

Rising voices

Mainstreaming women with disabilities
in India-EU international cooperation

Full report



Sightsavers

Recommendations from Building Partnerships for the Sustainable Development Goals (SDGs) – Empowering Disabled People’s Organisations, an India-EU international cooperation and SDGs implementation project.



About the European Disability Forum

The European Disability Forum is an umbrella organisation of persons with disabilities that defends the interests of over 100 million persons with disabilities in Europe. A unique platform, it brings together representative organisations of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families to ensure a strong, united voice of persons with disabilities in Europe.

www.edf-feph.org



Sightsavers

About Sightsavers India

Sightsavers is an international organisation working with partners in developing countries to eliminate avoidable blindness and promote equality of opportunity for people with disabilities. In India since 1966, Sightsavers’ work has enabled thousands of people to lead independent and dignified lives. We have been working with local partners in 100 districts across eight states of India to strengthen organisations and communities.

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Cover image: Indu, who has had an orthopaedic disability since birth, received training on making bangles and clothes.

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Foreword

People with disabilities have the right to play a full and active part in society. To this end, it is important that governments provide the right environment, support and facilities. This view is beginning to be accepted across the world, underpinned by the universal adoption of the Sustainable Development Goals and their overarching objective that ‘no one is left behind’. The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) states that it is the physical, cultural and social barriers to the participation of persons with disabilities, which is at the root of disablement or exclusion, rather than the disability itself.

According to India’s 2011 census, 26.8 million people in the country are recognised as having a disability, which is 2.21% of the total population. In Europe there are more than 80 million people with disabilities out of a population of 446 million. In the EU, the overall employment rate is expected to reach 75% in 2020. However, only about 47% of people with disabilities are employed, compared with 72% of people without disabilities.

Inclusive development is a priority for the European Union. The EU supports a number of initiatives across the world aimed at empowering people with disabilities, including this one. This report comes at a time when the global crisis of COVID-19 is deepening pre-existing inequalities exposing the extent of exclusion: highlighting work on disability inclusion becomes all the more imperative.

According to the Survey of Persons with Disabilities conducted by the National Statistical Office (NSO) of India in December 2018, the Labour Force Participation Rate among women with disabilities is 8% versus 36.8% for men with disabilities in rural India. While the overall literacy rate of people with disabilities is 3%, the UN Educational, Scientific and Cultural Organization (UNESCO) estimates that it is just 1% for women and girls with disabilities.

National Family Health Survey (NFHS) data indicates that over 30% of Indian women have been physically, sexually or emotionally abused by their husbands at some point. Girls and boys with disabilities are nearly three times more likely to be subjected to sexual violence, with girls being at the greatest risk. Women with disabilities often report about not being able to receive the health care services they need. They face a range of barriers in accessing health care, including lack of accessible health information, inaccessible facilities or facilities too far from home, a lack of privacy and confidentiality, a lack of affordability and negative attitudes from health care workers.

Sightsavers India and the European Disability Forum (EDF) are jointly implementing the project ‘Building Partnerships for Sustainable development Goals – Empowering Disabled People’s Organisations’ supported by the European Union. The project supports people with disabilities to engage in, shape and monitor the implementation of the Sustainable Development Goals (SDGs) in India.

This joint paper on women with disabilities has been developed in the framework of the project. It aims at bringing the voices of women with disabilities to the fore. It details how supporting women to know their rights has helped them to stand up for themselves,



Community health worker Madhumita conducts an awareness programme for local women on Sagar Island, West Bengal, about how women with disabilities deserve equal opportunities.

gain independence and aid others. It also clearly highlights the untapped potential of women with disabilities and their critical role in the implementation of the SDGs and in international cooperation. Furthermore, it features the struggles and challenges they face and celebrates their strength, abilities, resilience and victories. By sharing these stories, it tries to convey the transformational impact that engagement in the SDG processes can have on individual lives and on society at large.



Ambassador Ugo Astuto
EU ambassador to India

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- Nadia Hadad, Vice President of the Brussels City Advisory Council of Persons with Disabilities. Member of the Executive Committee of the European Disability Forum (EDF). Board member of the European Network on Independent Living (ENIL).
- Meenakshi Balasubramanian, Founder, Trustee and Coordinator Projects at Equals – Centre for Promotion of Social Justice in Chennai, a DPO working on legal harmonisation and budget advocacy in India. Fellow at the Center for Inclusive Policy, Washington.
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- Nidhi Goyal, Founder and Executive Director of Rising Flame, an Indian non-profit working for the rights of women and youths with disabilities. Member of the core group on persons with disabilities and elderly persons by the National Human Rights Commission, India. Member of the UN Women global multi-stakeholder steering committee of the Generation Equality Forum in the Beijing+25 process and the UN Women Executive Director's Civil Society Advisory Group. Board President of the Association for Women's Rights in Development (AWID).

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Frequent abbreviations

- **CEDAW** - Convention on the Elimination of Discrimination Against Women
- **CRC** - Convention on the Rights of the Child
- **CRPD** - Convention on the Rights of Persons with Disabilities
- **DAC** - Development Assistance Committee
- **DPO** - Disabled People’s Organisations (or organisations of people with disabilities)
- **EC** - European Commission
- **EU** - European Union
- **NCPEDP** - National Committee for the Rights of Persons with Disabilities
- **OECD** - Organisation for Economic Co-operation and Development
- **RPWD** - Act Rights of Persons with Disabilities Act
- **RTE** - Right of Children to Free and Compulsory Education Act
- **SDG** - Sustainable Development Goal
- **UN** - United Nations
- **WHO** - World Health Organization



Girls with visual impairments demonstrate various self defence techniques at an event organised in New Delhi.

Introduction

“I want to be head of Gender Committee formed under the SDG-CRPD framework training in my state. I feel knowledgeable and empowered due to information that has been given to connect from ‘local to global’ issues of women with disabilities. I learnt during the disability inclusive SDG score card process that ‘united we stand together’ and alone we cannot uphold all our rights!” Richa, DPO member, Jharkhand.

The adoption of the 2030 Agenda for Sustainable Development¹ (the 2030 Agenda) in 2015 marked a new phase of shared ambition for sustainable development. A global framework to guide development policy and practice to 2030, the Agenda and its 17 Sustainable Development Goals (SDGs) are a global call to action to end poverty, to protect the planet and to ensure peace and prosperity for everyone, everywhere.

Central to the 2030 Agenda is a commitment to inclusion with its pledge that ‘no one will be left behind’. However, participation of those left behind in the 2030 Agenda is low, suggesting that this core principle is not being implemented and that governments have not succeeded in running inclusive processes focused on the most marginalised people.² Moreover, while the framework emphasises the need for development

interventions to prioritise those left behind, little is known about who those left behind are, or how to ensure their inclusion. Understanding who is left behind is complex as there is limited attention and data on these population groups. A recent study on the SDGs’ status among less recognised, invisible and excluded population groups in India, identified 20 socially-excluded population groups, including people with disabilities and marginalised women.³

Belonging to both these groups, women and girls with disabilities face an increased likelihood of experiencing multiple and intersectional forms of discrimination. However, the discrimination they face as women with disabilities does not equate simply to adding both these aspects of discrimination together. Intersectional discrimination can be qualitatively different, or synergistic.⁴ As a result, “targeted



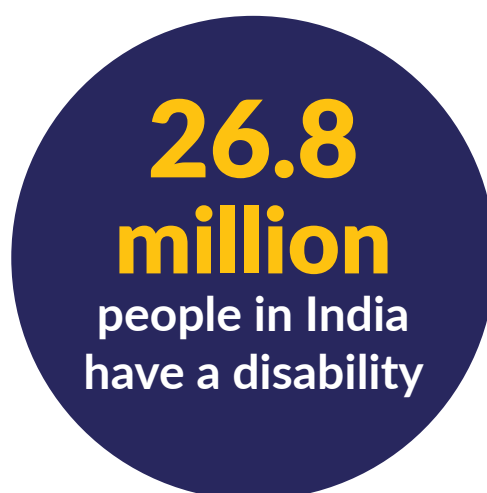
measures with respect to disaggregated data collection, consultation, policymaking, enforceability of non-discrimination and provision of effective remedies” are required.⁵

According to India’s 2011 census, 26.8 million people in the country are recognised as having a disability, which is 2.21 per cent of the total population.⁶ However, this is likely to be a significant under-estimation, as globally the prevalence of disability is 15 per cent.⁷ The World Bank notes that the actual prevalence of disability in India could easily be around 40 million people and perhaps as high as 80 to 90 million.⁸ In Europe, there are more than 80 million people with disabilities out of a population of 446 million.⁹

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) recognises that disability is an evolving concept. It sees disability as a result of the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. It refers to disability as “the long-term physical, mental, intellectual or sensory impairments which, in

interaction with various barriers, may hinder a person’s full and effective participation in society on an equal basis with others”.¹⁰

In an era where inclusive development is emphasised as a key component of sustainable development, focused initiatives for promoting gender equality are essential to achieve the 2030 Agenda. Furthermore, for gender equality and empowerment to become a reality for all women and girls, it is crucial that the specific concerns of women and girls with disabilities are mainstreamed across the entire 2030 Agenda framework and considered across all targets of SDG 5, which focuses on gender equality.



About this paper

This paper is informed by the findings of Building Partnerships for the Sustainable Development Goals – Empowering Disabled People’s Organisations, a European Union- (EU) funded project jointly undertaken by Sightsavers India and the European Disability Forum (EDF). The project supports people with disabilities to engage in, shape and monitor the implementation of the 2030 Agenda.

The paper aims to bring the voices of women with disabilities to the fore. It details how supporting women with disabilities to know their rights has helped them to stand up for themselves, gain independence and support others. It highlights the specific struggles and challenges they face, and celebrates their strength, abilities, resilience and victories. By sharing the stories of women with disabilities, it intends to convey the transformational impact that engagement in the SDGs processes can have on these women’s lives. It clearly highlights the untapped potential of women with disabilities and their critical role in the implementation of the SDGs, the CRPD and in EU international cooperation.

The methodology used to gather the findings included a mix of primary and secondary document reviews, including formal legislation and relevant literature. Interview guides were created with a focus on education, employment, health, gender and violence, and best practices. The case studies from three states in India (Jharkhand, Odisha and Rajasthan) were developed through one-to-one interviews and focus group discussions led by Anjlee Agarwal. Anjlee is a woman living with a disability and leads Samarthyam, an Indian Disabled People’s Organisation (DPO) and a close partner in the Building Partnerships project. The case studies in this report represent the experiences of the women we met but do not represent all women and girls with disabilities. Nor do the DPO networks represent all disabilities, a limitation openly acknowledged. It is still

difficult for many people with disabilities to access and join DPO networks, particularly for people with intellectual or psychosocial impairments. The review of EU policy on international cooperation was undertaken by EDF. An advisory panel of experts, made up of disability experts from both India and the EU, helped to guide the process and review the findings and recommendations.

The real names and identifying details of the women participants in the case studies have been changed to protect privacy and ensure confidentiality. This is especially true of the section on ‘areas of discrimination’. However, we have used the real names of women participants in the section on ‘good practices’ to acknowledge their accomplishments and successes, which they are really proud to share.

A range of relevant legislation and policy stipulations are referenced throughout this document. Please note that it may not be exhaustive.



Sudama, who has a visual impairment, and her sister-in-law Sapna outside her home in Madhya Pradesh. Sudama took part in a self-defence and judo training project run by Sightsavers and a local disability organisation, which is helping her gain independence.

The India-EU partnership

Together, the EU and India represent a population of close to two billion people, reflecting a “considerable reservoir of economic growth and a huge potential to influence positively the course of human development”.¹¹

India-EU cooperation focuses on issues of democracy, human rights, fundamental freedoms and multilateralism. This relationship is based on a 1994 Cooperation Agreement, which was upgraded to a Strategic Partnership in 2004.^{12, 13} The partnership has evolved over recent years, with enhanced commitment from both sides. An ambitious Agenda for Action 2020 was jointly adopted at the 2016 EU-India Summit, and at the October 2017 EU-India Summit the two sides agreed a Joint Statement detailing a common vision of global governance, shared values and principles.^{14, 15}

Most recently, in 2018, the EU released a Joint Communication which outlined how it would work with India to strengthen a Strategic Partnership Agreement by focusing on sustainable modernisation and addressing global challenges together. Sustainable development is increasingly the focus for the partnership, informed by the shared aspirations of the 2030 Agenda, which has framed the work of the partnership within a broader perspective. Building Partnerships for the Sustainable Development Goals Empowering Disabled People’s Organisations.^{16,17,18}



Sisters Janki and Shanti walk through the fields near their home. They started learning self-defence and judo so they could go out and about in their community more freely.

