

# 'If you stay quiet, you stay invisible'

Feminist disability  
rights activists  
share their stories  
of working for  
justice



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# Introduction

Mama Cash funds feminist groups and movements led by women, girls, trans people, and intersex people working to secure justice and freedom. We focus on funding organisations that are self-led by the people who benefit from the group's advocacy, that are putting under-addressed and/or contested issues on the agenda, and that are addressing the root causes of oppression and pushing for change that is transformational of systems and societies.

Consistent with these commitments, Mama Cash intentionally funds groups of disabled women, girls, trans people, and intersex people\*. In recent years, we have worked to bring new focus to supporting feminist disability justice activists. Over the past ten years (2011-2021), for example, Mama Cash has channelled approximately €2.18 million in grants to 16 feminist groups with a focus on disability rights and justice. We are committed to learning from these activists and to improving our work as an actively anti-disablist funder. This collection of partner profiles is a contribution to amplifying partners' voices and sharing what we are learning.

In recent years, we have seen the requests for funding we receive from groups of disabled women and girls grow. In our last analysis of this data (covering the period 2016-2018), the number of funding applications we

reviewed from groups led by disabled women increased ten-fold: from just two in 2016 to twenty in 2018. This speaks not only to the urgency of the issue, but also to the energy that feminist disability justice activists are bringing to their organising and to growing their movements.

*'If you stay quiet, you stay invisible'* is a collection of eight profiles of grantee-partners funded by Mama Cash that are working at the intersection of feminist and disability rights activism. With this collection, we aim to share with donors, other women's funds, feminist and disability rights movements, and other stakeholders, their stories of activism for justice. This collection also shares our key learnings from activists working at the intersections of feminist, women's rights, sexual rights, disability rights, and other movements. They are making clear demands, and we are working to listen to their voices to ensure that we

\* We occasionally use *disabled women and girls* in this introduction and in our conclusions as a shorthand designation for *disabled women, girls, trans people, and intersex people*; in all cases, this shorthand refers to the full breadth of disabled communities with which Mama Cash works.

provide better support for their urgent work.

These distinct stories come from eight countries in different parts of the world: Bangladesh, Colombia, India, Israel, Kyrgyzstan, Madagascar, Serbia, and one country that cannot be named for safety reasons. Most of these groups focus on disability, although the Women's Security Index Coalition in Israel offers the example of a feminist coalition that uses the strategy of creating research for advocacy and is working to integrate a disability rights perspective into its work on the issue of security. Most of the groups focus principally on physical disabilities; however, Anjali in India focuses on mental health, raising important questions about how we define illness and wellness.

As different as the eight groups and their stories are, common themes emerge: the experience of having to fight against the stigma of being seen as 'less than' and as a person who requires 'help'; the importance of coming together to unlearn these messages and to cultivate autonomy; the need for intersectional and cross-movement organising and for challenging both feminist and disability rights movements to include disabled women and girls; the need for funders who listen and respond with good-quality resourcing.

These stories are based on in-depth interviews with each partner. We wrote the stories and then asked partners to review the pieces to ensure that we had represented their stories accurately and in the way that they wanted to tell them. We conceived this as an exercise in listening.

It was our intention, and it is our hope, that these profiles reflect as closely as possible activists' own voices. We are honoured to share their stories.

**A note on the language we have chosen:** Members of disabled communities use a variety of types of language to discuss disability. There is no single approach that is 'correct', but the use of language involves choices about what you wish to stress. Some people with disabilities use 'person-first' language (e.g., 'woman with a disability') to put the emphasis on the individual person (before the label 'with a disability'). This emphasises that a woman with a disability is a person first. Others in disabled communities use 'disabled people', 'disabled women', etc. This is referred to as the 'social model of disability'. This use of 'disabled' indicates that there is a disabling agent at work: a society that is not designed to be mindful of people's diversity, including their impairments. In this framing, it is the society that is the disabling element (not the individual person's impairment).

Mama Cash uses both person-first and social model language depending on context. In this publication, we have chosen to use social model language because we wanted to stress that the way society is designed and organised is the major factor in disabling people. The language used in each of the eight profiles in this publication reflects the language that partners themselves use.

# 01 Cultivating autonomy

Colectiva

Polimorfás,

Colombia



Members of Colectiva Polimorfás. Photo: Ivan Castaneira.

**In 2014, when Bubulina Moreno and Yolanda ('Yoli') del Rocio Gil took stock of the movements most relevant to them, they saw little space for themselves or their issues. 'It became clear for us that within the disability rights movement there was not enough awareness or recognition of the specific issues faced by women and girls,' recalls Bubulina. 'There was no discussion about gender-based violence, or sexual and reproductive health. These were just some of the issues that the movement considered unnecessary or unimportant to address compared to more pressing issues, like education, labour rights and culture.' When Bubulina and Yoli looked toward the feminist movement, they encountered a similar problem. 'The feminist movement was very ableist,' recalls Bubulina. 'They didn't recognise the reality we face. They didn't include us in their activism.'**

That situation inspired Bubulina and Yoli to create Colectiva Polimorfias. Based in Bogota, Colombia, the group is dedicated to defending and promoting the rights of women and girls with disabilities – or, to use their preferred description, women and girls with 'functional diversity'. The collective's activities, from education to advocacy, are all geared toward strengthening the autonomy of women and girls with disabilities.

