysis' that tracked the emotional tone, opinions, and attitudes in response to influencers' content. The trend was shown to be positive throughout the campaign period, although it was also noted that a challenge is moderation of stigmatising comments. It was not clear how the sentiment analysis was conducted, and it would be useful to have a better understanding of that process. Measurement was post-campaign, so valuable in indicating reported changes in the short-term. Again, it is about capturing reported change in knowledge and attitudes.

#### **8.1.5. Proxy measures**

Staff reflect on outcome indicators which might suggest stigma is reduced. For example, improvement in referrals, uptake of services, and enrolment in schools. However, some of these measures do not easily translate into meaning there is a reduction in stigma has changed, or show how it has changed. Overall, these approaches reflect the findings of the desk review. Feedback from the Validation Group highlighted the value in looking at proxy measures such as participation,

#### **8.1.6. Research and evaluations**

It was beyond the scope of this learning review to examine all the research and evaluations conducted. However, we illustrate some examples here of the role of research and evaluations conducted, and learning in relation to tools and approaches to understand stigma change. There were Randomised Control Trials (RCTs) nested into selected projects, although as stigma reduction was not an outcome, there were no explicit measures of this. In the inclusive education project in Kenya, two strands of research were carried out: an impact evaluation with an experimental design, combined with qualitative participatory research at baseline and endline [17, 18]. The impact evaluation did not assess any stigma-related measures. The FGDs conducted in the qualitative research highlighted issues of stigma, and helpful examples of progress made, as well as persistent challenges.



### 8.1.7. Learning spaces

Interviews at both a global and local level highlighted that it would be helpful to have increased space for thematic learning, including stigma. For example, in reference to the learning products detailed below, it would be helpful to understand how they were used in order to be shared for future projects and across consortium projects. There was also a request from DIFs to be more fully engaged in monitoring, evaluation and learning opportunities so they can understand changes in practice. There were regular project learning meetings, but we did not gather information on how these worked in practice as it was beyond the scope of this review. Again, given that projects generally selected not to measure stigma, it was then unlikely that information on stigma was collected. Given the identified need to really tailor stigma messaging to the local context, intentionally integrating reflections on stigma into regular learning meetings and documenting it was felt to be key.

#### 8.1.7.1. Learning reports

The desk review included an appraisal of learning documents generated from three projects<sup>6</sup>. The learning documentation methodology was different across projects. For example, the Bangladesh inclusive livelihoods learning document was generated from a one-day participatory workshop with project staff. It was less clear how the compendium of learning was produced for the ECDE Kenya project and the Hamro coffee project in Nepal. Each paper provided some useful learning in relation to stigma, with different degrees of detail. What was less clear was how the learning documents were disseminated and integrated into the project and /or opportunities for learning across projects and/or future projects. This would require further inquiry. Future learning products would also benefit from a clear methodology and dissemination plan.

#### 8.1.8. The Disability Inclusion Score Card (DISC)

The DISC is a tool used in project Bangladesh and Kenya. It is included in this section because, whilst arguably not a measurement tool, participants who have used it refer to some value of the tool. Staff highlight that it can help capture organisational barriers, can be motivational, help set action plans, and may provide useful 'stories' about organisational change, which may include stigma. Care also needs to be taken in interpreting the 'scores', and there will be issues of reliability and validity for various reasons. It was also not designed to be a measurement tool, but arguably could be used in combination with other approaches to provide some qualitative data.

## 8.2. Key learning points

- Most projects selected not to measure stigma. And measurement of stigma was seen as challenging.
- There are several tools and approaches used in projects to capture elements of stigma change. The focus was more on capturing change in social stigma, where the main tool used was pre-post survey questions.

---

<sup>6</sup> Learning documents reviewed: Promoting inclusive Early Childhood Development in Kenya (TO20), Disability Inclusive Coffee Project in Nepal: Lessons Learnt (TO 16), Disability Inclusive livelihoods in Bangladesh (TO 12) and Youth Employment

- Qualitative data was collected by some projects but, with some exceptions, not systemically. The Wellbeing Checklist has potential to be useful as a proxy measure for stigma and is now at stage where it needs further testing and adaptation.
- There is recognition of the need to better understand change over time, given the complexity of stigma. For example, the fact that shifting social norms and changing beliefs takes time.
- There were regular project-level learning meetings and, for example, learning products produced. It was less clear how this learning translated into changes in stigma reduction approaches, and this was beyond the scope of this review. There was a call for a strengthened approach to learning on stigma, and ensuring there is adequate space in future projects for evidence and learning to feedback into practice and be documented.

