

Stigma, disability and development



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About Bond

Bond is the UK network for organisations working in international development. bond.org.uk

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This briefing considers how stigma affects people with disabilities and why challenging stigma is a critical issue for development.

Key messages

Stigma often lies at the root of the *discrimination* and *exclusion* experienced by people with disabilities in developing countries.

Stigmatising attitudes can be challenged by *empowering* people with disabilities through, for example, self-help groups and skills training, and building solidarity with other stigmatised groups.

Changes in understanding and attitudes can be realised by *awareness raising* through mass media campaigns, staff training and encouraging community interactions, by for example facilitating people with disabilities working in the community.

What is stigma?

Stigma is commonly defined as the mark of disgrace associated with a particular circumstance or quality. People who are stigmatised are treated differently from other members of the community. They are usually marginalised and discriminated against, often neglected, abused or exploited, and always made to feel ashamed. It is unjust – and also in clear violation of the human rights of the person or people stigmatised.

Stigma and disability

In many countries, people with disabilities are stigmatised. The stigma they experience is often the result of false assumptions, for example that people with disabilities are unable to learn or that their impairment is 'catching'. Cultural or religious beliefs can underpin stigma, for example the belief that disability is the result of witchcraft or the sins of previous generations. People with disabilities are sometimes said to possess particular characteristics, for example to be imbued with 'supernatural' qualities or endowed with special 'gifts'. These, too, are stigmatising false beliefs.

The stigma of disability can extend to entire families, for example when children with disabilities are believed to be a punishment for a family member having sinned or eaten forbidden food. The stigma of having a child with disabilities means that children with disabilities are often not reported, resulting in their not being included in official statistics. Mothers can be put under pressure to abandon, or even kill, their children with disabilities.

¹ Note that the term 'people with disabilities' is used throughout this document, rather than 'disabled people', as person-first language is preferred by the UNCRPD and many of the NGOs which make up BOND's membership. This should not be seen as at odds with the social model of disability and the preferred term used by the UK disability movement 'disabled people.'

Families though can also stigmatise their own relatives with disabilities.

As a result of being stigmatised – by family, community or both – people with disabilities can feel isolated and worthless. They can even take on society's false assumptions and beliefs and self-stigmatise. The stigma they experience is often reinforced by negative everyday language.

Some of the factors influence the depth of stigma experienced by people with disabilities:

- impairment type,
- severity of impairment, and
- gender.

Intellectual impairments are more stigmatised than physical ones, and girls and women are most affected by stigma.

A development issue

Around 15% of the world's population are people with disabilities². When people with disabilities experience stigma, there are broad ramifications. Stigma leads to people with disabilities being treated differently and often results in their being excluded from educational and training opportunities, employment and livelihood opportunities, health and other public services, and full participation in all aspects of society, including decision-making.

This discrimination and denial of basic rights resulting from stigma has very real negative social and economic impacts for girls, boys, women and men, and often their families too. As a result, many people with disabilities live in poverty and on the margins of society, with girls and women most effected.

International obligations

A social model of disability understands that disability is caused by the barriers to opportunities and participation erected by society, rather than by a person's physical or mental impairment or difference itself. It recognises that people with disabilities can live as equal members of society once these barriers to inclusion are removed. Both the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the Sustainable Development Goals (SDGs) support the social model and take a rights-based approach to disability, advocating the removal of barriers to inclusion, including attitudinal barriers to inclusion such as stigma.

The experience of stigma, and the resulting feelings of worthlessness and lack of wellbeing, also increase people with disabilities vulnerability to psychological and physical abuse, including neglect, domestic and sexual abuse, and exploitation.

² World report on Disability, World Health Organization and World Bank, 2011

Tackling stigma

Efforts to reduce and eliminate stigma address the root cause of exclusion and support the human rights of people with disabilities. The following are examples from the work of UK non-governmental organisations (NGOs) that have met with success doing this.

