

Breaking down barriers to inclusion: tackling disability stigma



Lessons from
Inclusive Futures,
2025

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Executive summary

Stigma and discrimination deny persons with disabilities their basic human rights every day. Too often, stigma acts as a barrier to prevent persons with disabilities engaging in or benefitting equally from international development projects. This learning report from Inclusive Futures showcases what we did – and did not – do to reduce disability-related stigma

in our international development projects. Using the learning presented here, we invite donors, government and non-government actors, and organisations of persons with disabilities to break down the barriers caused by stigma, and pave the way for a more equal world where everyone can access quality health care, education and employment.

Four lessons to reduce stigma:

1. Understand stigma as a barrier to inclusion.

Go beyond assumptions about what stigma is, or is not, and how it affects the people you want to reach. Work with persons with disabilities to understand what it means, how it operates as a barrier to inclusion, and why it is important to address, using examples from your project's context. Remember that stigma is intersectional and contextual, so people's experiences will differ.

2. Map out who you need to influence.

Stigma reduction needs to be planned for within a project – including who to engage and how it can be measured. Consider who can influence stigma and stigma reduction, and who experiences stigma. Most stigma reduction will require working with a range of actors, including persons with disabilities, as well as caregivers, community members and people in positions of influence.

3. Target activities to reduce different types of stigma.

When designing disability inclusion activities, include topics related to stigma and stigma reduction. Make these topics relevant and engaging to the audience, the type of stigma you are aiming to address, and the context. Activities need to empower and support persons with disabilities and their families or caregivers who experience stigma, target people in positions of power who perpetuate stigma, and facilitate dialogue in communities.

4. Partner with persons with lived experience.

Meaningful engagement of persons with disabilities and organisations of persons with disabilities (OPDs) is essential to address stigma, as projects designed and delivered with their input are likely to capture and respond to their experiences of stigma. Engagement needs to sustain or strengthen the capacity of the OPD, reasonably accommodate everyone, and integrate feedback and learning to capture observations and insights about stigma reduction.

About Inclusive Futures

Inclusive Futures is UK aid's flagship disability inclusion initiative, led by Sightsavers and the International Disability Alliance. It brings together a consortium of partners, including development and humanitarian organisations, disability inclusion specialists, and experts working in media, research, and academia, to innovate and scale approaches to disability inclusion in health, education, livelihoods, and tackling negative stereotyping and discrimination. We partner with OPDs to improve the lives of persons with disabilities, creating real results, and generating learning about what works, what doesn't and why.

Methodology

This learning paper summarises lessons learnt from the Inclusive Futures programme. The findings are drawn from multiple sources including: programme reports, discussions with the Inclusive Futures Fund Management Team and Sightsavers' Global Technical Lead for Social Behaviour Change, feedback from consortium members including the International Disability Alliance, and an independently commissioned technical paper; **Learning on disability stigma reduction: Concepts of stigma, implementing activities and demonstrating change.**

This learning paper does not aim to be authoritative or objective about stigma or its reduction. The lessons learnt are selected and summarised with the intention of guiding future decision-makers – programme directors, project officers, monitoring, evaluation and learning (MEL) colleagues and OPDs – to keep asking questions about how stigma impacts the effectiveness of their work with marginalised groups, and how they can integrate approaches to reduce it.

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Four lessons to reduce stigma

1. Understand stigma as a barrier to inclusion

What is stigma?

Stigma:

Stigma is 'a social process that leads to the marginalisation of individuals or groups'.¹ As a social process it changes across contexts and organisations and can be intersectional – affecting people with intersecting identities in different ways.² There are different types of stigma:

Social stigma:

Negative attitudes held by people in society about persons with disabilities, often shaped by culture and context. Also called public stigma.

Internalised stigma:

Feelings of low self-esteem, shame, negative self-belief and internalised oppression, which can result in self-isolation, for persons with disabilities. Also called self-stigma.