### 8.3. Recommendations

- Where stigma is a cross-cutting issue then embed a stigma outcome or output indicator/s into the MEL framework. This needs to be planned for at the design stage.
- Approaches to stigma measurement should be strengthened. Guidance on suitable indicators, and stigma measurement would be useful. Consider proxy measures such as participation and wellbeing to understand how the impact of stigma may have changed over time.
- It is important to move beyond assessing change in knowledge and attitudes and self-reported changes in behaviour. Explore how mixed methods, including data from people with disabilities, can contribute to a richer understanding of stigma reduction and mechanisms of change.
- Invest in adopting a longitudinal approach that looks at changes in stigma over time, For example, the drivers at different levels of society that may change, the different stigma types, and long-term shifts in social norms. Recognising that this can be a time and budget intensive approach, this could involve a small cohort:

*'It would have been good to revisit after a month, and then again, to understand the changes over time. We could have then seen changes: were they [the beneficiaries] still isolated/outcast? How were their feelings? Were they still bullied? Did they have equal pay in the workplace as others without a disability? We did not do this but I would recommend a mainly qualitative [approach] to capture different dimensions.'* (KII partner 03 Bangladesh)

- Create programmatic learning spaces on stigma so organisations can learn from each other, this is especially important in a large consortium that operates over multiple countries.

## 9. Conclusions

---

In conclusion, this review examines three key learning questions on stigma in the DIDIF programme, focussing on the language and framing of stigma, lessons from implementation and approaches to measuring change. Summary key learning points are presented in the executive summary and a broad range of recommendations are provided.

## 10. Strengths and Limitations

---

A strength of the study is that we had three research teams, including a team member with a lived experience of disability, and national researchers who knew the local context well. Our approach to analysis, particularly with the Kenya team, was to constantly compare and contrast perspectives across the sites, as we coded the information and drew out key themes. There was also triangulation with data from the rapid desk review, and a final opportunity to share and validate findings with the Validation Group.

However, a key limitation of this study is that there was little or no measurement of stigma across any of the projects or captured in routine project documentation such as reports. Therefore, data captured in this learning review is mainly perceived changes and mechanisms of change. Whilst this is of course still valuable, it emphasises the need to prioritise ways to better assess stigma.

There is greater weight in the data collected in the Kenya context, as this had a dedicated research team working in the field. In Nigeria we built on the existing mid-term review process, which whilst valuable was only the inclusion of one question on stigma. In Bangladesh the political unrest resulted in a more limited scope of study and data is drawn only from staff only, rather than a wider range of OPDs and beneficiaries.

## 11. Appendices

---

### 11.1. Appendix 1: Validation group members

- Action on Disability and Development (ADD)
- BRAC
- IMPEL Consultancy
- The Institute of Development Studies
- The International Disability Alliance
- Light for the World
- Sense International
- Sightsavers
- Organisations of Persons with Disabilities including Spandan Pratibandhi Unnoyan Sangstha, Chittagong Disabled Development Society, Shafol OPD Sirajganj, Alor Pradip OPD Sirajganj, and Spondan OPD Narshingdi

Video recording from this meeting is available here: [https://youtu.be/dVKX-f\\_KKr8](https://youtu.be/dVKX-f_KKr8)

## 11.2. Appendix 2: Sample interview guide

### FGD Guide: Kenya Beneficiaries (persons with disabilities) and caregivers (TO 50)

Updated 13/09/24

**Date:**

**Name/Code:**

**Interviewer:**

**Inclusive approach:** Check in advance if participants have additional needs that you need to accommodate for in planning for the FGD. See general guidance.

#### **Background Details of FGD:**

1) no of participants, 2) M/F mix, 3) types of disabilities represented/caregiver, 4) geographical spread background to participants, 5) other relevant contextual factors & characteristics

**Interviewer note** we use term 'stigma' here, but in practice use term that participants are comfortable with. If you use the word stigma, check in with them to check their understand of the term and/or preference for term and keep notes on that.