Building Partnerships for the Sustainable Development Goals – Empowering Disabled People’s Organisations

The Building Partnerships for the Sustainable Development Goals – Empowering Disabled People’s Organisations (referred to as Building Partnerships) project aims to boost the participation of DPOs in SDG processes, and support India and the EU with SDG implementation and monitoring. DPOs play a vital role in promoting and safeguarding the fundamental rights of women, men and children with disabilities. However, within Indian DPOs there is often a lack of awareness of rights and legal frameworks, as well as a lack of capacity to fully engage in policy processes and to hold duty bearers to account.

Women, girls and the 2030 Agenda

Gender is referenced throughout the 2030 Agenda, with Goal 5 dedicated to achieving gender equality and empowering all women and girls.

Goal 5 calls for:

- An end to all forms of discrimination against women and girls.
- The elimination of all forms of violence and all harmful practices against women and girls.
- Recognition of the value of unpaid care and domestic work.
- The full participation in decision-making, and equal opportunities for leadership, in political, economic and public life.
- Universal access to sexual and reproductive health.
- Equal rights to economic empowerment.

By the end of 2020, Building Partnerships will have engaged 15 DPOs and 14,000 people across five Indian states to advocate for disability rights and improve access to government development schemes and entitlements, such as social protection programmes, equal job opportunities, decent work conditions and equal participation in democratic processes. The project also aims to establish, strengthen and stimulate policy dialogue and partnership between Indian DPOs and EU institutions and member states, bringing the voices of India's DPOs to an international stage and ensuring that information on global processes reaches grassroots activists.

Building Partnerships includes a component on women with disabilities. This aims to build the capacity of rural women DPO leaders in order to:

- enhance their leadership skills.
- engage with Indian policymakers at national and state government level.
- partner with EDF to advocate on EU policy dialogue relative to disability inclusion in EU international cooperation.

This informs the findings and recommendations in this paper, which draws on two Building Partnerships initiatives, an SDGs disability inclusive scorecard process, and a DPO gender assessment. These two activities focused on raising awareness of the rights of women with disabilities.

Key policy and legal frameworks

Several key international policy and legal frameworks have the potential to increase accountability and disability inclusive development, from the bottom up.

1. The 2030 Agenda for Sustainable Development

The 2030 Agenda could be a game-changer for marginalised and hard-to-reach people, with its central commitment to leave no one behind and the pledge to reach the furthest behind first. The disability rights movement successfully advocated for the inclusion of disability during the framework's extensive consultation process. Disability is specifically referenced in the Declaration to the 2030 Agenda in the paragraphs on human rights, empowerment and education, and in the Goals on quality education, decent work, reducing inequality, sustainable cities and communities (for accessible transport and public spaces) and partnership for the Goals (to increase the availability of disaggregated data).

The EU played an influential role in the negotiations of the 2030 Agenda and has committed to implementing the SDGs in its internal and external policies. In 2017, it launched the innovative Bridging the Gap programme.¹⁹ In line with the 2030 Agenda and the CRPD, this programme promotes the rights, participation and inclusion of people with disabilities and works to build the capacity of women with disabilities. However, the EU has yet to develop an overarching vision to guide implementation and monitoring of the SDGs in its strategies and policies. Guidance to ensure the active engagement and participation of people with disabilities in the SDGs is required, too.

India also played a prominent role in the formulation of the SDGs and much of the country's national development

agenda is reflected in them.²⁰ India participated in the 2016, 2017 and 2019 meetings of the High-Level Political Forum and presented its first voluntary national review (VNR) in 2017.²¹ This focused on the Indian Government's multipronged initiatives to progress towards the ambitious targets set under the SDGs. However, people with disabilities were not consulted during the 2017 VNR process. India will present its second VNR in 2020 and extensive consultations with civil society are currently under way, including with people with disabilities.

2. The UN Convention on the Rights of Persons with Disabilities

The CRPD lies at the heart of disability rights campaigning. Adopted in 2006 by the UN, it became the world's fastest-ratified human rights treaty. It reaffirms that all people with disabilities must enjoy all human rights and fundamental freedoms, including to participate in civil, political, economic, social and cultural life of the community. The CRPD clearly stipulates what public and private authorities must do to ensure and promote the full enjoyment of these rights by all people with disabilities.

India ratified the CRPD in October 2007. In 2016, almost a decade later, the Indian Parliament passed the Rights of Persons with Disabilities Act (RPWD Act), the disability legislation needed to fulfil the country's obligation to the CRPD.²² The RPWD Act emphasises human rights principles, reflecting a paradigm shift in thinking about disability from a social welfare concern to a human rights issue.

However, the enforcement of many of its laws and provisions remains a challenge and the enjoyment of rights by women and girls with disabilities remains some way off to being realised.²³

India's initial CRPD country report under article 35 of the Convention was due in 2011, but only submitted in 2015.²⁴ The review process for India by the Committee on the Rights of Persons with Disabilities (the CRPD Committee) took place during the 22nd session of the CRPD Committee in 2019. The CRPD Committee highlighted positive developments, including making disability inclusion a component of several international cooperation programmes. It also made a number of recommendations, specifically regarding women and girls with disabilities, including to strengthen measures to address multiple and intersectional forms of discrimination, adopt national and state action plans, establish gender-responsive policies and budget allocations, and ensure the participation of women with disabilities in decision-making and policymaking at all levels.

The EU ratified the CRPD in December 2010, making the Convention the first international human rights treaty to have been ratified by a regional political body. The EU submitted its first report in 2014.²⁵ The CRPD Committee's concluding observations noted the EU's action as a positive trend and highlighted the EU's commitment to including people with disabilities in international cooperation.²⁶ It recommended that the EU adopt a harmonised policy on disability-inclusive development, mainstream the rights of people with disabilities in all EU international cooperation policies and programmes, appoint disability focal points, and put in place mechanisms to disaggregate data on disability. It also recommended

that the EU interrupt any international development funding being used to perpetuate the segregation of people with disabilities and re-allocate such funding towards projects and initiatives that aim to comply with the CRPD.

Women and girls with disabilities and the CRPD

The CRPD recognises that international and national laws and policies on disability have neglected aspects related to women and girls with disabilities. The Convention also recognises that women and girls with disabilities are often at greater risk of violence, abuse, neglect or exploitation.

It calls for signatories to:

- Uphold equality between men and women in the implementation of all rights in the CRPD.
- Ensure that women and girls with disabilities can fully enjoy all human rights and freedoms.
- Create legislation and policies to identify, investigate, and prosecute violence against people with disabilities, including women- and child-focused legislation and policies.
- Provide people with disabilities with the same range, quality and standard of free or affordable health care and programmes as others, including in the area of sexual and reproductive health.
- Ensure that people with disabilities, particularly women and girls with disabilities, have access to social protection and poverty reduction programmes.

On women with disabilities, specifically, it expressed concern that the EU had neither mainstreamed a disability perspective in all its gender policies, programmes and strategies, nor adopted a gender perspective in its disability strategies. It recommended affirmative action to advance the rights of women and girls with disabilities, establishing a mechanism to fund data collection and research and to monitor progress, and to accede to the Council of Europe Convention on preventing and combating violence against women and domestic violence.

In 2016, the European Economic and Social Committee released an opinion piece on the concluding observations of the CRPD Committee written by EDF President, Ioannis Vardakastanis, 'A new strategy for persons with disabilities in the European Union'.²⁷ It recommended integrating the 2030 Agenda into the revised European Disability Strategy and establishing European targets and actions to achieve the SDGs. It called on the European Commission (EC) to develop specific initiatives on the 2030 Agenda and on people with disabilities within the EU, as well as in its external policies, including development cooperation and international trade. It also emphasised that the perspective of women and girls with disabilities should be included in gender equality policy, including the data collection efforts of the European Gender Equality Institute.

In January 2020, the European Commissioner for Equality, Helena Dalli, confirmed that the EC will publish a new and strengthened European Disability Strategy post 2020. This commitment was presented in her speech at the conference, Towards Inclusion 2020.^{28,29} EDF is advocating for strong and inclusive work in international cooperation, covering intersectional

discrimination faced by certain groups of people with disabilities, particularly with regards to women and girls, lesbian, gay, bisexual, transgender/transsexual, intersex and queer/questioning (LGBTIQ) people, migrants and refugees, and ethnic minorities.

In March 2020, the EU started a consultation about the next 'Gender equality & women's rights worldwide – 2021-25 action plan'. This initiative reaffirms gender equality/women's rights as a key strand of EU foreign policy, building on the Commission's previous gender action plans. Women and girls with disabilities must be included in this new action plan.

3. The UN Convention on the Elimination of Discrimination Against Women

Often described as the international bill of rights for women, the UN Convention on the Elimination of Discrimination Against Women (CEDAW) is the primary international legal instrument on the elimination of discrimination against women and the promotion of equal rights for women. Its 1991 General Recommendation no.18 on women with disabilities requests all states parties to CEDAW provide information on women with disabilities in their reports, and in particular on measures to ensure equal access to education, employment, health services and social security, and full participation in social and cultural life.

In 2018, Ana Peláez Narváez, Vice-President of EDF and Chairperson of its Women's Committee, became the first person with a disability to be elected as a member of the CEDAW Committee. This election marked a turning point in the representation and interests of 600 million women with disabilities worldwide, enhancing their visibility and awareness.



Ana Peláez Narváez, vice-president of EDF and chairperson of its Women's Committee, is the first person with a disability to be elected as a member of the Committee on the Elimination of Discrimination Against Women.

In August that same year, concerned at the increasingly challenging environment for international human rights, the CRPD Committee and CEDAW Committee released a joint statement: 'Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities'.³⁰ It noted with concern that there remain considerable gaps across all regions in the protection of these fundamental rights and freedoms, and called on countries to increase their efforts to defend them.

4. The UN Convention on the Rights of the Child

The UN Convention on the Rights of the Child (CRC) is the world's most comprehensive children's rights framework and the most widely ratified international human rights treaty. It recognises education as a right of every child and guarantees free compulsory primary education for all, available and accessible secondary education to all, and higher education based on capacity. Article 23 outlines provisions for children with disabilities, including their rights to a full and decent life, special care and assistance. It also requires states to promote the exchange of information around disability and health care in the spirit of international cooperation.

The CRC has been ratified by all EU countries and India. The EU's Charter of Fundamental Rights guarantees the protection of the rights of the child by EU institutions and EU countries as part of EU law. India ratified the CRC in 1992 and enacted the Right of Children to Free and Compulsory Education (RTE) Act in 2009.



Prem cleans wheat at her home in Raisen after sight-saving cataract surgery in Bhopal, India.

Evidence

“I will connect with more women in the field and make them aware about their rights and to STOP violence at home and in the community. I want to work on the SDGs that promote health and wellbeing. I will promote rights-based advocacy focusing on sexual and reproductive human rights in the field.”
Asha, 27, DPO member, Rajasthan

The voices of women with disabilities too often remain unheard. To understand some of the issues they face and bring their voices to the fore, 15 female DPO members from three Indian states were interviewed about their lives and experiences. Part of the interviews focused on four key SDG themes: violence, education, health and employment. The stories that emerged highlight the many barriers that women with disabilities continue to face. Issues relating to the family also emerged as an important theme and are explored in this chapter.

The 15 women were further asked about their involvement in DPOs, local accountability mechanisms, and wider networks and systems. Their responses included stories of empowerment, newly gained independence and personal transformation. The ‘good practices’ section explores the elements that emerged as key to enabling these successes.

The final section of this chapter builds on this evidence to outline the issues and gaps that these findings highlight for SDG implementation in India and the EU.

Areas of discrimination

The nature of discrimination a person experiences depends on a complex interplay of the many factors relating to their place in society and their identity. For example, there is a strong link between disability and gender inequality.

Women with disabilities experience discrimination based on their gender and on their disability, as well as specific forms of discrimination based on them being women with disabilities. While a significant portion of women and girls are born with disabilities, others experience disability as a result of exposure to gender-related risk factors, including a lack of access to sexual and reproductive health services, exposure to violence and harmful practices, and a gender-biased distribution of resources within households.³¹

India, despite making progress in developments in the past three decades, lags on gender equality. Persistent issues include dowry, female infanticide, women's education and domestic violence, despite decades of successive governments' efforts to address them.

Inequality is further exacerbated for women and girls with disabilities who experience other forms of marginalisation, including as LGBTIQ, ethnic minorities, older people, children and those living in remote and rural areas. The different aspects of their identities put them at risk of heightened disadvantage and intersectional forms of discrimination.

While one woman interviewed as part of Building Partnerships spoke of disability as a unifying force overriding other dimensions such as caste and class, very often not all experiences are equal – both within disability groups

and within women's groups. Class and geography also play a role for women with disabilities from urban, middle-class backgrounds who may have greater access to education, health and employment. Gender stereotypes negatively impact on women with disabilities, and women with disabilities face significantly higher barriers to participation than their non-disabled peers.^{32,33}



Nidhi Goyal, founder and executive director of Rising Flame, presents issues of violence and access to justice in India to the UN CRPD committee in Geneva, September 2019.