Stigma-by-association:

The stigma experienced by people based on their connection with a person with a disability, such as family members. Also called affiliate stigma.

Structural stigma:

Systems including laws, policies, organisations and the media, which embed or promote stigmatising attitudes or actions about persons with disability.³

In Inclusive Futures we did not start out with an agreed definition or shared understanding across all consortium partners, projects and countries about what stigma is. What we did agree on was that stigma was important to address in our projects, because stigmatising attitudes and behaviours could be a barrier to disability inclusion. We included the need to challenge stigma at all levels of our programme theory of change.

Under the umbrella of the Inclusive Futures programme are many country-specific projects. Some, but not all projects, added stigma as a barrier in their theory of change and started the project by understanding and analysing disability-related stigma in their context. This included discussing stigma with OPDs during project design workshops, and involving persons with disabilities in designing research tools to unpack stigma.

In Kenya, qualitative research carried out by Inclusive Futures' partner the Institute of Development Studies, uncovered how stigma experienced by parents of children with disabilities then affected their own attitudes towards their child, including their willingness to see them educated.⁴ Meanwhile, our inclusive eye health project in Nigeria used a survey and focus groups to identify the fear of being stigmatised as a factor preventing persons with disabilities from accessing eye health care.⁵

Some projects were able to capture the nuance of stigma – how it can change and intersect according to a person's identity and environment, creating intersectional barriers, including based on their type of disability, gender, age, ethnicity or location. Our inclusive livelihoods project in Bangladesh found that stigma in rural areas is compounded by structural barriers including a lack of accessible transport, limited communication infrastructure, and lack of access to treatment and support.



Absalom hugs his primary-school-age daughter Irene, who has Downe Syndrome.



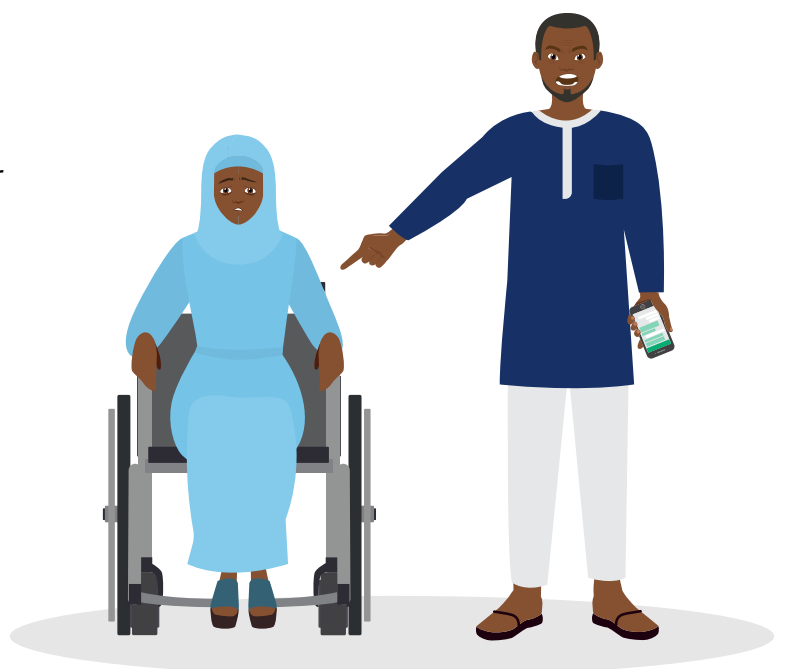
Israfil, a young man with disabilities, who received vocational training under our project led by BRAC in Bangladesh.

“

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 [an] intellectual disability. There will be less awareness about disability in the rural areas and less access to assistive devices.