### **A confidential and safe space**

Colectiva Polimorfias facilitates support groups, which meet regularly on the

weekends in Bogota. The support groups provide a safe space for the women and girls with functional diversity to share their experiences, express themselves freely, and discuss their problems, as well as strategies for dealing with them. Cases of sexual, psychological, and economic violence commonly arise as topics for discussion. According to Yoli, many women come to the group believing what they have been told their whole lives: that they are ugly, they are worthless, they are a burden on their families. Violence and abuse are so normalised that the women do not recognise it as such. 'The support group is a space for women to empower themselves and better understand the situation they are in,' says Bubulina. 'They learn more about their rights and how they can protect themselves.'

The COVID-19 lockdown measures had a severe impact on the ability of Colectiva Polimorfias to maintain the support group in-person. As a result, the group shifted to virtual meetings. But most women and girls with functional diversity have no privacy at home. They usually share a computer with their whole family, and few have their own room. 'We had quite a few women who wanted to join in the online support group,' explains Bubulina. 'But when they did, their family members would listen to what they were saying or try to stop them from participating. It is difficult – maybe even impossible – for women [with disabilities] to find confidential, safe spaces virtually.'

## **The richness and diversity of our disabilities**

Colectiva Polimorfias also organises regular workshops to go into depth on important topics, such as sexual and reproductive health. ‘Women with disabilities really lack access to comprehensive education on sexuality and reproductive health. They are very much inhibited from enjoying and exercising their sexual rights,’ explains Bubulina. ‘So it is important that we have an open conversation about the topic. It is important that they can enjoy their sexuality in a safe manner.’ Another key problem is the lack of representation of women with disabilities in the political sphere. Through the workshops, Colectiva Polimorfias educates women and girls about their political rights with the aim of strengthening their political participation and leadership. The workshops are a space for enrichment and knowledge building, not only for participants, but also for volunteers who assist Colectiva Polimorfias staff in organising them. Since Colectiva Polimorfias was founded, upwards of 100 women have been involved in the group’s workshops.

Inclusivity and accessibility are paramount in all of Colectiva Polimorfias’ activities: the group provides sign language interpretation and ensures accessibility of infrastructure. ‘One of the great things about Colectiva Polimorfias is that we don’t focus on one type of disability,’ says Yoli. ‘In Colombia, disability rights activism is very much divided by the type of

disability. Each movement sticks to their own and focuses on their own issues. That’s very concerning to us, because when the rights movement is divided, we end up fighting amongst ourselves rather than focusing on what we should be focused on, which is fighting for all of us and fighting for our rights.’ The group sees the range of functional diversity within Colectiva Polimorfias as an asset. ‘It brings us closer together. We celebrate the richness and diversity of our disabilities. It is something that actually strengthens our organisation.’

## **Deciding for ourselves**

Last year, the group launched an initiative to educate family members of women and girls with disabilities – to increase their awareness of their daughters’, sisters’, and granddaughters’ abilities to make their own decisions, to work, to engage in intellectual pursuits. Often, family members won’t allow women and girls with functional diversity to make even the most basic decisions, such as choosing what clothes to wear. ‘In Colombia, women with disabilities are viewed as eternal children,’ explains Bubulina. ‘Sadly, it is often families that most limit the lives of women and girls with disabilities.’ The workshop, which was very interactive, focused on the importance of being an ally and supporting women and girls in their journey to autonomy. ‘This is something the families are very reluctant to listen to or to recognise,’ says Bubulina. ‘It was not at all easy. But we keep trying.’

Autonomy also drives Colectiva Polimorfias’s political advocacy.

The group has helped organise a new network of disability rights organisations, called Red en Comunidad (Network in Community) that has come together to oppose two legislative proposals that are now in Colombia's Congress. The focus of the proposals is financial support – a minimal subsidy and paid work opportunities – for full-time caretakers of people with disabilities, who are usually family members. Proposals were drafted without the input and participation of people with disabilities. 'Neither bill recognises the autonomy of people with disabilities,' explains Bubulina. 'They take away our ability to decide who we want to assist us. And it makes no sense to give additional paid work to caretakers who are already working full-time. In addition to overloading caretakers with work, the proposal would eliminate the possibility of families to adapt to their own situation as they see fit.' Red en Comunidad is working with Senator Victoria Sandino on an alternative proposal, which will soon be introduced in Congress. The bill addresses the need for professional support and social protection, and includes both a personal stipend that people with disabilities would receive directly as well as support for full-time family caretakers who, because of their care-giving work, are unable to access paid employment and are therefore ineligible for an old age pension.

### **An invitation to listen**

When asked to reflect on what they are most proud of in the short history

of Colectiva Polimorfias, Bubulina and Yoli speak of the difficulty, as well as gratification, of working with and for women with disabilities. Bubulina emphasises that it's not easy for women with disabilities to come together and organise. Given the lack of accessible spaces and transportation in Bogota, even the effort to find a physical space for meeting was a struggle.

Of course, the challenges are not just physical: 'The society we live in is so exclusionary, and women with disabilities are constantly infantilised. It's as if we don't have voices, as if we can't speak for ourselves, or share our opinions,' Bubulina adds. Given this context, the ability of Colectiva Polimorfias to empower women with disabilities to speak up and have their voices be heard is a great achievement. 'The fact that Colectiva Polimorfias even exists is honestly an achievement, let alone that we have been able to reach so many women and they are exercising their autonomy.' Yoli echoes the sentiment: 'What stands out for me is the autonomy that some of these women have achieved – that they know their rights and are able to speak up when they are being harassed or are in an abusive situation. That they don't have to fight as hard to make their voices heard.'