Photo contribution: Rising Flame

Violence and access to justice

“I wish the police were aware of the vulnerability of disabled women.”
Anju, 41, DPO member, Odisha

Violence is a serious area of concern for all women with disabilities in both India and the EU.³⁴ Girls and boys with disabilities are nearly three times more likely to be subjected to sexual violence, with girls at the greatest risk.³⁵ Surveys conducted in Europe, North America and Australia have shown that more than half of women with disabilities have experienced physical abuse, compared to one third of women without disabilities.³⁶ Women with disabilities are also particularly at risk of forced sterilisation, medication and institutionalisation, including forced abortion and contraception.^{37,38,39} A Human Rights Watch report on the situation in India detailed how women and girls with disabilities are placed in institutions by their family members or police, in part because the government is failing to provide appropriate support and services. Once there, they often experience lives of isolation, fear and abuse, with no hope of escape.⁴⁰

Medical practitioners and wider society continue to consider people with disabilities as either asexual or hypersexual. This results in severe restrictions on their sexual behaviour, as well as increased exposure to sexual abuse and mistreatment. Forced hysterectomies are reported by some women with disabilities because of discriminatory attitudes around pregnancy. Rubina, a 42-year-old DPO member from Rajasthan who contracted polio when she was three, spoke tearfully of the devastating consequences of not being aware of her rights:

“Four years ago, I had some uterus related issues and so I went to see a gynaecologist. It was extremely uncomfortable to see that there was no female doctor when I went for ultrasound and sonography. I had a hysterectomy. I wasn’t informed about the pre- and post-surgery repercussions and was given medicines without my consent. I didn’t know about my right to be informed about medical treatment and felt miserable.”

Domestic violence is an acute problem.⁴¹ National Family Health Survey (NFHS) data indicates that over 30 per cent of Indian women have been physically, sexually or emotionally abused by their husbands at some point. There is also a recognition in the EU that women with disabilities are at risk of violence from their family members and carers, as well as from strangers.⁴²

Girls and boys with disabilities are nearly **three times more likely to be subjected to sexual violence, with girls at the greatest risk**

Several the women with disabilities interviewed in India had experiences of violence. Sneha, a DPO member from Rajasthan, was particularly affected. Now 36, she was badly burned in a household accident at 15 months old. Access to adequate health care in her local hospital was not available to her, but thanks to her uncle, who realised the seriousness of the situation, she was admitted to a district hospital. However, despite receiving six months' treatment there, her hands were permanently hurt as a result of the accident and she lost all her fingers. Her husband physically and emotionally abused her. She shared one horrific experience:

"I used to be very religious and believed that I should be submissive and follow my husband everywhere. I had always been a devoted wife. He used to hit me, and I would never say anything, just quietly bore it all. For seven years I went through all of this. One day, when my husband came home drunk, he became angry because I'd been unable to prepare food on time as I was busy handling my younger son. In anger, he killed my son by throwing him twice on the wall, then on the floor and finally on the bed. My child died but I continued to nurse him thinking he was injured, and he'd get better. But he was declared dead when I took him to the nearest hospital. Even then, I did not complain about my husband being a murderer and defended him."

The pain of losing her child was unbearable for Sneha and she was traumatised for years. She highlighted how a lack of financial independence and social welfare impacted her ability to leave this abusive relationship:

"When I was experiencing domestic violence, I needed more support from my family but there is no social security or other government support for women with disabilities who are victims of violence. Above all, there is no sheltered accommodation for us."

The lack of accessible shelters for women with disabilities is also a concern in the EU, where staff working in shelters lack disability awareness and knowledge of how to welcome women with disabilities.⁴³

Other women interviewed in India had also been physically abused by family members or at school. Rita, a 25-year-old DPO member from Jharkhand who uses crutches to walk, spoke of how this affected her mental health:

"My brother fights against my pursuit of higher education and my sister-in-law wants to get rid of me because I'm disabled. My parents want to give me a share in their property, but my brother and sister-in-law don't want that. They frequently verbally and physically abuse me, pushing until I fall. So, I lose self-confidence and I'm unable to fight back."

Despite their increased risk, access to effective and timely justice is a challenge for women with disabilities in both Europe and India. In many countries in Europe, even when women with disabilities do manage to raise issues, judicial buildings are barely accessible and justice personnel are not properly trained to provide an appropriate service.⁴⁴ In India, women with disabilities face a range of barriers at all stages of the process, from reporting and interacting with the police to navigating the judicial process and obtaining

compensation.⁴⁵ It was striking that many of the women interviewed were unaware of their legal rights and provisions to ensure justice. As a result, women with disabilities are often unable to demand accountability. This is made worse by the lack of statistics on crimes committed against women with disabilities, so there is no understanding of the level of violence.

After the fatal gang rape of Jyoti Singh Pandey in Delhi in December 2012, India made important legal reforms on sexual violence in its 2013 Criminal Law (Amendment) Act.⁴⁶ This added to a number of other laws that have provisions for women and girls with disabilities, including the Protection of Children from Sexual Offences Act 2012 (POCSO) to protect children from sexual abuse and the Protection of Women from Domestic Violence Act, 2005 (the DV Act), which enables access to health care, legal aid, counselling and a shelter in cases of domestic violence.^{47,48} However, the criminal justice system has largely failed to implement the amendments, which include providing police and

judicial training to create an enabling, supportive environment for survivors with disabilities.⁴⁹ Women and girls with disabilities may require distinct types of procedural and age-appropriate support, depending on their disabilities. This might include access to sign-language interpretation, the presence of someone to facilitate communication (a 'special educator'), the use of simple language and the option to file reports in braille. However, this support is often not available, even though the 2013 amendments and POCSO make it mandatory. Most police do not have the training or expert support required to handle such cases.

Kajal, a 30-year-old DPO member from Jharkhand, identified the need for training on the policies and schemes related to police procedures for women with disabilities – specifically on how women with disabilities can file complaints, what happens when a woman has a speech or hearing impairment, and what action can be taken if the police fail to respond. She also highlighted the need for more information on how the police support women with disabilities with dignity.

Even when they manage to report incidents, women with disabilities are often treated badly by the police. Anju, a DPO member from Odisha, shared her experience of harassment and discrimination by local police:

“For my sister’s marriage, my brother bought a necklace for my sister-in-law and I asked for one too. I gave them money for it and asked them to sell my share of rice for the extra amount. However, my brother shouted at me and my father and took the rice and money. My brother called me a thief



The Samarthyam team promotes mass awareness on violence against women in the One Billion Rising Campaign, in February 2017.



Laboni Singha, 27, is a community health worker who helps identify people, particularly women, who need eye care in the Sundarbans, West Bengal.

and launched a police complaint. I fought back but the police didn't bother to take me seriously as I was disabled. My brother kept troubling me about the property and assets that my father wanted to give to me. The police supported him and threatened me. I wish the police were aware of the vulnerability of disabled women and were able to implement disability-sensitive measures."

However, Radha, a 25-year-old DPO member from Jharkhand, was able to share a positive experience of engaging

the police. She spoke of how the abuse she experienced at the hands of her uncle motivated her to fight. She took the step of complaining and reported her uncle to the local police. On their intervention, a mutual compromise which went in her favour was agreed through the local government. Empowered to move forward, she resolved to continue to work on women's rights through her local DPO and to help other women with disabilities who experience domestic violence.

Family

“I am still fighting to remain single forever and not get harmed and abused in this male-dominated world.” Radha, 25, DPO member, Jharkhand

Families play a significant role in the lives of women with disabilities, but while families can be a place of refuge and support, they can also be a place of hardship. This puts women with disabilities at particular risk as they are often reliant on their families as their primary carers because of a lack of social security and government support for independent living. Sometimes, women with disabilities report that family members become resentful or even verbally and physically abusive as a result of financial and social strains.

In both India and the EU, women with disabilities are more likely to be victims of domestic abuse. Living in closed or segregated environments, women, in many cases, depend on the person perpetrating such violence for their survival.⁵⁰

Additionally, women with disabilities in both contexts are at risk of being denied their right to motherhood, with forced sterilisation continuing to be performed, particularly on women and girls with intellectual or psychosocial disabilities.^{51,52}

Naina, a 29-year-old DPO member from Rajasthan was an enthusiastic student who rarely missed school. Her parents were supportive and worked hard to give her an education.

However, Naina was very dependent on her sister who grew resentful at having to look after her at school and carry both her sister and her own bags. Additionally, Naina’s sister didn’t like to sit next to her in class. Naina felt awkward asking for help, even from others, so she often suffered in silence. At times, her sister was physically abusive:

“She used to fight me a lot and many times she hit me. I never said anything at home. She never hit me at home because she feared our father. Sometimes when my father found out about her hitting me, he would scold her. She would react violently and want to give up her studies. My parents were hurt by her attitude and decided to support me to continue my studies and aspire for a higher education. Currently I have a double MA and have made my parents proud.”

Often, it is family members and carers who are responsible for supporting the daily needs of people with disabilities.⁵³ In the process of caregiving, they may have to forego their own opportunities to attend work of their choice, to earn money, to progress in their career, to have a good social life and even to enjoy leisure time. In India, there are few of the benefits to caregivers provided in some European countries, such as tax exemptions and travel benefits and social protection measures. There is no separate funding agency or government department intended to help these informal caregivers.⁵⁴

Naina was eventually fitted with callipers to help her walk, enabling her to carry her own bag to school. However, she struggled as her books got heavier in higher classes. The route to school included crossing a busy road which scared her, and her sister continued to get angry when she was asked for help. Naina’s school Principal suggested she have two sets of books, one at school and one at home. It was a good solution, but it proved a financial strain for Naina’s father. She shared:

“My father earned 60 rupees a day and it was quite difficult for him to manage two sets of books for me. But he promised to do it in 15 to 20 days – and he kept his promise. This solution worked and I was saved from the humiliation of carrying a heavy bag daily to school.”

Property disputes, often instigated by siblings, were experienced by several interviewees. Anju, a DPO member from Odisha, aged 41, shared how her brother’s attempts to gain control of the family property drove the family apart:

“My brother tortured me for the property. I even went to the police station to complain about him. After getting tired of his abuse, my parents and I broke ties with him and started living elsewhere. I’m taking care of my parents and ensuring that they don’t feel neglected.”

Within the family, emphasis is placed on the institution of marriage, the family as a social unit and the importance of religion.⁵⁵ In many cases, women with disabilities are not expected to adopt the roles of wife and mother. Women with disabilities may face struggles as a result of dependence on their parents, siblings and extended families, and many, those with intellectual disabilities, are denied their right to motherhood and family life.

Some states run financial schemes that offer individuals financial benefits for marrying a person with a disability. Such schemes contravene the CRPD, are discriminatory and serve to stigmatise women and men with disabilities further. Interviewees also suggested it is common for families in rural areas to seek a daughter-in-law with a disability in order to produce a child, only to abandon her

once that child is born. Radha said she felt vulnerable to such a fate:

“While working in an NGO [non-governmental organisation], a friend arranged a marriage proposal for me from a man with a disability who had a good job, but my parents refused [to let me marry him]. They wanted me to marry an old man who had two girls and a wife who also lived with him. I came to know from close friends that this man wanted a son and I’m pretty sure that once I delivered a baby boy, he would kick me out of the family. Also, what is the certainty that I would give birth to a boy? What would happen if this child turned out to be girl?”

Many of the women interviewed expressed an interest in marriage but felt it was out of reach. Often this was aggravated by negative attitudes within the family and a lack of willingness to invest in a dowry. Some felt that their disability made them undesirable and that their prospects for marriage were slim. Richa, a DPO member from Jharkhand who is 26 and has a physical impairment, spoke of how her dreams of falling in love and finding a life partner were yet to be fulfilled:

“I’m not allowed to think about my future in terms of marriage prospects. Even in my daily work and networking with other women with disabilities, being in a relationship with someone who could appreciate our existence – in which one could be loved, cared for and enjoy life – is something that women with disabilities tend not to talk about. Ignoring our right to pursue happiness in all terms is something that’s been cultivated in our societies for centuries and is sadly still continuing.”

Education

“The day I graduated and got a degree, I saw both love and happiness in the eyes of my brother and father. They gave up their moments of luxury so that I could be educated. My desire for quality education and my aspiration to ‘go on’ was supported by my family and no one else.”

Meena, 23, DPO member, Odisha

Many children with disabilities have never even enrolled in school, let alone had the opportunity once there to work, play and learn. Globally, around 33 million children with disabilities are not in school⁵⁶ and twice as many girls as boys never start school.⁵⁷

Evidence from the World Bank shows that the enrolment rate for girls with disabilities is 71.9 per cent, compared to 84.6 per cent for girls without disabilities. Primary school completion and literacy are the areas where girls

with disabilities fall behind, in particular⁵⁸. According to the National Survey of Persons with Disabilities conducted July 2018 to December 2018, in rural India, the overall literacy rate is 33.3 per cent for women with disabilities, compared with 57.4 per cent for men with disabilities.