Inclusive Futures consortium staff member, Bangladesh

Similarly, project research fed into our global inclusive safeguarding approach, identifying how intersecting stigma experienced by women and girls with disabilities can create an increased risk of harm or abuse. Research in our inclusive family planning project in northern Nigeria identified stigma about women with disabilities being sexually active, which could contribute to gender-based and intimate partner violence. Women-led OPDs further emphasised that social stigma means women with disabilities may be more isolated and therefore less likely to communicate about the violence they experience, further contributing to the risk of harm.⁶



Lesson learnt



Not all projects built a shared understanding of stigma from the beginning. It can be budget and time intensive and could seem impractical for projects that did not have stigma-reduction as an explicit outcome, even after it had been recognised as a barrier to inclusion in their theory of change. We found that having an indicator for stigma-reduction which some projects reported on moved it from being a concept to something tangible and achievable. This indicator was particularly relevant for our media projects:

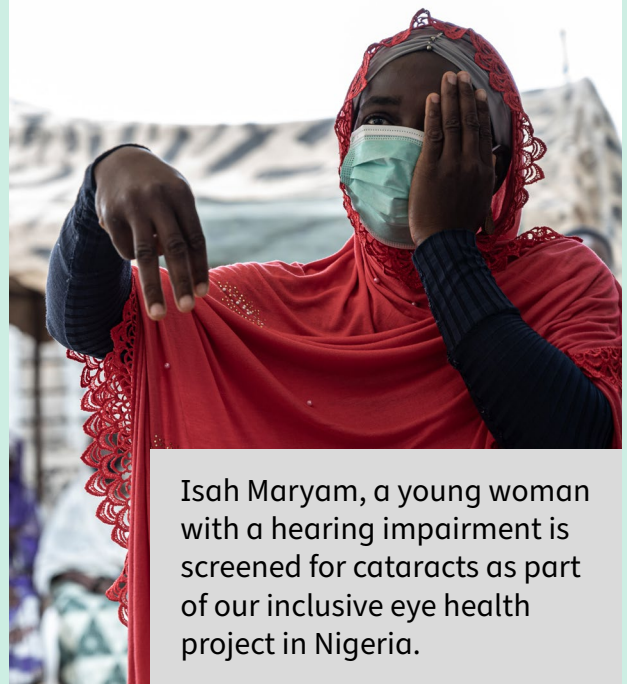
Evidence that women, men, girls, and boys, with and without disabilities, have been reached by behaviour change communication strategies aimed at reducing stigma and discrimination.

When project design did not explore stigma, we found that an assumption carried into the project that the main form of stigma they would encounter would be social stigma. This meant they potentially missed other forms of stigma which might have presented barriers in the project, and missed detail on how stigma can be intersectional.

Partners fed back that using more participatory and visual tools such as power analysis or social norms analysis⁷

to look at the connections between people, or a visual map of stigma as a Problem Tree, might have helped deepen their understanding of stigma during project design. Similarly, presenting a theoretical model of stigma, explaining broadly what it is and the types of stigma, might have helped partners move beyond assumptions.⁸

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Isah Maryam, a young woman with a hearing impairment is screened for cataracts as part of our inclusive eye health project in Nigeria.

Key learning



Go beyond assumptions about what stigma is or is not, and how it affects the people you want to reach. Work with persons with disabilities to understand what it means, how it operates as a barrier to inclusion, and why it is important to address, using examples from the project's context. Remember that stigma is intersectional and contextual, so people's experiences will differ.

2. Map out who you need to influence

Across our projects we identified a range of individuals and groups to engage – stigma has many parts and therefore requires many different people to be involved in reducing it.

These were often actors and structures that the project already planned to work with beyond stigma-reduction, aligning with other project outcomes.



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Head teachers, parents and OPD leaders holding copies of parent support guides, produced as part of our inclusive education project in Nigeria.



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.