To ensure that feminist disability rights activism is strengthened, Colectiva Polimorfias invites funders to listen to these voices and learn from them. 'I don't believe in the adage that you can walk in someone else's shoes,' says

Bubulina. 'But I do think we can work to cultivate empathy.' Donors can ask themselves questions about ableism within their organisations and work to change this. They can adopt policies to guarantee that their activities and spaces are accessible, so people with disabilities can participate. They can also change the language they use to talk about people with disabilities. Colectiva Polimorfás believes that these

measures are key for changing the image and narrative around people with disabilities. 'Donors should listen. That's the number one thing,' says Yoli. 'That's what we do ourselves – we listen to the voices of people with disabilities that may be different from ours. By listening to each other and understanding the opinions and lived experiences of others, we can really improve the lines of communication.'



Members of Colectiva Polimorfás. Photo: Ivan Castaneira.



## 02 'Sisters'

location

confidential

Sisters (For safety reasons, the names of the group and the activist in this article are not real, and the country where the organisation is located is not named.)

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**Given the current context in the country where they work, the fact that Sisters recently became a legally registered organisation is in and of itself a truly remarkable achievement. ‘It is the thing we are most proud of,’ says Ana, the organisation’s Development and Project Manager and one of its five founders.**

In recent years, feminist movements have faced significant political repression. Feminist activists, especially young feminists, run the risk of being detained or arrested. Despite this challenging situation, the young women behind Sisters – four of whom have a disability and several of whom are lesbian – forged ahead to realise their shared vision of building a diverse feminist movement. A few years ago, in their spare time and with their own money, they began their work. ‘When we set up the group, the first goal was gender education, because we are feminists,’ explains Ana. ‘A second goal was diversity education, because some of us are LGBT. And another goal was to support women and girls with disabilities.’

## **Diverse identities**

At the time, Ana worked for an organisation focused on the UN Convention on the Rights of Persons

with Disabilities (CRPD). ‘The organisation and the government were doing a lot for disability rights,’ Ana explains. ‘But we found that when it came to women’s rights, or LGBT rights, or the rights of women with disabilities, there was a gap. We realised that by drawing on our diverse identities – as feminists, as lesbians, as women with disabilities – we could bridge the gap between gender and disability issues.’

After a couple of years, Ana and other members of the group began fundraising so they could work for the organisation full-time. They were successful in securing grants from Mama Cash and several other donors. But the more critical and difficult step was registration, which was important for receiving foreign funding. The country had enacted a law that increased scrutiny of civil society organisations and funding from foreign sources.

‘We had a lot of difficulties,’ Ana says. To apply for registration, the group had to present themselves as a social work organisation. They needed to secure a minimum amount of funding and pay a registration fee, a sum equivalent to about 10,000 EUR. They needed to find politically acceptable individuals to join the group’s governing committee and an officer in the government who would serve as a ‘management partner’. Sisters managed to overcome all of these barriers, in addition to the general barrier of repression of feminist activism. ‘We were very lucky,’ explains Ana, with great satisfaction. ‘A couple of years ago, we were the only civil society organisation to be registered. And no

organisation has been registered since.’ Ironically, Ana thinks that the inability of society in her country to see women with disabilities as women may have been a factor in the group’s success. If so, it’s a prejudice that has worked to their advantage: ‘We are feminists. But maybe we are not seen as female,’ she says with a laugh. ‘They hate feminists, but they do not hate us,’ she adds.

According to Ana, there are some exemplary efforts by the government, especially at the local level in some cities, to address issues facing women with disabilities. But because the issues they face are very complicated, there is an important role for civil society to fill in gaps. ‘For example, problems around domestic violence are amplified for women with disabilities,’ she explains. ‘They may not have the courage to file for divorce, because they don’t have a job and are dependent on their spouse. The government is doing a good job in some places, but there is still a gap. Women’s issues need more care and attention.’

As a registered organisation working on disability rights, Sisters is a member of a national disability rights federation. The group is pleased to have recently been invited to participate in a prominent committee of the federation, where they hope to influence its policies. They will urge the federation to set up a Women with Disabilities group, which has the potential to have a huge impact. ‘We are very small,’ says Ana. ‘But the federation can reach millions of people with disabilities.’

## Accessible life

The formal mission of Sisters is to support women with disabilities to live independently. Education, including public awareness raising, is their key strategy. For example, the group has organised two public exhibitions featuring portraits – photos along with interviews – of women and girls with disabilities. (The first exhibition helped bring the group favourable attention from the government during the registration process.) The exhibitions both focused on women and girls in the context of their work. Next year, the group is planning to focus on women with disabilities as mothers.

Art and creativity figure prominently in Sisters’ activities. The group has an art therapy project that supports women and girls with disabilities (as well those without disabilities) to deal with trauma and violence – a seemingly uncontroversial objective in an otherwise difficult political context. ‘It sounds very gentle and beautiful,’ Ana says of the project. ‘But through the art therapy we raise awareness about gender equality and feminism.’ The women and girls take part in a series of workshops that follow a well-considered logic. The series begins with themes like going out in the world, having ‘a sunny life’, and employment. It then moves on to friends, intimate relationships, body, and gender. The next workshop, on ‘accessible life’, goes beyond the topic of accessibility of physical spaces, which has improved significantly in the last decade, to a discussion of what the group calls ‘soft accessibility’ – the

accessibility of community and social connection for girls and women with disabilities. It is a topic of particular relevance for the growing population of elderly women in the country, many of whom have a disability and live alone. In the final thematic workshop, participants discuss and apply their artistic skills to the question of 'How to be a feminist woman with a disability'. Ana describes the powerful effect of the art therapy programme: 'The art they make in the workshops allows women to show their anger, to express their emotions, to heal. We talk about bodies. We talk about vaginas. We talk about the idea that we're supposed to be virgins.' The group is thrilled to have recently received funding to move the programme from their tiny office to a large space of 100m<sup>2</sup>.