The Right of Children to Free and Compulsory Education (RTE) Act, 2009, provides for free and compulsory education to children aged from six to 14 years at elementary level in a



Riya, who was screened at school and given a pair of glasses, smiles and sits with her classmates. Previously her eye problems had stopped her from attending school.

neighbourhood school. But while this Act mandates enrolment, it does not provide the resources needed for the education of a child with disabilities.⁵⁹

There are several hurdles to girls with disabilities in India accessing and remaining in education, for instance, stigma is highly prevalent and many families will not support the education of a girl with disabilities. Additional hurdles include the availability of accessible transport and safe commuting options to school. Factors within schools include issues such as an absence of qualified teachers, lack of accessible learning materials and a lack of inclusive educational opportunities. Issues around adequate safety for girls with disabilities and basic infrastructural facilities, for example, accessible, private toilets, are also major barriers to the education of girls with disabilities. In many parts of the world, children with disabilities are effectively barred from school because schools are physically inaccessible.⁶⁰

Kajal described how she faced numerous challenges pursuing an education. She contracted polio at age three, resulting in her being unable to move independently. Her mother washed, dressed and fed her but with time she learned to move on her knees and later to walk with the help of a stick. However, just the thought of approaching school was terrifying for her as a young girl. She was always accompanied to and from school but one day a cruel comment from a fellow villager caused her to drop out:

“I used to crawl on my knees to the entrance of my school and ask people I knew to drop me home. Sometimes I used to wait for as long as an hour to find someone I knew. When I was in

second grade, I asked someone from my village for help. He said, ‘You trouble your family a lot! Why don’t you die?’ I was deeply hurt and left the school.”

Following this incident, Kajal enrolled at an evening school where she was again tormented, this time by demeaning comments from the teachers and students. Again, she decided to leave, both because of the negative treatment and because of her difficulty accessing the school, which was far away, leaving her no option but to crawl to get there. Eventually, aged 11, she received a tricycle and was admitted to another school. Her education resumed briefly but she soon faced another setback when she had an accident and her tricycle was damaged. She couldn’t attend school for five months. Fortunately, Kajal’s mother ensured she received the surgery and callipers she needed, and her classmates and teachers helped her too.

**Globally, around
33 million children
with disabilities
are not in school**

However, although she was encouraged to join a computer class to further her skills, she had to again drop out because the training centre was on the fourth floor. Kajal's request to move the class to the ground floor was rejected by the trainer who said he could not do it for just one student. Kajal said:

"I wanted to take the computer course as vocational training. However, I was extremely hurt and felt discriminated against by the trainer's statement, 'I cannot bring the classes down for just one student.' All my dreams came to a standstill and for the first time I realised that there should be stringent policies and inclusive vocational training set-ups."

Across the EU, girls with disabilities face many challenges accessing education. A 2018 report found that European Schools, a network of thirteen intergovernmental schools primarily teaching children of EU employees, failed to do enough to accommodate the needs of children with disabilities.⁶¹ Parents described facing persistent hostility from management and being repeatedly asked to attend meetings to hear complaints about their children.

Many women interviewed recounted stories of harassment, cruel taunts and insults, both by their peers and teaching staff. These experiences left them feeling fearful, hurt and inferior, with consequent negative effects on their mental health and confidence. In several cases, taunts from other children caused women to stop using their assistive devices, which resulted in their impairment getting worse without the right support. As Seema, a 24-year-old DPO member from Odisha who contracted childhood polio, recounted:

"In fourth year, my parents bought me a tricycle from the block office, but the school kids used to play or sit on it and I couldn't use it, so I dumped it at home. Growing up, sometimes my friends would tease me by taking away my crutches while I washed my hands and legs at the well. I complained and my teachers would do nothing. I decided to dump the mobility aids as they'd become a cause of mockery and harassment. I managed to walk to school but my deformity increased until, one day, I started crawling on all four limbs."

Asha, a DPO member from Rajasthan, who is 27 and has a physical impairment following a surgical error, shared a similar story:

"The girls started to humiliate me... I used to feel very bad and I took off my callipers. The doctor had always emphasised that I should not stop wearing callipers as they supported my legs and helped me walk better. But I stopped wearing them and slowly my situation got worse. Eventually, I lost my ability to walk and I started crawling."

Negative attitudes to disability do not just exclude children from the chance of gaining an education, but also from the social activities that are so key to ensuring their inclusion, developing a sense of belonging and making friends. For Asha, not being able to take part in extracurricular activities was a painful memory:

"I never participated in extracurricular activities such as dance and PE. I was tempted to participate but I couldn't because I felt I wasn't good enough and that I might not be able to perform like the others. So, I always compromised,

and teachers wouldn't select me for any event or activity. I decided to sing prayers during assembly time, however, I withdrew when I felt I was being stared at and talked about afterwards."

Another key barrier to education for girls with disabilities is the lack of water and sanitation facilities. Not only were there no experiences of disability-friendly toilets, sanitation facilities were inadequate and basic, if they were available at all. As a result, girls sometimes opted for open defecation or staying home, particularly when menstruating. This was the case for Seeta, a 28-year-old DPO member from Odisha:

"The toilet in the school was usually dirty and I had to crawl on the ground. My hands and dress got dirty, and finally I decided to opt for open defecation. During the rains I missed classes throughout my schooling days. During menstruation, I used to opt for open defecation and felt uncomfortable and embarrassed."

Inadequate facilities also affected Rubina, from Rajasthan:

"There was no light and water and we only had urinals without running water. It used to stink a lot. During my periods, I couldn't adjust my cloth pad with one hand. I used to be scared that my uniform would stain. Once it did happen and I was ashamed that everyone would know that I had my period. So, I turned my skirt around and hid the stains by folding it in front of me. As there was no water in the toilets, I used to wipe my hand with leaves or mud but there was nothing to wipe my private parts."

The added costs of education for women with disabilities for appropriate transport, assistance and devices meant that some worked extra hard to earn money to fund their studies. Radha, aged 25 from Jharkhand, told how her motivation to be educated spurred her on despite the strain she experienced:

"It was challenging to commute 12km to school every day and then work in the field in afternoons to earn money for my education. I was exhausted by the end of the day. But the need to gain a higher education and earn a decent living in future was my only goal. My family was not against my education, but there was no financial support from them, as they couldn't spare any money."

In rural India, the overall literacy is 33.3% for women with disabilities compared with 57.4% for men with disabilities

Health

“There are unlicensed doctors available in every village to which most of us go.” Sarita, 30, DPO member, Odisha

Despite substantial improvements in the past decade, access to health services in India remains weak, with services unable to meet the needs of the population. Large health disparities between states, between rural and urban populations, and across social classes persist⁶². More than 700 million people (70% of the population) live in rural areas where access to health and rehabilitation services is particularly weak.

Poor infrastructure, inaccessible facilities and information, weak governance, poor quality health services, a lack of qualified health workers, unaffordable health care costs and inadequate access to medicines means that people, particularly those with disabilities, struggle to access the care they need.

Meena experienced severe fever when she was three. After taking medicine from an unlicensed village health practitioner, she fell unconscious for seven days. She was admitted to a city hospital where she was treated but, once out of trauma, she was diagnosed with cerebral palsy. Almost half of the women interviewed developed their impairments as a result of poor-quality health care. Reasons for this included negligence by doctors and a lack of accessible hospitals. In some cases, vision loss was caused by malnutrition. Sneha, 36, a DPO member from Rajasthan, shared her experience:

“The hospital was 15km away and there was no burns specialist there. They took me in a camel cart as there was no other transport. Poor treatment meant I became deformed and lost my fingers completely. Doctors would visit me, but they didn’t take my burn and swelling seriously.”

There are strong links between health, gender and disability. Women experience higher rates of disability than men and higher rates of depression and anxiety too, a fact that has been linked to gender discrimination as well as poverty, hunger, malnutrition, violence, overwork and disproportionate care burdens.⁶³ Depression and anxiety are approximately twice as prevalent in women.⁶⁴ Women and girls with mental health conditions are particularly vulnerable to physical and sexual violence, but those who have experienced violence are also more likely to develop a mental health condition in the first place.⁶⁵ Poor maternal health care is another major cause of disability among women.

Women with disabilities commonly report needing healthcare services but not receiving them⁶⁶. They face a range of barriers to accessing health care, including lack of accessible health information, inaccessible facilities or facilities too far from home, a lack of privacy and confidentiality, negative attitudes of health care workers, and a lack of affordable medicines.

Physical barriers to health care include uneven access to buildings, inaccessible medical equipment, poor signage, narrow doorways, internal steps, inadequate bathroom facilities and inaccessible parking areas. Women, and women with disabilities, are not prioritised in health care, even during emergencies, with other patients being attended to first. There is a lack of availability of emergency care and gynaecologists for women with disabilities.



Nursing assistant Bandana checks a patient in the Sundarbans, West Bengal.

All of these factors contribute to a widespread reliance on unlicensed doctors in rural areas. Sarita, a 30-year-old DPO member from Odisha who developed low vision as a result of childhood malnutrition, said:

“There are unlicensed doctors available in every village, to which most of us go. There is a primary health centre 4km away but usually we only go there if we don’t get cured by the unlicensed

doctor. In primary health centres, doctors are usually not available, so villagers go to ‘quacks’ for medicine. Often their medicines are ineffective and then we go to district health centres. It’s not easy to access facilities at district level and I’m always accompanied by my parents.”

When Kajal, who at age three acquired polio, sought treatment after a tricycle accident, she and her mother experienced inaccessible facilities as well as poor

treatment by health care staff. During their visits to health institutions, there were times when Kajal was forced to wait in a queue despite having explained her condition. It left her disappointed and distressed.

Affordability of health services is one important reason why people with disabilities do not receive health care in many low-income countries. Rakhi, a 26-year-old DPO member from Rajasthan, was four months old when she fell from the first floor of her house and was severely injured. There were no specialised medical facilities in the nearest available health centre, so she failed to receive treatment. Rakhi's uncle was supporting the family at that time as her father was not earning, so it was difficult for the family to support her treatment. Rakhi underwent several operations in her teens but she and her family felt humiliated by their poverty in health centres and were treated badly by medical staff. Now 26, Rakhi has a physical impairment. She shared how difficult it was for her and her family:

“There are no big hospitals in my village. I was injured when I was four months old and admitted to a big hospital at the age of three where I got proper treatment. As I couldn't walk, my father had to be with me all the time. Later, I was taken to Mumbai for treatment, but it was very difficult as we were very poor.”

Many of those interviewed spoke of their discomfort at the lack of female health care professionals available to attend to their health issues, particularly those concerning women's health. Asha said this resulted in her being abused by a health care professional:

“When I was in first year of graduation, I was abused by a ‘body massager’ who was hired to massage my deformed legs. He used to touch my upper body, intentionally. For a few days, I asked him to behave and only to massage my legs. However, he continued to be abusive and then I mentioned it to my mother. She said, ‘If you want to get cured, adjust and accept.’ But I was not comfortable and prayed to God that it should stop immediately. However, I never had the courage to raise my voice against his ‘bad touch’”