Inclusive Futures consortium staff member, Nigeria

Persons with disabilities

All Inclusive Futures projects worked directly with persons with disabilities. We worked with the understanding that including persons with disabilities in projects which build knowledge and skills is likely to result in their self-empowerment and reduce their internalised stigma. We combined this with awareness that other forms of stigma and other actors also

need to be targeted.⁹ In Kenya, our inclusive livelihoods project strengthened the skills of microentrepreneurs with disabilities to run successful businesses and increase their personal independence. We measured changes in confidence and self-esteem at the end of the project, with an increase indicating that their internalised stigma had reduced.



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.

This quote was taken from a focus group discussion carried out with OPDs from our projects in Kenya.

Families and caregivers

Many of our projects chose to work with the families of children with disabilities, which gradually uncovered two important areas of stigma. Firstly, that they can experience stigma from neighbours, community members or institutions about having a family member who is a person with a disability. Secondly, they

can also recreate societal stigma towards their child through attitudes and behaviours. In our inclusive education project in Tanzania, we often visited family homes to build relationships and address any family concerns about the child's education. These visits uncovered that the families feared being stigmatised for having a child with a disability, and this was preventing them from enrolling their child in school.

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Sophia and her son Isaya, at their home in Shinyanga, Tanzania.



In the past, the community members made me lose hope because they told me Isaya would amount to nothing.

Sophia from Shinyanga, Tanzania



Our livelihoods project in Bangladesh ran sessions with families, community members, and market employers to challenge stereotypes about disability.

Community members

Targeting stigma at the community level focused on the attitudes and behaviours of people in the project area, often in neighbourhood-based groups or semi-formal structures of local leadership. Community-focused work included raising awareness about disability inclusion and the project in general. For example, in our inclusive livelihoods project in Bangladesh, we worked with young community members to design and share culturally-appropriate inclusive messages, and engaged neighbourhood-based groups in dialogue by hosting community awareness events.¹⁰

People in positions of power

People with influence, often those with authority or in trusted roles in society, can help with stigma reduction. These people can be gatekeepers to communities, such as the leaders of religious, traditional, youth or OPD groups. They can lead the way for other people to follow, including by demonstrating new language, behaviours and norms which are less stigmatising.

Structures

Some Inclusive Futures projects worked with structures and organisations – schools, local authorities, health systems – by providing guidance or feedback on their policies, language or service provision. This can form part of addressing structural stigma. In our inclusive sexual health and livelihoods project in Nepal, OPD members trained in disability inclusion became ‘Vulnerable Focal Points’ embedded in the municipality office. They supported more than 830 persons with disabilities to access social services and provided feedback to the municipality about how to make the service more accessible, resulting in service improvements.

Lesson learnt



Many projects in Inclusive Futures worked with persons with disabilities, their families and caregivers, community members and institutions, without directly focusing on stigma reduction. This meant that we did not always find the right people to engage for stigma reduction or measure the effectiveness of working with different people. In Nigeria, partners highlighted a gap in engaging religious leaders, who can be instrumental in shaping public values and beliefs about disability and

can contribute to perpetuating or reducing stigma. In Nepal, the OPDs embedded in the local municipality office might have been effective in reducing structural stigma, but the project did not set out to measure this, measuring instead the general improvements in accessing Disability Identity Cards that the municipality had made. Both points show that stigma reduction needs to be planned for within a project, and part of that planning includes who to engage and how it can be measured.



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Nanda, a young woman with disabilities, acting as a vulnerable focal point in Birendranagar local municipality office in Nepal.

Key learning



Stigma reduction needs to be planned for within a project – including who to engage and how it can be measured. Consider who can influence stigma and stigma reduction, and who experiences stigma. Most stigma

reduction will require working with a range of actors, including persons with disabilities, as well as caregivers, community members and people in positions of influence.