### **Activist influencers**

Another project focuses on building the presence of women and girls with disabilities in a digital art space, namely the social media app TikTok. In an online training, women and girls who live in the provinces learn about disability rights issues, as well as strategies for telling a good story on TikTok and attracting followers. Participants are eligible to receive small grants, up to about €500, which they can use for online income-generating activities, such as the sale of handicrafts or make-up. Sisters boasts ten young women who have become well-known TikTok influencers, one with upwards of 20,000 followers.

Since its founding, Sisters has also involved about 100 women and girls

with disabilities from across the country in a multi-day leadership training, which covers disability and gender issues, as well as organising and project management skills. Graduates of the training have gone on to form activist groups in their own cities. Sisters now supports ten of these groups, including by providing small grants for local activities, and organising regular meetings to connect and share.

### **Find a way**

Are there lessons to be learned from Sisters' success as a relatively young organisation? Ana's English skills, and the assistance of a native English speaker, were critical for the organisation's early fundraising success. Other feminist disability rights organisations may be at a disadvantage in this regard: 'This is a big problem for the movements in Asia and Africa. Because they don't have strong English skills, they have no chance to access the global funds.' Funders could diminish this barrier by providing information in more languages.

Ana also thinks that organisations and funders alike need to learn to be flexible and problem solve when faced with a challenging political environment. The key is to be creative while staying true to your principles. 'If you face difficulties, it is important to stick to your beliefs and figure out how to solve problems,' she says. 'Insist on your beliefs and find a way. That's really important.'

# 03 'Into the light'

Association des Femmes

Handicapées

de Madagascar,

Madagascar



Members of AFHAM participate in a march at a national meeting of disabled women in Madagascar.  
Photo: Association des Femmes Handicapées de Madagascar.

**In Madagascar, women are expected to stay at home. They're not supposed to work. They are denied access to an inheritance. They are excluded from political life. Women with disabilities face all this and more. It's what Fela Razafinjato, Founder and President of the Association des Femmes Handicapées de Madagascar (Association of Disabled Women of Madagascar, AFHAM), calls 'double discrimination'. In addition to the discrimination they face as women, women with disabilities are denied the ability to develop their full capacities. Their specific needs – for accessing health care or employment, or to engage in political decision-making – are not taken into account.**

AFHAM was founded in 2011 to promote the rights of women with disabilities in the framework of the fight against poverty. The group believes in the principle of 'Nothing about us without us'. Women with disabilities are at once AFHAM's stakeholders and beneficiaries. They lead the Association and implement its actions. The Association has learned from experience that this strategy is the most effective for ensuring that the concerns of women with disabilities are heard and addressed. 'Women with disabilities stay in the shadows because of prejudice and discrimination. They are afraid to express themselves,' says Fela. 'The challenge is first to change the attitude that women with disabilities have about themselves, and second to change the attitudes of others. There is

a huge amount of awareness raising and advocacy to be done. The government has no plan to support women with disabilities.'

When AFHAM marked its tenth anniversary earlier this year, the group had much to celebrate. 'AFHAM has grown to 600 members. That's 600 women with disabilities who know their rights,' says Fela. 'Our members have reclaimed decision-making power over their bodies and their lives. One hundred members have gained financial autonomy and some are now actively participating in electoral processes. We have enabled many women with disabilities to come out of the shadows and into the light – to shed their invisibility.' The Association operates nationally and is active in 19 of Madagascar's 23 administrative regions.

## **Learning to welcome women with disabilities**

Advancing the sexual and reproductive health and rights of women with disabilities is one of AFHAM's priorities. The group is working to improve accessibility of Madagascar's health centres, which often lack measures such as ramps for women who use wheelchairs, or interpretation and translation for women with visual or auditory disabilities. 'The health centres are not closed to us,' explains Fela. 'But our specific needs are not taken into account.' AFHAM trains health care workers to welcome women with disabilities and to better understand their needs. The group advocates for

adjustments, such as providing services on the ground floor of buildings, to make sure women with disabilities can access care. As part of this work, AFHAM has collaborated with a group in Madagascar that specialises in family planning and sexual and reproductive health.

In Madagascar, most people believe that women with disabilities don't have skills or the ability to study or work. The majority of women with disabilities do not have the opportunity to go to school. AFHAM endeavours to create employment opportunities and improve the economic situation of women with disabilities. A solidarity fund supports income-generating activities of AFHAM members, such as sewing, cooking and handicrafts. The group also raises awareness and educates employers about the abilities and special needs of women with disabilities. The association has conducted surveys and research on the professional integration of women with disabilities. 'Some women with disabilities have skills to offer employers. They just need specific adaptations,' explains Fela. Through a partnership with the Women Entrepreneurs of Madagascar, a group of women leaders from 50 companies, AFHAM has helped find and negotiate employment for thirty of the Association's members. AFHAM also supports women with legal issues, like alimony claims and legal complaints in cases of violence. The group assists women in filing necessary papers and paying fees.

## Equality in rights and equity in access

The main message that AFHAM wants to drive home is this: the needs of women with disabilities must be taken into account – in public programmes, development initiatives, the design of buildings and spaces, employment, political processes. 'We need equality in rights and equity in access,' insists Fela. One without the other is not sufficient. 'We have the right to vote. But how are we supposed to participate in political processes if, for example, discussions are not translated into sign language for women with a hearing disability?'