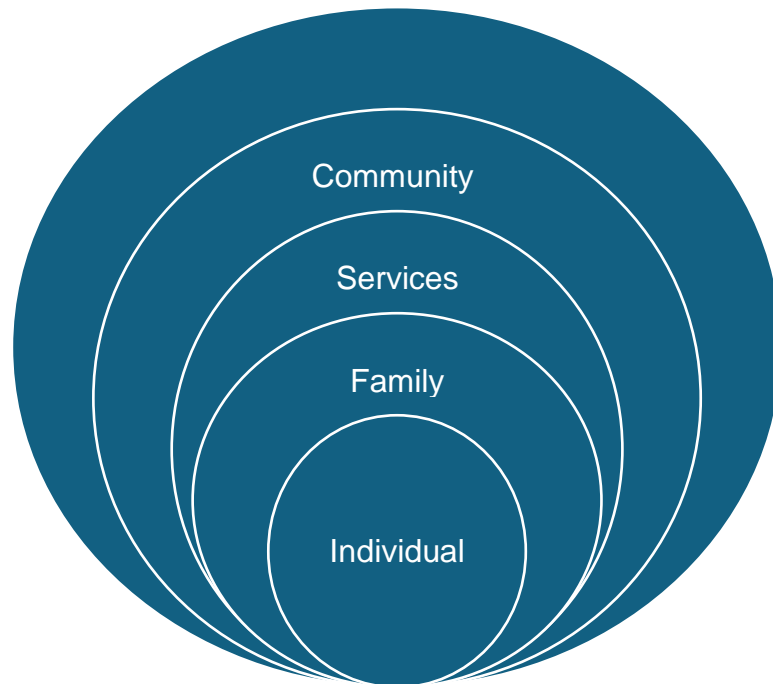
- Prepare the flipchart in advance of the FGD (see diagram below).
- Check in advance for additional accommodation to be made/ levels of literacy and plan for that
- In addition to recording, have a note taker is needed to write detailed note. Some of this can be written on the flipchart (LQ2)
- Read out and check that they have understood the information sheet and whether there are any questions to clarify.
- Remind participants that the main focus is about sharing and learning, with a focus on approaches to reducing stigma and discrimination.
- At the end of the session take a photo of the flipchart. Provide detailed notes to accompany the key points on the flipchart.
- Adapt to a KI interview if home visit

#### **Introductions**

Welcome. Introductions/name/the business they are running, and one thing they enjoy about their work.

#### **LQ 1: Understanding of stigma**

- **Interviewers note:** Put up flipchart (prepare in advance) and explain that at the outset of their project, stigma, negative attitudes, and discrimination were identified as barriers at these different levels; for the individual, family, health services, community, at a higher level of policy and in media. The purpose of today's session is to talk about and reflect on these issues.



- Ask what ‘stigma, negative attitudes and discrimination’ means to them? What local terms do they use? Keep a note of the language they use, and way they describe it. (Graffiti board)
- If they *don't talk* about different elements of stigma, then explain briefly and simply that for us we consider different elements of ‘stigma’ as: **1)** negative attitudes and prejudice held by people in your community which often results in discriminatory actions (we call this social stigma). **2)** how people with disabilities can feel as a result of these attitudes and actions e.g., some people feel a loss of self-confidence, perhaps feelings of shame (internalised stigma). **3)** where families can be affected by stigma as a result of having a child with a disability e.g., a mother stigmatised for having a child with a disability and **4)** policies and laws which can reinforce stigma, including the media (we call this structural).
- What do they think about having these different ways of thinking about stigma? Is that helpful? Or complicated? Is this totally new to them?

### **LQ 2: Perceived early effect of their participation in the project**

- Can you tell us what you think the most ‘significant’ (most important to you) change is that you have seen in participating in this project.
- **Interviewer note:** participants are most likely to talk about business achievements. Take a note of this but aim to steer them back to exploring different dimensions of stigma and what has helped.

### **1 About how you feel about yourself?**

- Any changes? How do you think that came about?