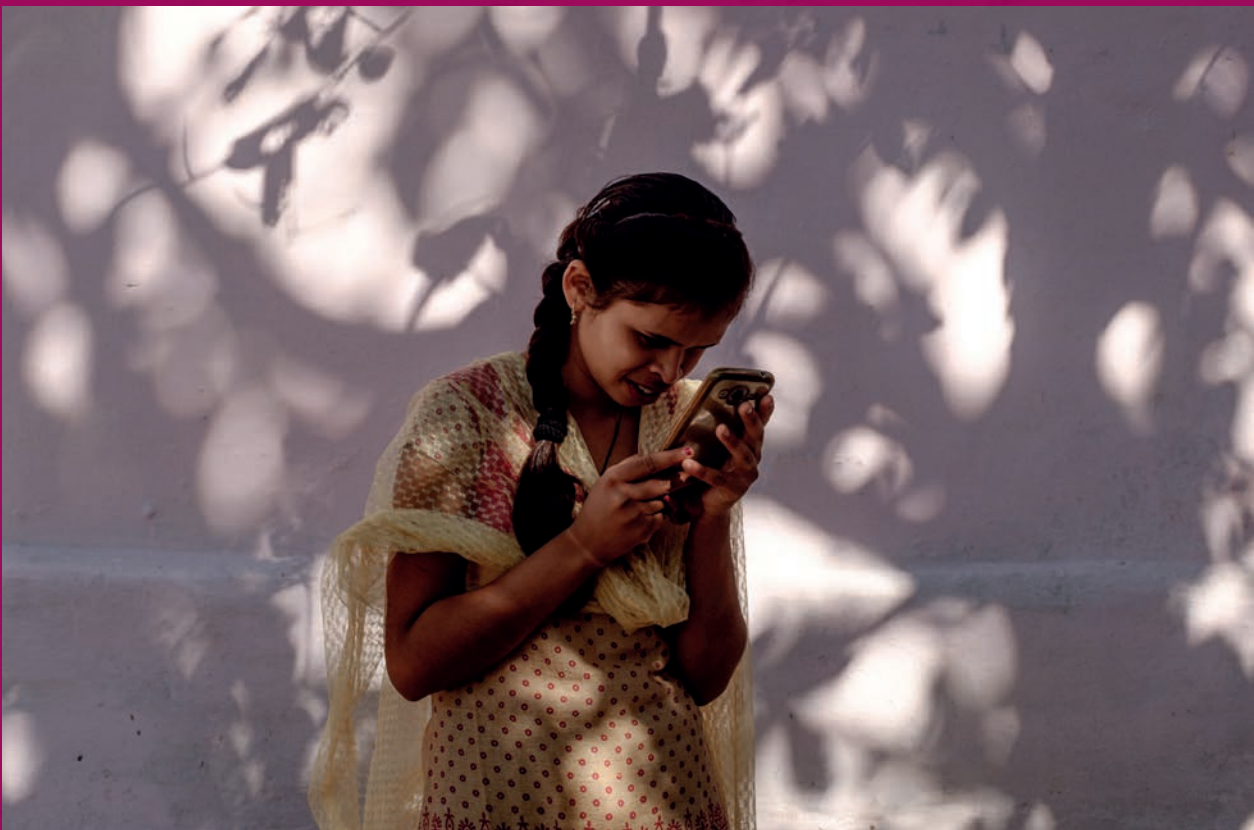
Many of the issues that women with disabilities face in India continue to prevent women with disabilities in Europe having the same standard of health care as the average EU citizen. This is despite the EU and its members states having committed to providing the highest standard of health care to people with disabilities in several ways, including as an area of action in the European Disability Strategy.⁶⁷ Many health care facilities remain inaccessible to women with disabilities in Europe, including gynaecology facilities. There is also a lack of accessible, easy-to-read information as well as adequate training for health care professionals.

In India, even in health care settings, negative attitudes towards people with disabilities are pervasive, for example, women with disabilities reported health staff making derogatory comments about them and their capacity to care for their children. There is no accessible information for women with disabilities on childbirth to support them and interviewees recounted feeling humiliated in health centres by rude and abusive medical staff. Sneha said:

“During childbirth, women with disabilities are taunted when they scream during labour pains. The nurses are very rude to these women. They usually say, ‘You didn’t think about it when you had fun with your husband, then now why are you shouting.’ Even during my first pregnancy, my mother told me not to shout or cry during delivery because she said that it’s a sign of weakness. I bit my inner lips with my teeth so as not to shout. It was very painful for me. My lips were swollen for days. Later, I realised how male power dominates our community. We are the one to give life to a male child but can’t express our pain! These attitudes in society are strongly oppressive towards women with disabilities and people need to be made aware about the value of us as humans first.”

In India, even in health care settings, **negative attitudes** towards people with disabilities are pervasive

In many countries, including India and European Union countries, people with disabilities are still treated without their free and informed consent.⁶⁸



Since learning self-defence skills, Sudama has been able to return to her education.

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Employment

“I want to explore the world, grow and become empowered.” Rubina, 42, DPO member, Rajasthan.

The economic independence of women with disabilities is key to their empowerment, yet they are systematically excluded from the mainstream workforce and often stigmatised, too. In the EU, the employment rate is expected to reach 75 per cent in 2020.⁶⁹ However, only about 47 per cent of people with disabilities are employed, compared with 72 per cent of people without disabilities. Moreover, women with disabilities in the EU are more likely to be discriminated and excluded from the labour market.

In India, a similar situation exists. According to the Survey of Persons with Disabilities conducted by the National Statistical Office (NSO), India, in December 2018, the Labour Force Participation Rate among women with disabilities is 8 per cent versus 36.8 per cent for men with disabilities in rural India.⁷⁰ Many of the interviewees spoke of discrimination and exclusion. Kajal related how her family fought against her attempts at employment:

“In 2001, I applied for an Anganwadi job and the government refused me it as a result of political pressure from my uncles. My uncles won and I did not get the job. I re-applied and was supported by Jan Jagaran [an NGO] and got the job as part of the disability quota.”

Kajal still works at the Anganwadi, a rural childcare centre which also provides basic health care. However, disappointed by the lack of employment opportunities for people with disabilities, she now aspires to run a business.

In India, there is a 4 per cent quota for people with disabilities in employment and a 5 per cent quota in higher education, but no specific provision for women with disabilities. Their inequality is exacerbated in rural areas, where there are fewer economic opportunities for women compared to men. For Rubina, this prevented her engagement in the workforce for some time:

“I was married when I was 16 years old. I studied only up to class 10. I was not allowed to study further by my in-laws. I got burdened with family chores. There were lots of issues in society such as early marriage and patriarchal restrictions, and I wasn’t allowed to work outside [the home]. I was discouraged and told, ‘We have everything at home, so there’s no need to step outside.’ I couldn’t take it anymore and revolted. Getting food and shelter is not everything for me. I want to explore the world and grow and become empowered.”

A person acquiring a disability can also affect the employment opportunities for other members in a household. Very often someone in the household is required to take on caring responsibilities. This was the case for some of the women interviewed and, as we have seen in issues relating to the family, it often caused resentment – which in some cases escalated to abuse. Rakhi shared:

“My father often taunted me for taking me to the school as he could not go to work outside.”

Accessibility is a cross-cutting issue for all areas of women’s lives. It was also cited as a barrier to employment – from inaccessible training centres to the physical strains of commuting and travelling for work and the lack of appropriate toilet facilities. Naina currently works with an NGO for people with disabilities. She trains other women with disabilities on provisions in the Indian Disability Act but spoke of the challenges she faced, including commuting for fieldwork, working odd hours and the lack of accessible toilet facilities. She said a lack of reasonable understanding of her specific needs and accommodation to them was a challenge:

“Many women ridicule me, asking me why I am fussy during periods when they don’t have any problems. I face heavy bleeding and nausea and am unable to travel for fieldwork. I’m taunted that they take heavy work during menstruation, while I excuse myself from work and need time off! They don’t realise that every woman has individual menstruation management needs and we need empathy and flexibility in our working days.”



Champa (second from right) formed a group with other women with disabilities, who learned tailoring skills.

Kajal felt she was denied a job due to her marital status, highlighting some of the stifling gender discrimination that still exists in India:

“I was refused a job because of my disability and being unmarried. I spoke to a high officer, but she kept finding excuses for not recruiting me. I’ve escalated the issue further and the matter is still pending. I’m shocked that being unmarried is a curse and those who are married get a job, as if being married is a blessing.”

The Labour Force Participation Rate among women with disabilities is 8% versus 36.8% for men with disabilities in rural India

Good practices

This section outlines some of the empowering practices that were used in Building Partnerships. The real names of the women participants are used based on their consent and to acknowledge their accomplishments and successes.

Awareness raising

“Today, I stand with my chin high and confidence in my heart, and I know, yes, I can.” Danjai, DPO member, Odisha

Detailed measures to combat stereotypes and to promote awareness of the rights and capabilities of people with disabilities through public awareness campaigns, the education system, media and training programmes are included in the CRPD in article 8, on awareness raising.

The need for awareness raising extends to women with disabilities themselves who, as a result of discrimination and exclusion, often lack the skills, resources, opportunities, confidence, access to information and knowledge to become effective advocates of their own rights. To support this, Sightsavers India ran a gender assessment, and an SDG disability inclusive scorecard process focused on

education with DPOs. The scorecard process supported DPO members, children with disabilities and other stakeholders to develop a scorecard assessing local school services and facilities. It also convened the school staff to undertake the same process. Then it brought both sides together, along with other stakeholders and decision-makers, such as local government representatives, to develop a common assessment and action plan for improving services.

As a rights-based methodology, the process started with an orientation session on rights and entitlements. This was situated within the 2030 Agenda, the CRPD, the RPWD Act and the CEDAW, and it included a specific focus on the rights and entitlements of women with disabilities. The gender component built on a participatory gender assessment already undertaken with the DPOs.

The strength of feeling and sense of empowerment that the interviewees recounted as a result of their participation in these processes was notable throughout the interviews. Many women spoke of their personal transformation, increased confidence and new-found assertiveness. In the words of Danjai, “My dreams have wings now.” She continued:

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A two-day workshop on empowering women DPO Leaders on Advocacy and Gender Equality under the EU project was held in Bhopal, Madhya Pradesh, on 26-27 July 2018.

“When I was nominated group leader of the parents and DPO group to develop the ratings for the SDG disability inclusive scorecard recently in Behrampur, I ‘found myself’... This was my first community exposure and I learned how to lead active advocacy and stand up for the rights of girls and women with disabilities. For me, now, there is no looking back. It’s one of the things I will never want to give up, no matter what people say to me.”

Similarly, Leela, DPO member from Jharkhand, recounted with joy her experience of speaking publicly for the first time as part of the SDG scorecard process:

“I was nervous while holding the mic, but when I looked around, I got my confidence back and could recall all my opening speech lines. I spoke with a mic for the first time in my life as part of the scorecard process and now I’m confident that I can address community meetings better and actively advocate for other women with disabilities.”

Interviewees spoke of how their confidence spurred them on to support others too. In Rekha’s words:

“Before, we would discuss our rights only among ourselves. Now, we exert them.”



Rekha Meghwal says that after the gender training, she has become tech savvy.

Salma, DPO member from Rajasthan, felt empowered to stand up for a man being abused on public transport. She said:

“While travelling on the bus, the conductor behaved badly towards a man with a disability and slapped him. The man had a bus pass, yet the conductor wouldn’t let him stay on the bus. I couldn’t let that happen, so I walked up to the conductor and challenged him by telling him that he was wrong, and he should stop humiliating the passenger. The conductor realised that the passenger wasn’t alone and let the man remain seated.”



Salma Bano says there is no caste, class and religion divide for her. People recognise her as a disability rights activist.

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Leela Kumari recommends the monitoring of schools to ensure children, particularly girls, with disabilities are admitted and can learn effectively.

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Implementation of the Disability Inclusive Score Card on SDGs took place in five states. The first pilot focused on inclusive education. Women with disabilities played a leading role in the process.

The value of building the confidence of women with disabilities should not be understated. The gender assessment study of DPOs found that women were reluctant to come to DPO training sessions and other meetings as they could not always understand the content and felt they could not actively participate because of their lower levels of education and low self-esteem. This is one small insight into a fundamental way in which women with disabilities are made invisible.

As well as transformation on a personal and interpersonal level, the advocacy skills the women gained as a result of the training is resulting in positive and tangible outcomes on a wide range of issues. Nageshwari, a DPO member from Jharkhand, was an active contributor to the SDG scorecard process in Jharkhand and was selected to assess the accessibility of public buildings. As part of this, she facilitated a group

discussion with children with disabilities to understand their challenges and needs. The findings were used to advocate for accessibility improvements to support inclusive education and will benefit many children in her village.

Anuradha, a DPO member from Rajasthan, focused her efforts on improving environmental accessibility and health care:

“An accessible environment is very important under the SDGs. I am actively advocating for it and it’s been implemented in a few of our neighbourhood streets. I’ve also succeeded in getting the sewer lines maintained. These had been neglected, with dirty water entering our houses. Implementation of an accessible environment helps not only people with disabilities but everyone. I want good roads, light and cleanliness in my village.”

I'm also fighting for accessible public toilets for women with disabilities and advocating for a school toilet facing the market within the school premises."

Anuradha has also been advocating for more hospitals and more qualified female doctors. Interviewees particularly valued learning about their sexual health and reproductive rights. A DPO member interviewed shared her sadness that there was no information given to young girls regarding menstruation and hygiene management, resulting in distress and unhygienic practices. She recalled:

"I got my first period when I was 14. I told my mother that I saw blood in my urine and asked her what was happening to me. I was scared! When my mother told me that I would have to live with this throughout my life and every month I'd face this, I was shocked. At 16, before I could even understand more about my body and the biological changes I was experiencing with puberty, I got married."

Shweta, a DPO member from Rajasthan, spoke of how she'd previously been hesitant and embarrassed to talk about issues such as menstruation but feels liberated since undertaking gender training.



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Shweta Garu runs a boutique at home and also gives training to other women on disability rights.

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Anuradha Pareek, a disability campaigner, was elected to local government as Panchyat Samiti director.

"At 16, before I could even understand more about my body and the biological changes I was experiencing with puberty, I got married."