3. Target activities to reduce different types of stigma

Not every project in Inclusive Futures had activities designed directly to reduce stigma – many activities aimed to indirectly reduce it through inclusive messaging and the participation of persons with disabilities. Planning activities to reduce stigma was a logical step in projects where stigma reduction was an intentional part of a project’s aim, such as our media projects in Tanzania and Nigeria. In other projects, stigma reduction was integrated as part of broader inclusion aims, such as including points on stigma in trainings on disability inclusion. Across Inclusive Futures we therefore had a combination of two areas and activities: (1.) Empowering and supporting persons with disabilities and their families/caregivers who experience stigma, and (2.) Targeting influencers and people in positions of power who perpetuate stigma.

Building relationships in communities

We designed for personal engagement between persons with disabilities and people we wanted to influence, including parents and caregivers, and local leaders. In Nigeria, we supported persons with disabilities, youth and female leaders, to become Inclusion Champions, leading peer education sessions and speaking with families and communities. They tailored disability inclusive messages to address specific stigmatising stereotypes and attitudes, which they delivered through this interpersonal approach.



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Abubakar, an inclusion champion, leads a board game session, during a workshop with young men with disabilities in our family planning project in Nigeria.

Peer groups for caregivers

In all our countries, we worked with parents and caregivers to equip them with parenting skills to best support children with disabilities, building a sense of personal empowerment. These

spaces focused on livelihood and parenting support, and in doing so created a space where experiences about stigma could be shared, and self-confidence and collective voice to counter stigma was strengthened.



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 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.

This quote was taken from a focus group discussion carried out with safeguarding focal points in Inclusive Futures.

Peer support groups for persons with disabilities

Inclusion Champions in our family planning project in Nigeria ran peer group sessions amongst persons with disabilities, creating a space where they could open up about issues important to them. For the peer group of women with disabilities this included stigma around their sexual and reproductive health choices and their experiences seeking access to sexual and reproductive health information or services. The role of Inclusion Champions combined education, representation and interpersonal relating to shift internalised stigma for persons with disabilities.



When one has experience of disability there is so much that they can share with others in the same situation.

This quote was taken from a focus group discussion carried out with Disability Inclusion Facilitators in our projects in Kenya.

Community dialogue

We looked for entertaining ways to spark dialogue. Our inclusive education project in Tanzania used community drama to counter stigmatising beliefs in a non-confrontational way, with recognisable characters and situations creating points for dialogue and consideration. In Nigeria, we used local radio dramas and phone-ins to encourage discussion specifically addressing stigmatising myths. People with disabilities worked as editors and actors, bringing their in-depth knowledge on experiences of stigma, guiding dialogue and storylines and how it can be addressed.



Actors with disabilities recording an episode of Madubi, a popular BBC Hausa-language radio drama, as part of our family planning project in Nigeria.



To get change in society you need to get society to talk.

Inclusive Futures consortium staff member, Nigeria.

Skill-building and training for caregivers

In Tanzania and Nigeria, we worked with parents and caregivers to equip them with positive parenting skills to best support children with disabilities, building a sense of personal empowerment. Topics included disability and children's rights, stereotypes and labelling, and how to emotionally support their child. These topics had the potential to reduce stigma from the parent towards their child, and the parent's own internalised stigma.

Skill-building for persons with disabilities

Skill-building was a significant component of many Inclusive Futures projects. In our inclusive livelihoods project in Bangladesh, young persons with disabilities learned a trade – ranging from tailoring to mechanics.

Many young people reported that their self-esteem increased because of their newfound skills and their sense of financially contributing within their family, addressing some of their internalised stigma.

Mass media for broader community reach

In Nigeria, as part of a broader media campaign, we worked with 55 social media influencers to post key messages on different platforms where they had large followings. The messages were designed to directly counter stigmatising myths identified by formative research, using a trusted messenger.

Advocacy training for persons with disabilities

Our inclusive livelihoods project in Kenya equipped people to be self-advocates through a one-day training covering disability rights and confidence-building techniques, delivered by Disability Inclusion Facilitators. Participants at the end shared that they felt more empowered, allowing them to challenge their own internalised stigmatising beliefs and to challenge social stigma in their setting.