AFHAM conducts research that feeds into its advocacy work: 'We need arguments, facts and numbers,' says Fela. In one study, AFHAM compared Madagascar's law on people with disabilities to the International Convention on the Rights of Persons with Disabilities and found, for example, that Madagascar's law on persons with disabilities lacked sufficient binding or enforcement provisions to ensure that disabled people could enjoy and exercise their rights. AFHAM is part of a national platform of disability rights organisations, where it plays a valued role as the only organisation representing women with disabilities.

Collaboration is fundamental to AFHAM's way of working. 'AFHAM does nothing by itself,' explains Fela, 'especially when it comes to monitoring legislation and advocating for the rights of people with disabilities. We

do everything through the platform.’ A highlight of the group’s advocacy work was pushing for ratification of the International Convention on the Rights of Persons with Disabilities. Madagascar signed the Convention in 2007, but had yet to ratify it, which required approval in the National Assembly and Senate. The platform pushed hard for ratification and finally succeeded in 2014.

Over the years AFHAM has learned that working with the media is hugely beneficial for raising awareness and having an impact. As Fela puts it: ‘If you stay quiet, you stay invisible.’ Organising press conferences and work with journalists has helped put AFHAM on the map. The group has been featured on television programmes and in news articles, which has helped to build support for the organisation.

## **Lack of visibility in feminist movements**

Through the national platform of disability rights organisations, AFHAM feels firmly embedded in Madagascar’s disability rights movement. Within the platform, AFHAM is recognised as the organisational voice of and for women with disabilities, a role that is advantageous, both for the group and its issues.

The situation with the feminist movement, however, is different. ‘Women with disabilities are not visible in the general feminist movement. That’s why we are really excited that Mama Cash is publishing this report,’

says Fela. ‘Every time I engage with the feminist movement, I preach for my own parish. It is really necessary to call people out about the situation of women with disabilities and to let people know that we are still left out of the feminist movement. Women with disabilities exist. We need to be respected, just like other groups within the feminist movement. We need to celebrate the diversity of humanity.’

A major concern is the lack of financial support and prioritisation of disability rights work among funders. Fela states it plainly: ‘We need money to realise this work. The challenges are huge and there is very little funding for the disability rights movement. Everything we do requires sustainable funding.’

# 04 The language to describe oneself

Iz Kruga Vojvodina,  
Serbia



Iz Kruga uses 'body language' to visualise that the body can be a site of protest. The translation of this text is: 'Tell me, you say you wish me well, but you don't see me hidden in a body with no speech.'  
Photo: Iz Kruga Vojvodina.

**As a child, Svjetlana Timotic did not want to think of herself as an ‘invalid’, the word she grew up hearing. ‘The hidden message behind the word invalid,’ she recalls, ‘was that I was not able to educate myself. I was not able to work. I was not able to do a lot of things that people without disabilities could do. I was not a complete person.’ Given this context, she didn’t want to acknowledge that she had a disability, let alone be an activist for disability rights.**

But that changed when she was in her late twenties, in the early 2000s. She became involved with a university group of people with disabilities, whose approach was radically new and different than what she was familiar with. Most disability rights organisations active at the time subscribed to the dominant biomedical model of disability, which treats disability in medical and physical terms. ‘The focus was on what a person cannot do and how to medically treat them,’ explains Svjetlana. In contrast, the university group advanced a social model of disability, where the focus lay on obstacles in society that make a person disabled. In the social model, disability is understood in terms of society’s failure to take people’s needs into account.

Svjetlana describes the profound and empowering change she underwent as she learned this new perspective. Through her work with the university group, and her subsequent work at another local disability rights organisation, she learned the language to describe herself. She learned to

accept herself and her disability as an essential, and positive, part of her identity. ‘What’s important about the term “person with disability” is that it gives you the right to think about yourself as a person – a person with a disability, and with a lot of other traits,’ she says.

All the knowledge and skills she learned from these two organisations helped Svjetlana fight her internalised shame and prejudice against being active in the disability rights movement. She went on to co-found Iz Kruga Vojvodina, which focuses on women with disabilities. The organisation is based in the Serbian region of Vojvodina. Svjetlana now serves as its Executive Director.

### **Out of the circle, out of the red zone**

Svjetlana’s early experiences with the disability rights movement helped her see herself not just as a person with disabilities, but as a woman with disabilities. That awareness coincided with her growing interest in women’s rights issues, including violence against women, sexuality, and sexual and reproductive health and rights. When she looked for research and analysis in Serbian on these issues as they pertained to women with disabilities, she was dismayed to find that none existed. Around the same time, she got to know the pioneering feminist disability rights activist, Lepojka Čarević Mitanovski, from Belgrade, who inspired and encouraged Svjetlana to start an activist group in Vojvodina.

Since its founding in 2007, Iz Kruga Vojvodina has campaigned for increased recognition of the problem of violence against women with disabilities. Iz Kruga means 'out of circle', a reference to getting out of the circle of violence. Iz Kruga Vojvodina maintains a helpline that is designed to ensure that women with different types of disabilities, including those with a hearing disability, can access a wide-range of support and information. Users can reach the helpline via a variety of channels, including phone, text, Facebook, or email. In addition, the organisation offers legal counselling and psychological support for individuals and groups, both in person and online.