- What/who helped most? (e.g., role of OPD volunteers, DIFs? – has anyone visited their homes? What did they do? How did that make you feel? Was it helpful?)
- Anything you felt didn't help?
- Suggestions for what you think would help more in addressing stigma (tailor to their language)

## **2 Changes within the family environment**

- Any changes? How do you think that came about?
- Are here key people who have helped? How?
- Anything you felt didn't help that we need to better plan for?
- Suggestions for what you think could improve – other things that we need to consider

## **3 Changes in the community**

## **4 Changes in the Businesses community**

## **5 Changes at a policy level**

### **Intersectionality**

- **Interviewer note:** if in an FGD, you can draw these out in different colours to highlight differences
- Explore differences in approach needed to address stigma for:
  - People with different types of disability?
    - Prompt: SENSE is supporting working with people with very complex disabilities (deaf/blind). If you are talking to caregivers then explore how families perceive the experience of having a child
    - As a person who is visually impaired/deaf ....
- Explore whether as a man/woman with a disability you are treated differently? Has the project worked with you to help with that? In what way?
  - Prompt: TO 50 summary statistics state: 301 women with disabilities supported/159 men. And also, largely female caregivers So emphasis on women in project. Explore
    - Other characteristics- age/socio-economic class

### **Thank you and 'Other'**

- Invite everyone to look at the flipchart/s and summary of key issues. Thank them for their valuable time and helpful reflections which will be very useful for future work in Kenya and other parts of the world.
- Overall views/reflection on the key points. Do you feel that this has captured your key ideas?
- Is there anything else important related to stigma reduction within disability inclusive approaches to livelihoods which we have not covered?

### 11.3. Appendix 3: Example topic guides: Global, DIFs/inclusions champions/Programme staff

#### Topic Guide: Klls programme staff & partners TO 50 Kenya

Targeted at: Sightsavers, HI, SENSE, UDPK staff, DIF facilitator

Updated 13/09

Date:

Name/Code:

Interviewer:

In-person/phone interview:

- Check that they have understood the information sheet and whether there are any questions to clarify.
- Remind them that the main focus is about sharing and learning, with a focus on approaches to reducing stigma and discrimination.

**Field notes:** Background to interview, any relevant contextual factor. Note: we are using term 'stigma' here, but in practice use term that the KI most comfortable with. If using the word stigma, check in with them to check their understanding of the term and/or preference.

**Interviewer Note:** We use term 'stigma' here, but in practice use term that the KIs most comfortable with. If you use the word stigma, check in with them to check their understand of the term and/or preference for term and keep notes on that.

There are prompts below which provide some background information and provide additional questions which you can tailor to individual KI interviews to probe further.

#### **Introductions**

- Welcome and introductions/name/how long they have been in the role/area that they work in
- Explain that we want to draw from their experience today

#### **LQ 1: Understand/address disability-related stigma in design and planning phase**

##### **Language and concepts of stigma**

- We are interested in understanding how people talk about 'stigma'. What in your view is the best way to describe this concept in this project/s? What does it mean to staff? Beneficiaries? What language do you use in your work? Why/why not use the term stigma – what's the general feeling around the word stigma.

*Prompts:*

- TO 50: Main focus was addressing ‘stereotyping and discrimination’- is that the language they used within the project i.e in mass media work? Any learning from research conducted which informed use of language?
- In practice, for example in the latest annual report, there is no explicit reference to ‘stigma’ – explore why? Is it that the term ‘stigma’ isn’t helpful or ...?
- Some people in international development talk about different types of stigma: 1) social stigma (views of people in the community), 2) self-stigma or internalised stigma (how people view themselves) 3) structural stigma – relating to policies and advocacy. 4) by association. Do you think this is a useful way to think about what stigma means? Is this a way of thinking about stigma that you are familiar with? What in your view is most helpful?
- Design and planning
  - At planning and design stage - what was useful at this stage/less useful for planning on stigma reduction?
  - Prompts/notes:
    - Resources/people/approaches/research
    - TO 50: There is reference to key learning from the pilot phase of the project. Was there specific learning which shaped the work on stigma?
    - T050: across the 4 pillars of the approach, how and where, is stigma reduction woven into the different pillars?
    - Was there intentional planning to address different aspects of stigma at the outset? Did it evolve over time?
    - How was research used? What was helpful/less helpful (provide a concrete example of how used)
- Recommendations:
  - Any recommendations can you give for improving the design and planning for stigma reduction