Agnes, a micro-entrepreneur who received self-advocacy training through our inclusive livelihoods project in Kenya.



[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.

Inclusive Futures consortium staff member, Kenya

Lesson learnt



Many Inclusive Futures projects started with a focus on 'educating for change', using a single or short package of trainings, meetings and workshops on disability inclusion. While this worked in building knowledge about disability rights, some stigma experienced by people with disabilities can happen over a lifetime and be deeply embedded in social norms and structures. Increasing the spaces and opportunities for community dialogue, moving beyond training and education, might be a way to challenge more ingrained forms of social and structural stigma.

Key learning



When designing disability inclusion activities, consider the importance of including topics specifically related to stigma and stigma reduction. Those topics should be relevant to that audience and to the type of stigma most important and realistic to reduce in your project and context. Activities need to both empower and support persons with disabilities and their families or caregivers who experience stigma, and target influencers and people in positions of power who can perpetuate stigma.

4. Partner with people with lived experience

In Inclusive Futures, all projects meaningfully engaged persons with disabilities and OPDs. Projects designed and delivered with input from people with lived experience of disability-related stigma are more likely to capture and respond to their experiences and identify priority approaches to reduce it.



In our inclusive livelihoods project in Kenya, OPD members became Disability Inclusion Facilitators (DIFs) after training on disability inclusion, inclusion principles and the ACAP framework (attitude, communication, accessibility, and participation). They then delivered disability inclusion training to project stakeholders, including public and private institutions. The DIFs, paid to take on these roles, noted that they were able to motivate and empower people during training to bring inclusive changes to their institutions, and that their role and work provided examples to those they were training of ‘disability inclusion in action’. DIFs fed back that taking a central role in the project raised their self-esteem and increased their sense of empowerment, challenging their own internalised stigma.¹¹

A recording session of Madubi. People with disabilities have played a key role in content research, script writing, recording and post-production for the BBC radio drama.



Alongside interpersonal roles, persons with disabilities also co-created content and materials for activities including radio dramas, positive parenting manuals and behaviour change campaigns. OPDs in community-facing roles were well-placed to identify changes in stigma, such as the attitudes

of parents and caregivers, and persistent or emerging barriers. We needed feedback loops and learning between OPDs and consortium partners to ensure their insights were used to adapt project activities towards continually addressing barriers to inclusion, including stigma.

Lesson learnt



Persons with disabilities and OPDs might not be experts in stigma reduction, and because of negative connotations and power dynamics, might choose to avoid naming it as an issue, even though it is important. We found we needed to support OPDs to build their technical capacity on stigma – including the types of stigma and how they can be reduced – and, where possible, involve them in data collection and analysis about stigma in their context.

Alongside this, we needed to have clear and agreed roles and responsibilities when working with OPDs, reasonably accommodate everyone to participate equally, budget to cover their costs of engagement, and create structured opportunities to use their insights about stigma – particularly from community and home visits – to better reduce stigma throughout projects.

Key learning



Meaningful engagement of persons with disabilities and OPDs is essential to address stigma, as projects designed and delivered with their input are likely to capture and respond to their experiences of stigma. Engagement needs to sustain or

strengthen the capacity of the OPD, reasonably accommodate everyone, and integrate feedback and learning to capture observations and insights about stigma reduction.

Conclusion

Stigma and discrimination deny persons with disabilities their basic human rights every day. In international development, too often, stigma acts as a barrier to prevent persons with disabilities engaging in or benefitting equally from projects. Through our actions and lessons learnt, Inclusive Futures has shown the value of taking steps to understand stigma in local contexts, and using this to inform project design. By learning from what we did and didn't do, donors, government actors, international NGOs and OPDs can help to break down the barriers caused by stigma, and pave the way for a more equal world where everyone can access the quality health care, education and employment they need.



Yakubu, a wheelchair user, after receiving treatment thanks to our inclusive eye health project in Nigeria.

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Inclusive Futures partners

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