Iz Kruga Vojvodina also works to improve access to gynaecological health care for women with disabilities. In cooperation with health institutions, the group organises gynaecological check-ups and provides assistance for women with disabilities. One of Iz Kruga Vojvodina's earliest successes was to get Vojvodina's main medical centre to purchase a hydraulic chair, thus removing a major barrier to gynaecological exams.

A key goal of Iz Kruga Vojvodina's work is to build the skills of women with disabilities to advocate for their sexual and reproductive health and rights. Graduates of the group's training programme are replicating Iz Kruga Vojvodina's activist work in their own municipalities, including by advocating for hydraulic chairs in their own municipal medical centres. Iz Kruga Vojvodina has developed an informal network of 29 women with disabilities

in 11 different municipalities in Serbia who are active in their communities. At the height of the COVID-19 crisis in 2020, a group of Iz Kruga-trained activists sprang into action when their local medical centre's hydraulic chair fell within the centre's 'red zone', designated for COVID-19 patients only. The group succeeded in having the chair moved to the 'green zone', where it would remain accessible. Another activist recently succeeded in raising 1.3 million dinars – about €11,000 – in a crowdfunding campaign for the purchase of a hydraulic chair for the medical centre in her small municipality. Iz Kruga Vojvodina encourages and mentors the local women activists as they develop and carry out their own activities. The organisation recently supplied the activists with smart phones so they can stay connected to each other, as well as easily access online information.

## **Protagonists and creators**

When asked to reflect on what has changed since the founding of Iz Kruga Vojvodina, Svjetlana conjures the image of stepping stones, the slow path toward change. 'When you are young, you believe you can change the world,' she states. 'But the most important change has actually been our growth – the fact that we as women with disabilities have developed our resources and our capacities. We started the organisation working out of a private apartment. Now we have a fully accessible office which serves as a safe place for women with disabilities, where they can access different resources – educational programmes, books, the

Internet – both for themselves and for implementing programmes and providing services for other women with disabilities.’ Iz Kruga has nine full-time staff members and engages as many as 100 women each year to carry out specific activities. The group’s informational materials and booklets are available in Braille, audio and easy reading format.

Iz Kruga Vojvodina has charted new territory in Serbia in its efforts to ensure that intersecting topics of disability, gender, sexuality, bodies and violence are visible and reflected in various media, from research to writing to art. Among other things, the group has advocated for more academic attention to issues relevant for women with disabilities and has conducted its own research on women with disabilities and sexuality. Thanks to these efforts, the Centre for Gender Studies at the University of Novi Sad now includes a module ‘Sexuality of Women with Disabilities’, based on Iz Kruga Vojvodina’s work, in its Women and Health course.

Iz Kruga Vojvodina also runs a registered media outlet known as ‘Disability Portal’, which promotes the visibility of women with disabilities and features coverage of issues that affect them. It is one of the only places where the voices of women with disabilities can be heard. In 2021, on International Day of the Girl (11 October) the portal featured ‘letters’ written by six women with disabilities to their younger selves in which they shared some insights they now have as adults.

Through a workshop series, ‘Empowering through Art’, Iz Kruga Vojvodina positions women with disabilities as protagonists and creators. Over the years, the workshop has covered diverse topics and used a wide range of artistic mediums, including photos, video, and performance. At the end of each workshop, participants collectively create a piece of art. ‘I call myself unspoken’, the title of one particularly memorable performance, emphasised how women’s sexuality and bodies – vaginas, breasts, menstruation – are often not spoken about.

### **Disability is a political issue**

Working at the intersection of disability rights and violence against women is and remains challenging. It took time and perseverance for Iz Kruga Vojvodina to gain recognition from institutional actors as an expert on violence against women. But that has changed significantly. Now, the group receives so many requests to participate in meetings and activities that they don’t have the capacity to respond. Yet Iz Kruga Vojvodina still encounters problems and barriers. ‘The women’s movement still sees disability as an *individual* issue,’ explains Svjetlana. ‘They don’t understand that the issue of disability is political, that it is something to be solved by *society*.’

### **Support for continuity**

Svjetlana describes some of the challenges in fundraising for Iz Kruga Vojvodina’s work, including funders who try to shift the group’s agenda: ‘A lot of

funding is for projects. Funders expect us to address other problems or change our course. It makes our work more difficult,' she says. The organisation has found some donor reporting requirements so burdensome, especially in relation to the small amount of funding provided, that it will no longer apply.

At the same time, the group really appreciates when donors ask good questions that give them the opportunity to really reflect on their work and the organisation. Sijetlana mentions Mama Cash's structural assessment tool as a

great example: 'It asks us questions about our mission, our structure, where we are and where we want to go. When we filled it out, it helped us see all the conferences we've participated in, all the services we've provided, all the actions we've done. It made us really proud. It also gave us insight into the strengths and weaknesses of our organisation and prompted us to think about how to improve our governance and operations.' What kind of support does Iz Kruga Vojvodina need to sustain its activism? The answer is categorical: long-term, core support. 'We need support that enables continuity. We have issues we want to solve.'



*Iz Kruga's Director, Sijetlana Timotic, speaks about the challenges faced in the field of securing women's human rights on 6 March 2020 at the National Library of Serbia in Belgrade, as part of an event to launch UN Women's Generation Equality campaign. Photo: Marija Piroski.*

05

# Supporting women with disabilities to achieve their life goals

Nazyk Kyz, Kyrgyzstan



Participants in Nazyk Kyz's 2021 Leadership School training in Bishkek.  
Photo: Alexey Skachkov.