Participation and representation

“They see me as a future political leader.” Salma, DPO member, Rajasthan

Ensure responsive, inclusive, participatory and representative decision-making at all levels. SDG Target 16.7

Women with disabilities in both India and the EU face many environmental, attitudinal and political barriers to participation. Consequently, they remain largely excluded from decision-making processes on issues that affect their lives. Often, women with disabilities are invisible during consultations and decision-making, and are under-represented in organisations that represent disability or women’s issues. Organisations of women with disabilities both in the EU and India are very few,⁷¹ with limited funding and resources. They often lack visibility in both the agendas of the disability and the women’s movement.

Many of the women interviewed for Building Partnerships found engagement in their DPO an invaluable platform for advocacy. Leela, an active Secretary in her local DPO in Jharkhand, shared how she takes decisions and how her male

colleagues appreciate her participation and pay attention to her views. She manages the provision of tricycles, provides guidance on loans and raises awareness of rights to other women with disabilities. She also assists the development of her DPO’s gender committee and undertakes accessibility audits of public spaces, such as schools and rural childcare centres. Salma spoke of how her DPO involvement and advocacy work has inspired her to get involved in politics:

“People have started recognising my work and my position. My neighbours have started seeing me as someone very influential due to my DPO position and connection with high-profile people in the government and gram panchayat. They see me as a future political leader and if I’m given an opportunity I’d like to be in politics. My neighbours have encouraged me to become a ward member of their area and say they will vote for me. Other religious communities have started recognising me as well, such as the

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Orientation of elected Panchayati Raj (local administration) representatives on SDGs in Sirohi district, Rajasthan.

Jain community. There is no caste, class and religion divide for me. People have started recognising me as a woman with disabilities rights activist. And this is me, new Salma, without any prejudice. I live for myself and my family, and want my sisters, women with disabilities, also to live like me – chin up and smiling. We have coined a new word too: sisterhood. United we stand together to uphold our rights.”

In India, there are very few women with disabilities in local government, despite a 50 per cent allocation of seats for women. The views of women with disabilities are often ignored or disregarded in favour of experts, professionals, parents, guardians and carers. Enabling environments and positive attitudes to women with disabilities are essential to promote their political participation. This, in turn, will result in public policy that is more disability inclusive.

In Europe, women with disabilities are also under-represented in public and political life. In November 2018, the European Parliament passed a motion about the situation of women with disabilities. It asked for the introduction of “policies to enable and encourage the participation of women and girls with disabilities in public, social, cultural, economic and political life, in particular by reducing barriers to mobility and encouraging women with disabilities to form and join organisations and networks, as well as through training and mentorship programmes”.⁷² Representation was highlighted as an important factor for engaging more women to become empowered. In Leela’s words:

“If more women join the DPO, it will be a motivating factor for other women. They will feel empowered like me.”

Anuradha, a DPO member from Rajasthan and a member of her local government, is admired for her power and position to

carry out advocacy and help find solutions to issues facing people with disabilities. She has gained status and respect in her community. She said:

“I am known in my village for my work and contribution. My father is known for my work and people say, ‘Look, there’s Anuradha’s father.’ I feel proud and confident that now I have an identity.”

However, Anuradha still faces many challenges in her work. She represents women with disabilities from her area in the Social Welfare Department but has found that even that department discriminates against women with disabilities. She has also faced issues within her own DPO, where she says she has frequently faced aggravation from male DPO members if someone from her village is nominated for a post in the DPO. She added:

“When there is visibility of women with disabilities required during events and seminars, I am invited. However, in an urgent decision-taking meeting where my representation is necessary, I’m not called.”



Women DPO members are trained on making jewellery, which builds a sense of solidarity, independence and empowerment.

©Puran Sharma, APNO, Rajasthan

Economic empowerment

“I have decided to be a member of a local self-help group and earn a decent living for myself and save for my family. It will help me to stand up with economic empowerment.” Dhanjai, DPO member, Odisha

By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value. SDG Target 8.5

Economic empowerment is key to a person’s independence and can further contribute to self-esteem and self-fulfilment. Access to decent work, social protection and financial inclusion all play a crucial role. This was confirmed by Building Partnerships. In particular, the project highlighted the role of social protection and work in supporting interviewees’ self-sufficiency and, in turn, building their confidence, developing their wellbeing and fostering their independence.

A key part of the journey to economic empowerment is access to training to gain the skills needed to earn a living. When Neha started a stitching and beautician course, she was excited, but demotivated by her neighbours:

“When I told my sister that I need 1,500 rupees to undertake a beautician course, one of my neighbours taunted me, saying, ‘You can’t even walk properly, what is the point of doing such a course?’”

Fortunately, a local NGO, the Jharkhand State Livelihood Promotion Society (JSLPS), supported her to do the course for free. She now uses her skills to support her family. On completion of the course, the same neighbour began to respect her for the quality of the services she provides and now visits her regularly for beauty treatments. In Neha’s words:

“People’s attitudes have changed, and they look up to me. I have become quite popular... Daily earnings got me respect and this is what I treasure the most!”

Gaining respect and status in the community came up again and again as a result of the women defying expectations to become educated, employed, running their own businesses and running for government. These attitudes created positive reinforcement which developed the women’s confidence to reach even higher and achieve more.

DPOs also play an important role in facilitating the access to employment and livelihood opportunities by making connections, providing training and setting up self-help groups. Through self-help groups, many of the women involved in

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Neha Khatun is self employed and independent. She runs her own beautician business.

Building Partnerships were able to support each other to earn reasonable incomes, for example, by making spices or providing tailoring services. This was a striking source of empowerment and pride. Salma, a DPO member in Rajasthan, who works in a self-help group earning a reasonable monthly income, was involved in raising funds to run the first self-help group for women with disabilities in her district. She said:

“This has never happened before... we have created history.”

Shweta, another DPO member in Rajasthan, handles her DPO's accounts and runs a small boutique at home. She now works to empower other women with disabilities as a self-help group trainer, teaching other women with disabilities to stitch. She said:

“With SDG training, my strength and faith in my own self has increased. I train women to become financially empowered and earn a decent income by becoming part of self-help groups. Now the women have started earning slowly and are confident as they are recognised as productive citizens of society. I helped create opportunities for these women for their financial empowerment and self-respect.”

It is efforts like these which will help women like Jayanti, who would like to run a shop in future with the aspiration **“to be a taxpayer and feel proud of it”**.

Through her DPO, Jhumuri, aged 24 and from Odisha, received training on how to make soft toys, fast-food preparation and farming. She started to work from home with her sister-in-law. She said:

“I sell soft toys in the village fair. I've managed to save 6,000 rupees so far and have bought a mobile phone on my own. I feel happy and contented with the business as I'm self-sufficient.”

In terms of social protection, India's disability pension scheme was highlighted as a valuable provision. The government provides a small monthly pension for minimum sustenance to people with disabilities who are over the age of 18 and living below the poverty line. While the amount is very small, Leela, a DPO member from Jharkhand, was able to save her disability pension and, with further support from her mother, set up a grocery shop. She now supports her family, including her brother who also has a disability. Leela volunteers in a government affordable housing initiative, where she verifies the documents of those who have applied for the scheme. People in the community who previously ignored her now approach her with respect.

Leela's experience illustrates the importance of countering negative stereotypes of women with disabilities as incapable of work and reinforces the importance of initiatives to promote awareness of the capabilities and contributions of people with disabilities, as outlined in the CRPD's article 8 on awareness raising.

Many countries use quotas to counter the exclusion of women with disabilities from the workforce. Some of the women interviewed had benefited from disability quotas for gaining access to college and employment. While international frameworks don't explicitly reference quotas, the CRPD does call for promoting the employment of people with disabilities in the private sector “through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures”. In its review of the EU report, the CRPD Committee also recommended that the EU develop affirmative actions to advance the rights of women and girls with disabilities.

Solidarity, alliance building and learning exchange

“Meetings with international NGOs were an eye-opening and inspiring experience.” Neeta, DPO member, Madhya Pradesh

This Partnership (Agenda 2030) will work in a spirit of global solidarity, solidarity with the poorest and with people in vulnerable situations.⁷³

The benefits of creating alliances to foster an enabling environment for people with disabilities to effectively and fully participate in social life is recognised in the CRPD in article 29, which includes stipulations around the importance of forming and joining organisations of people with disabilities to represent people with disabilities at international, national, regional and local levels.

The importance of solidarity and alliance building was recognised by most interviewees. As they spoke of becoming empowered through learning their rights, undertaking advocacy and becoming economically empowered, the interviewees increasingly spoke of reaching out to support other women with disabilities and of their desire to share what they had learned and build solidarity. Salma, a DPO member from Rajasthan, spoke of her efforts to build an alliance of people with disabilities at the local level:

“In our DPO, we have started recognising and identifying women and men with disabilities in the community. We connect with them to understand their current situations and motivate them to join our DPO. We’ve started one-to-one conversations with everyone. This is not a job for me anymore. I’m living with disability and for people with disabilities.”

The importance of linking local advocacy with higher levels is recognised by the CRPD in article 32, which recognises the importance of measures to foster international cooperation in support of

national efforts. Among other things, it stipulates the need for capacity-building initiatives, such as the exchange and sharing of information and experiences and the development of training and best practices in partnership with civil society organisations, particularly organisations of people with disabilities. The value of this is reflected by the enthusiasm of Neha, a DPO member from Jharkhand:

“I feel knowledgeable and empowered, thanks to the information I’ve been given to connect local and global issues relating to women with disabilities. I’m already engaged in rights-based advocacy and want to be an advocate of disability rights. During the disability inclusive SDG scorecard process, I learned that ‘united we stand together’ and alone we cannot uphold all our rights!”

To extend this transformational impact from the local to the global, Building Partnerships supported initiatives to facilitate rich and significant exchanges between grassroots rural DPO representatives from India and EDF partners. In December 2018, a group of Indian DPO members were welcomed in Brussels.⁷⁴ The delegation was invited to share their learnings from Building Partnerships with the EU, EDF, Sightsavers, the EU Bridging the Gap project and the International Disability and Development Consortium (IDDC). Nadia Haddad, Board member of the European Network on Independent Living (ENIL) and of EDF, shared:

“It was very interesting to hear about the Indian laws and policies protecting women with disabilities and the work of Sightsavers in advancing capacity-building of DPO members, in particular



Indian DPO representatives participate in European Disability and Development Week in partnership with EDF in Brussels, Belgium, in December 2018.

women members, through projects and programmes such as self-defence courses, employment schemes and workshops on sexual and reproductive health and rights.”

In June 2019, a second delegation of six DPO members attended EDF’s Annual General Assembly where they had the opportunity to present the work undertaken so far under the SDG scorecard project.⁷⁵ The Indian team presented Sightsavers’ experiences of advancing the rights of women with disabilities in India in a seminar on CEDAW, chaired by Ana Peláez Narváez, EDF Vice President and

member of the CEDAW Committee. It was hugely empowering for the Indian DPO members to engage with and share their learning with EU organisations. Neeta a DPO member from Madhya Pradesh who took part in the exchange, reflected:

“I had the most remarkable visit to Brussels with fellow DPO members. It was the first time that I travelled to an international workshop where I had the opportunity to express my own experiences and share my successes and listen to international speakers.”



EDF delegates meet with APNO, a state-level DPO network supported by Sightsavers, in Udaipur, Rajasthan.

During the exchange visits to Brussels, the delegation from India also had the opportunity for extensive learning about the situation of women with disabilities in Europe. They took part in a wide range of disability-related events and met with many other European and international disability organisations and EU institutions to learn and share. Neeta further shared how much she had benefited from the exchange:

“I came back with lots of learnings and I feel very confident. I would appeal to every DPO of India to work together in a united way and motivate each other to achieve what EDF has achieved in Europe. I saw that in EDF women with disabilities have a strong voice and participate more and that should be replicated in Indian DPOs.”

In November 2019, a delegation of EDF members was supported to visit India to meet DPO representatives working at grassroots level in Rajasthan.⁷⁶ The visit was a successful exchange of mutual learning between EDF and the state-level DPO, All People’s Network Organisation (APNO). It also included a meeting with the Municipal Department of Dungarpur, in which EDF stressed the importance of including DPOs and women with disabilities in all processes and consulting with them as experts, not simply as beneficiaries.

The success of these exchange visits proved a powerful intervention, both for EDF to share its expertise to build the capacity of grassroots Indian DPOs and for Indian DPOs to share evidence from the Indian disability context to influence EU development cooperation and institutions.



APNO and EDF representatives at a state-level DPO meeting in Udaipur, Rajasthan, in 2019.

Way forward

While many of the gaps that have emerged in Building Partnerships are addressed by the rights and entitlements found throughout the 2030 Agenda, the CRPD, the CEDAW and the RPWD Act, the reality is that there is still a substantial way to go before the rights of women with disabilities are fully realised. While their rights and entitlements exist in theory throughout high-level international policy frameworks and human rights treaties, significant challenges remain to ensure they are known, upheld and monitored. Practical steps and initiatives are needed to mainstream gender and disability into policies, programmes, budgets and action plans. Strengthening the two key areas below could be a game changer for millions of women with disabilities in India and the EU.