## **LQ 2: How to deliver effective interventions to reduce disability-related stigma?**

- **Interviewer note:** Tailor questions specifically to each KI- to their specific role and probe further.
- Types of approaches: What areas of stigma have been addressed in your work?
  - Probes:
    - Link back to earlier question on understanding of stigma and seek to clarify what of following areas have been a focus: **1)** social stigma (views of people in the family / community), **2)** self-stigma or internalised stigma (how people view themselves) **3)** structural stigma – relating to policies and advocacy. **4)** stigma by association (experienced by family members)

- Perceived early effect: Where do you think there was most significant (important) change in reducing stigma? And how?
  - Prompts:
    - Explore change at different levels: 1) with the individual, 2) in the family, 3) across business services, 4) at policy level.
    - What helped most to facilitate delivery and why?
    - Role of the DIFs is to improve inclusion. Understand more about their role. Who are they? Training and support they receive for that role around stigma? Any learning here on what works particularly well and why? Is their role enough on its own for effecting change in social norms? who else key did they work with?
    - ‘Self-advocacy’ described as KEY in ‘improving confidence and has helped challenge stereotypes and biases against people with disabilities. Can you clarify what the mechanism is for how self-advocacy works to address stigma? Training on this provided by the DIFs
    - Advocacy is a key part of this project. Can they comment on how advocacy work contributes in their view to stigma reduction? Sometimes it’s hard to make those direct links – what does this look like? Good to have a concrete example.
    - Ask to see the animated video produced to raise awareness about rights of PWD – does this explicitly talk about ‘stigma’ in any way. Reflect
    - Other key areas which have not been explored in the 4-pillar approach?
- Anything you would do differently based on implementation so far?

### **Participation of people with disabilities**

- Can you reflect on the role of persons with disabilities in your different approaches to stigma reduction. Any learning here? Any recommendations
  - Prompts:
    - Working with 8 OPD networks across the programme- and they are described as ‘spear heading advocacy and awareness creation’ – how is this mainly done?
    - UDPK is a key delivery partner. How used at planning stage specifically in terms of planning around stigma reduction?
    - DIFs (one DIF per county) and OPD members. Clarify how are their roles different? Especially in relation to stigma reduction. Explore how they work

### **Intersectionality**

**Interviewer note:** these questions refer to both 1) design and planning stage and 2) delivery

- Is there any learning in relation to planning and design phase, or from the delivery of programme for:

- People with different types of disability?
  - Working with people with complex disabilities (e.g., deaf/blind) and role of caregivers is highlighted in summary document describing key learning. Clarify if there is learning here in approach to stigma reduction.
- Women with disabilities & Female caregivers
  - Families can experience 'stigma by association' – what is their experience working with the families and how do they work to address that? Any lessons here?
  - Gender: summary statistics state: 301 women with disabilities supported/159 men (CHECK on latest beneficiary numbers as this is from summary report). And also, largely female caregiver/. Is there a difference experience of stigma for the men and women with disabilities? And the caregivers? Does that require a different approach in how they work to address it? How? Any valuable learning here?
- For Urban/rural context
  - ProLucy identified urban/rural context will be different, was that planned for from outset or did that come from learning through delivery?
  - Other (see if other characteristics emerge such as poverty and age)

### **Safeguarding**

- Can you explain how your project understood and planned, and delivered on any links between stigma and safeguarding issues? Did you explicitly plan for this, how?

### **LQ3: Demonstrating change in disability-related stigma**

- From the various approaches adopted to measure change, is any data collected about stigma reduction?
- Probes:
  - If yes- how?
  - If not- why? (too difficult? Not required to....)
  - Have you discussed at planning phase the use of proxy measures for exploring how you assess stigma? If yes- what was the thinking? If not, why? Any views on this in terms of what would be useful?
  - 
  - 'Collecting and sharing evidence' is one of the key 4 pillars. If stigma is a cross-cutting issue – has anything been collected to help understand stigma reduction?
  - Reference in annual report to a 'ripple effect in community' on attitudes – sounds interesting. How is that/can be captured?
  - Any recommendations for how capturing change might be improved?

- Anything you would do differently in approaches to measuring change?

**Other**

- If you were to prioritise 1-2 key learning messages on stigma reduction from this project, what would they be?
- Anything else you want to add which we haven't covered?