**When Ukei Muratalieva was in her early twenties, she had no place to go for the information she needed as a woman with a disability. She was connected to a disability rights organisation, the Association of Parents of Children with Disabilities. But as the name suggests, the focus of the organisation was on the rights of parents with children with disabilities. The issues and challenges that she and her age group were facing were not addressed.**

‘We were entering adult life,’ Ukei recalls. ‘And we encountered many challenges and problems – access to education and work, health issues, issues around sexual and reproductive health and rights. No one could answer our questions. There was no organisation to protect our rights.’ In 2008 Ukei teamed up with others she knew from the Association of Parents of Children with Disabilities to found Nazyk Kyz. Nazyk Kyz is dedicated to supporting and advocating for the rights of women and girls with disabilities, whose needs and concerns often go unaddressed. ‘Programmes on gender don’t take into account people with disabilities and programmes on disability don’t take into account gender,’ continues Ukei. The group is part of and works closely with the Central Asian Network of Women with Disabilities.

One of the key issues that Nazyk Kyz works to address is violence against women with disabilities, which is common in Kyrgyzstan. ‘Women with disabilities are highly exploited by their

families,’ Ukei explains. ‘They are forced to be servants, to do all the housework. They are denied an education. All their life they are servants to their family.’ According to Ukei, in Kyrgyzstan’s Muslim society, it is believed that God will forgive a man his sins if he marries a girl or woman with a disability. In such cases, she is often a second wife and the marriage is religious in nature, meaning the marriage is not officially recognised by law, so the girl or woman has no legal protections. Last year, due to the financial impact of the COVID-19 pandemic, Nazyk Kyz provided support to many girls and women with disabilities whose husbands had decided to divorce them. Since the beginning of the pandemic, Nazyk Kyz, together with the Central Asian Network of Women with Disabilities, has provided food aid, hygiene products, and other assistance to more than 400 people in need.

## Evacuation to a safe shelter

Over the years, Nazyk Kyz has supported many girls and women who have been abused by their family members. Nazyk Kyz operates the country’s only hotline and shelter for women with disabilities. Women with disabilities run both the hotline and shelter, applying their own life experience in their efforts to support others. The women receive special training to help prepare them for this work. Many women and girls with disabilities turn to the hotline with questions and problems related to sexual and reproductive health and rights. Their cases often revolve

around families trying to control their reproductive decisions, usually by pressuring them to have an abortion if they become pregnant. Nazyk Kyz is proud to have supported four women with disabilities in their journey from pregnancy to childbirth. Just recently, a baby girl was born to a woman who had originally been refused pregnancy care, because of her disability. Through its relationship with the national gynaecological association, Nazyk Kyz was able to find her a doctor who would provide her care and supported the woman throughout her pregnancy. 'I feel like I gave birth!' laughs Ukei.

If the situation calls for it, Nazyk Kyz will decide to evacuate a woman who is in danger and bring her to its shelter, in Bishkek, the nation's capital, where the group is based. While there are other shelters in the rural regions outside of Bishkek, none are accessible to women and girls with disabilities. In the future, the group aims to open more shelters in the regions, where most women and girls with disabilities live.

Increasingly, Nazyk Kyz is providing legal support to women and girls with disabilities who are challenging violence and other rights violations in court. The group is currently supporting a girl who was repeatedly raped by her grandfather and uncle. The girl's family is falsely claiming that the girl has a mental disability so the court will dismiss her allegations as untrue. Nazyk Kyz is disputing a diagnosis given to the girl that was based on an examination that was not properly conducted. 'This is just one of many examples of relatives, parents, and grandparents using and

abusing disabled women and girls,' says Ukei.

## **Bringing life plans to fruition**

Alongside of direct support and legal services, Nazyk Kyz is strengthening leadership of women and girls with disabilities. In cooperation with the Central Asian Network of Women with Disabilities, Nazyk Kyz organises summer camps for girls, as well as a programme called the School of Independent Life for Women with Disabilities. For several days some thirty women and girls gather to discuss matters that concern them, their challenges and goals. Participants in the School develop a life plan, which Nazyk Kyz then supports them in bringing to fruition. The group supports women and girls in breaking down specific barriers – be it discrimination or abuse or violence – that stand in the way of achieving their life plans.

Nazyk Kyz has developed strong, lasting relationships with many of the School's participants. Four graduates of the programme are running for Parliament in the upcoming election. 'It's the first time that people will be voting for a specific candidate rather than a party. So we think there's a big chance that the voice of women with disabilities will finally be heard,' says Ukei with excitement. Another talented girl first attended Nazyk Kyz's summer camp when she was 17. She began working for Nazyk Kyz and later attended the Leadership School. One of her main goals in life was to attend university, but she did not have the required documents for admittance. Nazyk Kyz helped her in

obtaining the documents, and the girl went on to graduate with the highest marks. At 26, she now heads Nazyk Kyz's evacuation programme.

## **Holding authorities to account**

Barriers to education are all too common for girls and women with disabilities in Kyrgyzstan. Ukei describes her own struggle to attend university, just over a decade ago, as a 'war'. She explains the situation, which includes structural barriers: 'Every child with a disability is assessed by a special medical commission that determines whether the child will attend a regular school, which does not offer accommodations for people with disabilities, or a special school that does. The problem is that the special schools do not provide the same curriculum as the regular schools, nor the necessary papers needed for college or university admission. Universities require applicants to pass a national test, which is contrary to the law and discriminatory. Persons with disabilities are doomed to fail.'