Policy and programming

In 2019, the CRPD Committee recommended that India adopts national and state action plans for promoting equality and the inclusion of women and girls with disabilities in all areas of life; ensures that the national policy for women mainstreams disability; and ensures the effectiveness of campaigns to raise awareness, reduce stigma, gender and disability stereotypes, involving women with disabilities through their representative organisations in awareness-raising programmes following the Committee's general comment No. 7 (2018). It also recommended that India establish gender-responsive policies and budget allocations at the national and state levels to address the rights of all women and girls with disabilities to better inform policy and provision of services.

In 2015, the CRPD Committee recommended that the EU mainstream a women and girls with disabilities perspective in its forthcoming gender equality strategy and its policies and programmes, as well as a gender perspective in its disability strategies.

While some initiatives have been undertaken, the EU has not recognised women with disabilities in much of its policymaking and programming. Some examples include:

The Spotlight Initiative on women's rights, launched by the EU and the UN in December 2018, with an initial investment of 500 million euros.⁷⁷ Despite its intentions to prioritise the gender dimension within development cooperation, it does not systematically include women with disabilities.



Nidhi Goyal, founder and executive director of Rising Flame, on a women with disabilities India network panel at the National DPO consultation on CRPD concluding remarks in March 2020.

Photo contribution: Rising Flame

The Gender Action Plan (GAP) aimed to strengthen the EU's commitment on gender equality but failed to mention disability. This was despite the European Disability Strategy 2010-20, which aimed to implement the CRPD and stipulated the need to pay attention to the cumulative impact of discrimination that people with disabilities may experience on other grounds, including gender.

Jutta Urpilainen, the new European Commissioner for International Partnerships, has announced the preparation of GAP III, saying that it represents a major opportunity to mainstream the rights of women and girls with disabilities.

Gender Equality and Women's Empowerment: Transforming the Lives of Girls and Women through EU External Relations 2016-2020, also known as GAP II and established as a continuation of GAP. GAP II mentions disability as a factor leading to multiple discrimination and intersectional barriers, as well as the need for women and girls with disabilities to take control over decisions that affect them at all levels; but it does not systematically address the rights of women and girls with disabilities.

GAP II suggests excellent tools for gender mainstreaming and concrete examples of successful experiences. However, there are few examples that include a disability perspective or that address the intersectionality between gender and disability. There is no mention of women or girls with disabilities in the proposed actions or indicators which include priorities and objectives.

EU Gender Equality Strategy post-2019. During the past decade, the EC adopted a strategy for equality between women and men, 2010-2015 and a strategic engagement for gender equality, 2016-2019.^{78,79} Neither addressed the specific situation of women and girls with disabilities.

The 'rights-based approach encompassing all human rights for EU development cooperation' is a toolkit which aims to help operationalise the EU's commitment to implementing a rights-based approach to development cooperation.⁸⁰ It only briefly mentions people with disabilities as part of the vulnerability criteria and fails to provide concrete examples, good practice or practical guidance on how to ensure the participation and inclusion of people, and more specifically women, with disabilities.

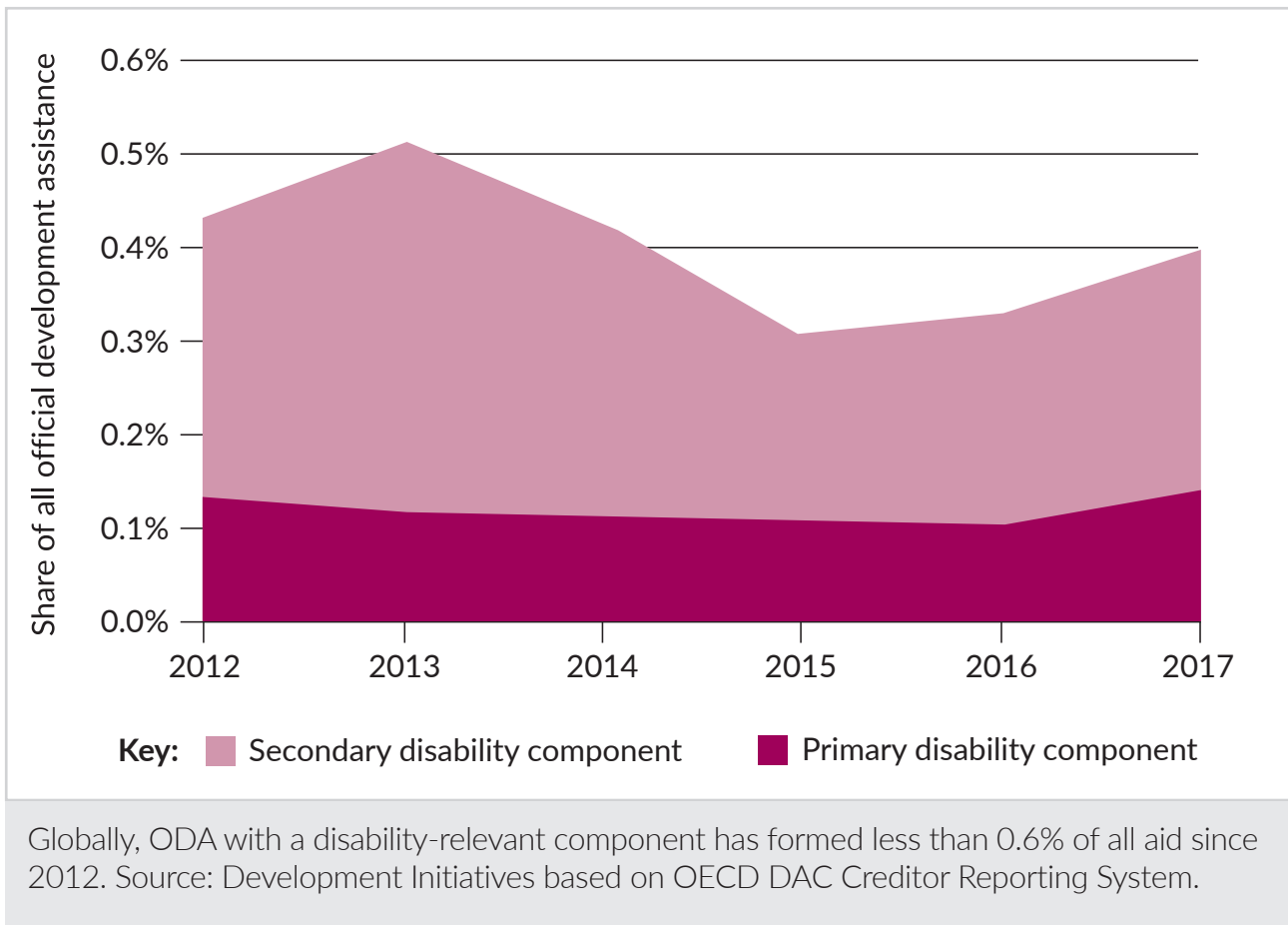
Data and research

Another major gap in addressing the needs of women with disabilities is the lack of research and data. These are currently difficult to compare because of the different definitions adopted across countries – sometimes even within the same country by different public administrations.

The 2030 Agenda clearly requires that SDG indicators should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics. However, in the EU there is a gap in the collection of gender-specific data and disability – this, despite the CRPD Committee recommendation that the EU identify and put in place mechanisms to disaggregate data on disability in order to monitor the rights of people with disabilities in its development programmes. In June 2012, the Council of Europe also recommended that EU member states develop consistent statistics and data for people with disabilities, women and girls.

In 2018, the EU made an important commitment to using the OECD (Organisation for Economic Co-operation and Development) DAC (Development Assistance Committee) disability inclusion marker in its international cooperation work. This marker could be critical to improving the availability and quality of data collected on disability in relation to Overseas Development Assistance (ODA). The marker will effectively start to measure how much programming aid reaches people with disabilities, and advance our knowledge on how inclusive EU spending is and the impact it has on women with disabilities.

In India, disaggregated data on disability is scarce. The 2011 census and the National Sample Survey Organisation (NSSO) Disability Survey 2018 remain the most significant contributors of disaggregated



data. However, the publishing of this data is very infrequent, and the census happens once in 10 years.

The NSO, a wing of the Ministry of Statistics and Programme Implementation, has conducted a Survey of Persons with Disabilities during July 2018 to December 2018 as a part of the 76th round of the National Sample Survey (NSS). Prior to this, the survey on the same subject was carried out by the NSO during the 58th round (July to December 2002). However, the survey did not use the Washington Group of Questions to ensure internationally-comparable data.⁸¹

Disability does not figure in India's routine macro-data collection. The macro-level data available on disability in the public domain is outdated and offers only a limited understanding of the prevalence of the problem of disability and its gender implications. From the list of indicators

released by the Ministry of Statistics and Programme Implementation, only three indicators specifically mention disability, out of a list of more than 300. This is substantially lower than the indicators mapped by the 2030 Agenda, which has specific mention of disability in seven targets and 11 indicators.

No specific indicators for people with disabilities or, more specifically, women with disabilities are included in any of the goals and targets which have a reference to vulnerable groups. Furthermore, current indicators are not developed in harmony with the CRPD and the RPWD Act. However, the National Committee for the Rights of Persons with Disabilities has proposed some key indicators to capture the inclusion of women with disabilities.

Recommendations

Below, the paper makes recommendations for action by the EU and India, and at a global level. The recommendations from India are the voices of the women with disabilities interviewed for this paper. The recommendations on the European Union were drafted by EDF.

Madhumita Das, a community health worker, visits homes to talk to people about eye care.



India

The following recommendations were made by the 15 women DPO members interviewed as part of Building Partnerships. They are specific to SDG implementation in the Indian context and recognise the key concerns of the interviewees, as vividly illustrated in their stories.

Access to justice

- **Raise awareness of the right to justice.** Raise awareness of police complaints mechanisms and reporting processes. Sensitise and implement training among the police on disability inclusion and the rights of women with disabilities to access justice, including the specific issues faced by women who are blind and have speech or hearing impairments.
- **Promote accessibility of all judiciary buildings, including courts and police stations.** Ensure women's desks at police stations have female police available and that they are trained to uphold The Criminal Law (Amendment) Act, 2013.

Family

- **Amend state policies that discriminate against women with disabilities. Develop policies in line with CRPD.** Remove, with immediate effect, those discriminatory laws that offer financial benefits for marrying people with disabilities.
- **Provide an allowance for women with disabilities to support setting up a home.**
- **Provide support to families. Ensure that all disability programmes work with families to raise awareness,** improving their understanding of disability and how they can support and empower people with disabilities.



©Samarthyam

Samarthyam, under its project Women with Disabilities Forum for Action, raised awareness on violence against women with UN Women at India Gate, New Delhi, in December 2015.

Education

- **Ensure accessibility of buildings, transportation and sanitation facilities for students and teachers with disabilities**, in terms of the physical infrastructure of buildings, including regular maintenance of schools, training centres, hostel facilities and staff accommodation, as well as adequate and accessible water and sanitation facilities for managing menstrual hygiene needs.
- **Provide assistive devices and technologies and provide reasonable accommodation**, including comfortable chairs and seating arrangements, scribes for blind children and children who cannot access learning without assistance, and games for children with disabilities.
- **Ensure children with disabilities are in school and are learning effectively**. Ensure schools act to retain girls with disabilities in school and promote learning. Ensure local authority intervention to support out-of-school children. Record when girls with disabilities drop out and why.
- **Raise awareness of the rights of girls and women with disabilities in the curriculum**, including on sexual health and reproductive rights, safety and gender equality. Train teachers on the rights of girls and women with disabilities, with a specific focus on girls.
- **Provide gender-sensitive skills training and scholarships for women with disabilities in higher education**.

Health

- **Ensure access to health care**. Ensure that quality health care service provision in rural India meets the needs of women with disabilities. Support mobile community outreach services to dispense medicines. Ensure access to rehabilitation services.
- Enable community health workers to provide medicines at home, under the health service provision scheme of the National Rural Health Mission.
- **Make sure health care is available through people's lives**. Provide preventive care, for example, through the provision of free medical check-ups twice a year for women with disabilities and early intervention for girls with low vision. Support rehabilitation services. Prioritise women with disabilities and provide a health care to support priority check-ups.
- **Ensure the availability of qualified female doctors and gynaecologists for women and girls with disabilities** in primary health centres, community health centres and other government hospitals. Promote privacy during consultations and provide accessible health information.
- **Raise awareness and train medical staff and women with disabilities on the health care rights of girls and women with disabilities**, including the rights of women with disabilities to their sexual health and reproductive rights. Stop treatment without free and informed consent. This includes abortion, contraception and sterilisation.