## 12. Bibliography

---

1. Adams, K., *Principles for global action: preventing and addressing stigma associated with conflict-related violence* available at at [https://assets.publishing.service.gov.uk/media/5a82a842ed915d74e3402e70/PSVI\\_Principles\\_for\\_Global\\_Action.pdf](https://assets.publishing.service.gov.uk/media/5a82a842ed915d74e3402e70/PSVI_Principles_for_Global_Action.pdf). 2017.
2. Heijnders, M. and S. Van Der Meij, *The fight against stigma: An overview of stigma-reduction strategies and interventions*. Psychology, Health & Medicine, 2006. **11**(3): p. 353-363.
3. Hartog, K., et al., *Stigma reduction interventions for children and adolescents in low- and middle-income countries: systematic review of intervention strategies*. Social Science & Medicine, 2020. **246**: p. 112749.
4. Smythe, T., J. Adelson, and S. Polack, *Systematic review of interventions for reducing stigma experienced by children with disabilities and their families in low and middle-income countries: state of the evidence*. Tropical Medicine & International Health, 2020.
5. Sightsavers, *Disability-related stigma and discrimination in sub-Saharan Africa and south Asia: a systematic literature review* at <https://research.sightsavers.org/wp-content/uploads/sites/8/2021/08/Sightsavers-systematic-review-into-stigma-and-disability-FINAL-UPDATED.pdf>. May 2021.
6. Rohwerder, B. *Disability stigma in the Disability Inclusive Development (DID) programme countries: an overview of the evidence* @[https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15131/Stigma in the DID countries 2.9.19%20%282%29.pdf?sequence=1&isAllowed=y](https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15131/Stigma_in_the_DID_countries_2.9.19%20%282%29.pdf?sequence=1&isAllowed=y). 2022 [cited 2024 10/05/2024].
7. Van Brakel, W.H., et al., *Out of the silos: identifying cross-cutting features of health-related stigma to advance measurement and intervention*. BMC medicine, 2019. **17**: p. 1-17.
8. Stangl, A.L., et al., *The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas*. BMC medicine, 2019. **17**(1): p. 31.
9. Corrigan, P. and A.B. Bink, *On the stigma of mental illness*. 2005: American Psychological Association.
10. Weiss, M.G., J. Ramakrishna, and D. Somma, *Health-related stigma: rethinking concepts and interventions*, P280. Psychology, health & medicine, 2006. **11**(3): p. p.280.
11. BRAC. *Combatting Disability-Related Stigma in Bangladesh: A Behaviour Change Communication Toolkit* at <https://www.brac.net/program/wp-content/uploads/2023/05/BCC-Toolkit-Disability-Stigma.pdf>. 2022.
12. UNICEF. *Addressing stigma and discrimination toward children and youth with disabilities through SBC Disability Toolkit* at <https://www.sbcguidance.org/do/addressing-stigma-and-discrimination-toward-children-and-youth-disabilities-through-sb>. 2024.
13. Mak, W.W. and R.Y. Cheung, *Affiliate stigma among caregivers of people with intellectual disability or mental illness*. Journal of Applied Research in Intellectual Disabilities, 2008. **21**(6): p. 532-545.
14. Gaventa, J., *Reflections of the Uses of the "Power Cube" Approach for Analyzing the Spaces, Places and Dynamics of Civil Society Participation and Engagement* available at <https://www.participatorymethods.org/resource/reflections-uses-power->

- [cube-approach-analysing-spaces-places-and-dynamics-civil-society](#), in *CFP Evaluation Series No 4*. 2005: Institute of development studies.
15. World Bank. *Inclusion Matters The foundation of shared prosperity* at <http://documents.worldbank.org/curated/en/114561468154469371/pdf/814780PUB01ncl00Box379838B00PUBLIC0.pdf>. *New frontiers of social policy* 2013 [cited October 2024].
  16. Institute of Development Studies. *Report on Development of Children with Disabilities' and Parents' Wellbeing and Inclusion Checklist Tool 2023 - Phase 2* available at <https://www.inclusive-education-initiative.org/knowledge-repository/report-development-children-disabilities-and-parents-wellbeing-and-inclusion>. November 2023.
  17. Institute of Development Studies, *Children with disabilities', their parents' and teachers' changing perceptions and experiences of disability inclusive ECDE in 2 sites in Kenya*. 2023.
  18. Wickenden, M., J. Njungi, and B. Rohwerder, *Inclusive early childhood development and education in Kenya: What do parents, teachers and children understand, perceive and experience?* 2023.