Self-help

Self-help groups, peer support and training groups, and parent support and training groups, such as those run by Motivation, tackle stigma by offering information and support to people with disabilities and the parents of children with disabilities. They can help dispel myths, for example that people with disabilities can never earn a living, and offer people with disabilities and their families new hope and confidence.

"Before, we didn't want Faluk to play with other children as we didn't like what the neighbours said about him. They used to say he had no future. After the training, we realised that it was our role to educate the community and encourage our child to go out and play." Adam, father of six-year-old Faluk, who has a physical impairment, after attending Motivation's Parent Carer Training in Malawi.

Alliances

In India, Bangladesh and Mozambique, inclusive self-care and self-help projects set up by Lepra united people with leprosy and lymphatic filariasis (LF) with people with other disabilities, such as blindness and paraplegia, and those considered vulnerable by their communities, such as widows and people who are ultra-poor. Group members helped individuals overcome self-stigma, and as community interaction with group members who faced the least stigma (such as widows) forced interactions with those facing the most (people with leprosy), so the various stigmas were slowly chipped away.

In Uganda, an ADD project turned to disabled people's organisations (DPOs) to foster solidarity with people with albinism, who face stigmatising myths and are subject to the same discrimination and exclusion as other people with disabilities. The ADD project engaged key stakeholders, including DPOs, before a widespread campaign of awareness-raising activities. Following the project, people with albinism reported being more confident and receiving more "respect", schools took action to give inclusive support to students with albinism, and more children with albinism enrolled in schools.³

Staff training

Disability training for staff within development organisations can help development practitioners understand the social model of disability and ensure inclusion becomes accepted development practice (mainstreaming). World Vision India saw a clear link between the training and awareness raising it organised for its staff and changes in its staff motivation to pursue disability inclusion in their work.⁴

³ Final evaluation report: Promoting full and equal enjoyment of human rights by persons living with and affected by albinism in Bugisu and Sebei

⁴ World Vision UK ex-post evaluation of the Programme Partnership Arrangement (PPA) funding for disability inclusion: A case study review of WV India's progress towards mainstreaming disability.

"Once people understood it was possible to make a difference to people's lives by reducing barriers rather than by having to offer medical or rehabilitative services, then [inclusion] became more of a practical, programmatic issue." World Vision evaluation.

Skills training

Projects offering training to people with disabilities can counter stigma. Sightsavers' Connecting the Dots project delivered training to young people with disabilities in Uganda while also working to transform the attitudes of self-stigmatising young people. By demonstrating the young people's skills, the project also addressed negative societal attitudes in the wider community.

"I got courage, I got hope, I believe in myself. Now I am someone." Najiba, Connecting the Dots trainee.

"The project has done a lot to change negative attitudes... it has contributed to great change in the community that a person with a disability can also sustain him or herself, and make money like any other person." Godfrey, Connecting the Dots trainer.

Wider awareness raising

Disability awareness campaigns can lead to changes in perceptions and knowledge about disabilities. Community-Based Rehabilitation (CBR) work by Plan in Togo saw communication and educational tools such as training manuals, posters, documentary films and T-shirts produced. Parents who had previously denied having a child with disabilities started acknowledging their child publicly and cases of abuse and discrimination against children with disabilities became less common.⁶

In conclusion

Women, men, girls and boys with disabilities in developing countries are subject to unjust and falsely-based stigma. Stigma is at the root of much of the discrimination and exclusion that is too often their everyday experience. Unless stigma is adequately considered and addressed when development policies, programmes and other initiatives are designed, then they are likely to fail people with disabilities – who will remain marginalised and subject to the negative personal, social and economic impacts that follow.

⁵ www.sightsavers.org/programmes/connecting-the-dots/

⁶ Outside the Circle: A research initiative by Plan International into the rights of children with disabilities to education and protection in West Africa.

About the Bond Disability and Development group (DDG)

The purpose of the Bond DDG is to influence UK international development and humanitarian policies and processes to be more inclusive of people with disabilities and in line with a human-rights-based approach to disability. Much of our work focuses on the UK Government and particularly DFID, but we also engage with UK Parliament, other relevant Departments, and other development organisations where strategic.

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