Economic empowerment and employment

- **Provide reasonable accommodation to women with disabilities at their workplace**, for example, through the provision of personal mobility devices, adapted vehicles, availability of accessible transportation, transport allowances, female assistants and mobile crèches for working mothers with disabilities.
- **Implement fair, accessible and equitable recruitment processes**, for example, by prioritising qualified women with disabilities, raising awareness of the 4 per cent quota in government jobs for people with disabilities, and holding job fairs to connect women with disabilities with companies and service providers. End the criteria of marital status as a requirement for employment.
- **Provide social protection for women with disabilities**, including adequate quality-of-life protection and the provision of accessible shelters, including, where necessary, domestic violence shelters for women with disabilities at block and district level.
- **Promote and support financial inclusion.** Make low-interest and flexible loans available to women with disabilities, including for self-employment, higher education and travel. Recognise self-help groups run by people with disabilities. Provide vocational training to women with disabilities.

Accessibility

- **Make voting facilities accessible during elections.**
- **Ensure public transport is accessible and affordable.** Recruit women drivers and conductors to combat violence and abuse towards passengers.
- **Promote independent living** through access to rehabilitation services with subsidised and regularly maintained (where appropriate) assistive devices, and personal support for girls and women with disabilities. Ensure assistive devices and technologies are gender and age appropriate.
- **Protect women with disabilities.** Use gram panchayat (village council) funds to ensure the safety and security of women with disabilities by, for example, providing free volunteer escorts for travel to school and college or support with banking services, excursions and health centre visits.



Youngest voter and DPO member from Bojunda in Chittorgarh District, Rajasthan.

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Anuradha presenting at the UNESCAP-led Asia-Pacific Forum on Sustainable Development on the challenges faced by women with disabilities in India.

Awareness, participation and representation

- Include women with disabilities equally in all social, political, cultural and economic areas of life.** Build an inclusive culture at grassroots level, including the gram panchayat, starting with raising awareness of the rights of women with disabilities among the women themselves. Make local government and gram panchayat policies available to all women without discrimination.
- Build a supportive ecosystem.** Encourage advocacy and support groups for women with disabilities. Create wider platforms and opportunities to connect women with disabilities so they can share knowledge and information on rights.
- Raise awareness of the 2030 Agenda.** Train all DPO members on SDG targets and indicators, and monitor SDG implementation through a scorecard process.
- Create avenues for increased participation,** for example, through creating gender committees within DPOs to address rights-based advocacy and prevent abuse and violence against women with disabilities.

Data, research and monitoring

- **Collect data on women with disabilities who have applied and/or received certificates, pension and appropriate assistive devices and technologies.** Include reasons for delays or denials.
- **Conduct access audits of public places.** Implement recommendations.
- **Monitor access to gram panchayat services in rural areas.** Compare quality of service provision for people with disabilities to that for people without disabilities.
- **Conduct social audits.** Collect data on women with disabilities at the village level to monitor their educational, medical, social, economic, political and cultural inclusion.

PRIMARY SCHOOL

S/No.	Indicators		Very bad	Bad	OK	Good	Very good	Not answered	Total	
1	Accessible environment	Children	3	4	0	3	0	0	10	30
		Parents	11	1	0	2	0	0	14	
		Service providers	0	6	0	0	0	0	6	
			14	11	0	5	0	0	30	
2	Training of teachers on children with disabilities	Children	0	0	0	0	0	10	10	30
		Parents	7	6	0	0	0	1	14	
		Service providers	6	0	0	0	0	0	6	
			13	6	0	0	0	11	30	
3	Availability of assistive devices	Children	5	4	0	1	0	0	10	30
		Parents	13	1	0	0	0	0	14	
		Service providers	6	0	0	0	0	0	6	
			24	5	0	1	0	0	30	
4	TLM for all types of disability	Children	2	8	0	0	0	0	10	30
		Parents	9	5	0	0	0	0	14	
		Service providers	6	0	0	0	0	0	6	
			17	13	0	0	0	0	30	
5	Accessible toilet	Children	10	0	0	0	0	0	10	30
		Parents	13	1	0	0	0	0	14	
		Service providers	2	4	0	0	0	0	6	
			25	5	0	0	0	0	30	
6	Participations of children with disability in sports and cultural activities	Children	6	3	0	1	0	0	10	30
		Parents	9	5	0	0	0	0	14	
		Service providers	0	0	0	1	5	0	6	
			15	8	0	2	5	0	30	
	Total	Children	26	19	0	5	0	10	60	180
Parents		62	19	0	2	0	1	84		
Service providers		20	10	0	1	5	0	36		
	Grand total		108	48	0	8	5	11	322	

Consolidated scorecard on Inclusive Education as part of the DPO-led process on the Disability Inclusion Score Card.

European Union

The following recommendations call for a greater, more nuanced understanding of the complex, and often cumulative, nature of the discrimination girls and women with disabilities face. This is explicit in the call for funding for further research, which acknowledges the important role the EU can continue to play in respect of this area.

Legislation and programming

- **Mainstream the rights of women and girls with disabilities in international cooperation, including in the next Gender Action Plan III and the new EU Action Plan on Human Rights and Democracy.**
- **Showcase policy coherence between EU internal legislation and EU external action.** For instance, international cooperation must also be included in the next European Gender Equality Strategy as well as in the EU Disability Strategy 2020-2030. Include women and girls with disabilities and accessibility across the EU external actions budget for the period 2020-2027 and invest in developing the capacities of the disability rights movements in the Global South to meaningfully engage in development and humanitarian action.
- **Formally include women and girls with disabilities in the Spotlight Initiative,** the global, multi-year partnership between the EU and the UN to eliminate all forms of violence against women and girls.
- **Include an intersectional approach in implementing the Beijing Declaration and Platform for Action.** Guarantee the human rights of all women and girls with disabilities in all EU legislation and policies, including international cooperation.



Pirkko Mahlamäki attended the Civil Society Forum and UN ECE meetings on Beijing +25 in Geneva in October 2019.



EDF Women Committee participated in the consultation on the evaluation of the European Disability Strategy 2010-2020.

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- **Invest in strengthening the technical capacity of EU staff,** both at headquarters and in the EU delegations so they understand of the rights of women and girls with disabilities.
- **Create a network of disability focal points across EU institutions and throughout EU delegations,** including clear support and guidance on the rights of women and girls with disabilities.

- **Ensure accessible consultation with women with disabilities and their representative organisations** at all stages (design, implementation and monitoring of the gender action plan; programming, implementation and monitoring of subsequent projects and programmes) and at all levels (European and country levels). Including women and girls with disabilities will ensure their full and effective participation.
- **Recognise women with disabilities as experts and leaders, supporting the empowerment of women with disabilities and the capacity development of their organisations.**
- **Ensure all EU-funded actions for international development uphold the principles of accessibility, dignity and the rights of women and girls with disabilities** to make their own decisions, live independently and be included in the community.
- **Ensure specific attention in EU-funded actions to the most marginalised groups** of persons with disabilities (women and girls, children, indigenous people, persons who are deaf-blind, persons with psycho-social disabilities and persons with intellectual disabilities, among others).
- **Apply the twin-tack approach to disability inclusion in development cooperation to the new Gender Action Plan.** The approach comprises mainstreaming a gender perspective and the rights of women and girls with disabilities of all ages, and initiatives targeting women and girls with disabilities. Provide several and good examples of mainstreaming and targeted actions in the documentation.
- **Mainstream an intersectional analysis at country level** and support the design and implementation of policies and initiatives that do not adversely impact on women and girls with disabilities, including through conducting needs and risk assessments.

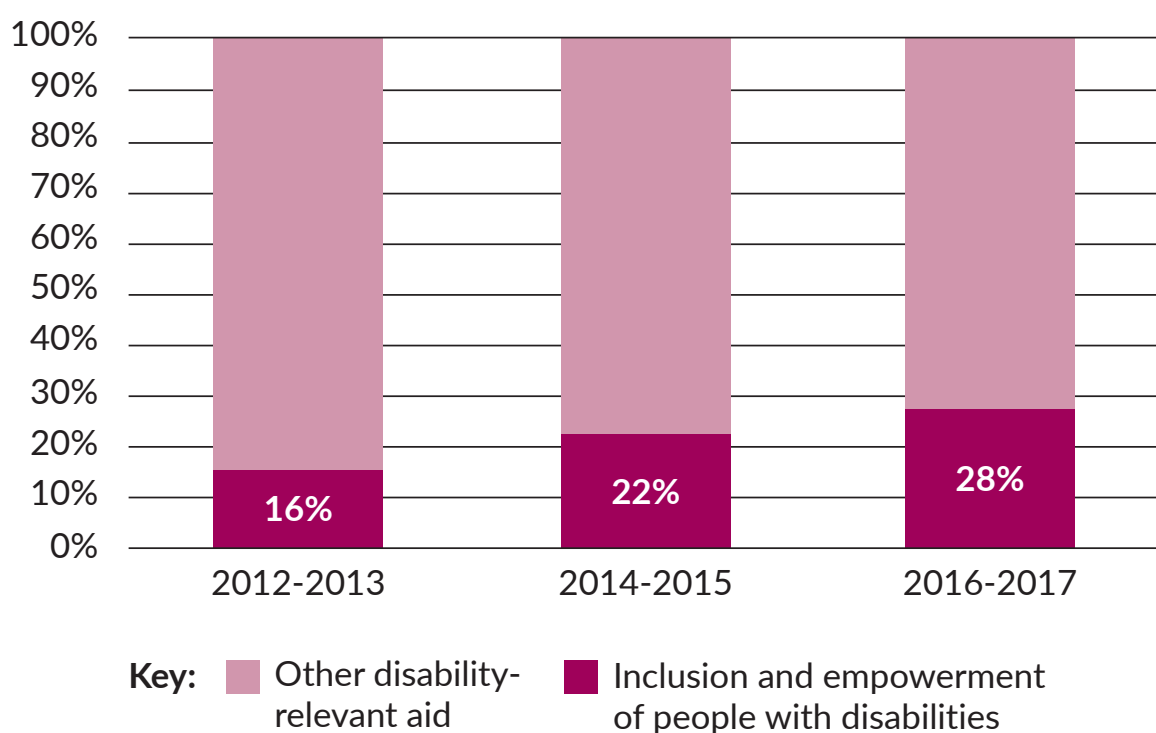
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EDF prepared and conducted a training course on CEDAW, the role of the CEDAW Committee and how to provide alternative reports to the CEDAW Committee. This took place after the EDF General Annual Assembly in Brussels, Belgium, on 2 June 2019.

Monitoring and accountability

- **Strengthen and develop new EU disability-related indicators.** These should be in line with the 2030 Agenda and the CRPD and use existing technical capacity to measure the inclusion of persons with disabilities in the EU's approach to the SDGs, including international cooperation.⁸²
- **Collect and disaggregate data by sex, age and disability, and provide systematic support to partner countries** in this through using existing tools, including the Washington Group on Disability Statistics Questionnaire. The EU should ensure support and fund research at European and national levels on the intersectional discrimination and social exclusion that women and girls with disabilities face within the EU and in international cooperation.
- **Use the OECD DAC disability inclusion marker** to ensure human rights programming is inclusive.
- **Follow the Inter-Agency Standing Committee (IASC) guidelines in humanitarian action** and use appropriate indicators disaggregated by sex and disability, such as the indicators developed in the framework for Bridging the Gap I, in projects and programmes implemented in partner countries.



Globally, 28 per cent of disability-relevant aid between 2016 and 2017 had the purpose of inclusion and empowerment
Source: Development Initiatives based on OECD DAC Creditor Reporting System.



Accredited Social Health Activist workers Usha Devi, Sonai Devi and Rekha Devi at an eye care screening at Gola community health centre, Ramgarh.

Conclusion

As the world's leading provider of development assistance, the EU has the potential to deliver transformational change in the lives of women with disabilities through its international cooperation grants and programming.

Building Partnerships is testament to this and evidence of effective EU-India cooperation in disability rights. The positive impact it has had on the lives of the women that participated reverberates throughout this paper.

But much needs to be done and there are significant opportunities to strengthen and address the gaps in central and state legislation and policy in India and in the European Union's international

cooperation policy, programmes and practice, as identified by EDF. If these gaps are not addressed, we will not be able to meaningfully make progress on the SDGs, nor implement the CRPD in full.

The voices of the women from India involved in the Building Partnerships project that are amplified in this paper paint a vivid picture of the impact that failing to address these gaps makes to the lives of women with disabilities living in India today. But they also describe just as vividly and profoundly the impact and real change that learning about their rights has brought to their lives. To reiterate Rekha's words:

“Before, we would discuss our rights only among ourselves. Now, we exert them.”

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www.sightsavers.org

 **SightsaversUK**

 **@Sightsavers**

 **@sightsavers**

 **SightsaversTV**

Bumpers Way
Bumpers Farm
Chippenham
SN14 6NG
UK

+44 (0)1444 446 600

info@sightsavers.org

 **Sightsavers**