In an effort to enhance inclusive education, some universities and colleges provide government-subsidised spots for students with disabilities. But only persons who desperately demand their rights manage to get these spots. Nazyk Kyz recently discovered that one university had given away their subsidised spots to students who did not have a disability. The group challenged the university's actions and ultimately supported five girls with

disabilities to lay claim to these spots and enrol.

In addition to assisting girls and women with disabilities to get the education they want, Nazyk Kyz is putting pressure on the government. In 2019 Kyrgyzstan ratified the Convention on the Rights of Persons with Disabilities. Together with the Central Asian Network of Women with Disabilities, Nazyk Kyz is closely monitoring the government's efforts to implement the Convention. The group works closely with the country's Office of the Human Rights Ombudsman, which now includes a Councillor of People with Disabilities, thanks to the efforts of disability rights activists. The Councillor acts as an independent advocate for the human rights of people with disabilities. Nazyk Kyz aims to see the government put such a Councillor in every ministry of the government.

## **Pressing for action**

In 2020 Nazyk Kyz joined 15 disability rights organisations in presenting a baseline report on the situation for people with disabilities to the President. In response to the report, the government-led Council on People with Disabilities, on which Nazyk Kyz sits, issued an order to all Ministries to make necessary changes to laws to comply with the Convention on the Rights of Persons with Disabilities. In addition, the government adopted an 'accessible country programme', which identifies priority measures for improving social protection and services for people with disabilities.

But none of these commitments have actually translated into action by the government. ‘They didn’t do anything!’ Ukei explains. ‘The government has not signed the document with actual measures for implementation of the Convention. So this accessible country programme so far is just a recommendation.’ Nazyk Kyz is putting pressure on the government to match its words with deeds, and the government will soon issue a report on the measures it has taken since adopting the Convention. Anticipating that the government’s report may be quite positive about the steps that it has taken, Nazyk Kyz has teamed up with

other disability rights organisations to prepare a shadow report in response.

Nazyk Kyz has come a long way since its founding just over a decade ago. The group values funders that have been consistent and comprehensive in their support of disability rights activism, funding all aspects of disability rights, from employment to culture to education. Flexible, long-term funding has given Nazyk Kyz a chance to develop as an organisation. Despite the enormous work that lies ahead, Ukei is very optimistic about the future. ‘We’re very powerful now,’ Ukei says. ‘Now is the time we can really make a change.’



Participants in Nazyk Kyz's 2021 Leadership School training in Bishkek.  
Photo: Alexey Skachkov.

06

# ‘You have to ensure our rights’

Women with Disabilities

Development Foundation,

Bangladesh



WDDF participates in a conversation to raise awareness about violence against disabled girls; in this village, WDDF is providing legal support to a girl with an intellectual disability who was raped. Photo: Women with Disabilities Development Foundation.

**In the early years of the Women with Disabilities Development Foundation (WDDF), it was extremely difficult for the organisation to be recognised as a legitimate voice on the rights of women with disabilities. There was a lack of understanding and attention to both the diversity of disabilities, as well as the diversity of women's experiences. Ashrafun Nahar ('Misti'), the organisation's Executive Director and one of its founding members, remembers a meeting in 2009 of a platform focused on monitoring implementation of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) in Bangladesh. Misti recalls: 'On the first day, a feminist leader from the platform came up and asked me: What is your name? Why did you come here? You can just send us a short note about what you want to do.' Misti politely told the woman that her meaningful participation in the meetings was very important. It was the only way the platform would understand what is needed to eliminate discrimination against women and girls with a diversity of disabilities.**

Misti continued to engage in the platform, reviewing documents, attending meetings, and regularly speaking up to give WDDF's input into the platform's forthcoming shadow report on the status of CEDAW implementation. When the report came out, none of WDDF's input had been included. Misti recalls confronting the authors: 'You forgot me! All year long, I have been coming to these meetings and giving my input, but still you forgot

me. You forgot disability issues, because you cannot recognise that there are women and girls in our society who are living with disabilities and who are being discriminated against.'

It was a pivotal moment for the CEDAW platform and for WDDF. 'After that,' Misti laughs, 'they never again forgot about women and girls with disabilities.' Women and girls with disabilities are now a standard subject in the shadow report, and WDDF is recognised by the platform as an important source of information and analysis about needs and gaps relating to women and girls with disabilities.

Misti is one of a group of seven women with disabilities who co-founded WDDF in 2007. Despite significant barriers to education, all seven have earned a Master's degree. Misti's own experience is telling. Her disability stems from a spinal cord injury that occurred when she was 14. Following the accident, her father rebuilt the house to accommodate her wheelchair. Her family was extremely supportive and sensitive to her needs. But Misti soon saw how exceptional her own family was. When she applied to a university, she was rejected solely because the university would not accommodate 'a girl with a wheelchair'. She went to a college instead and eventually received her Master's, but regularly faced bullying and discrimination. She even encountered discrimination when she applied for a job with an organisation that worked on disability issues, which told her they would not accommodate her particular needs. (Fortunately, another disability rights organisation hired her.)

## **Access to justice**

At the time, there was no organisation in Bangladesh advocating for the human rights of women and girls with disabilities. WDDF's co-founders set out to fill the gap. 'We saw that we needed a platform to raise our voices and influence laws and policies,' says Misti. 'We understood that women and girls with disabilities faced different kinds of human right violations – from their families, from society, from institutions. But these were not on the agenda of human rights organisations.'

Since the beginning, advocacy for improved laws and policies has been a top priority for WDDF. In 2007, Bangladesh was in the process of reviewing and revising its Women and Children Repression Prevention Act 2000. WDDF called on the law commission, which was responsible for reviewing the act before it went to parliament, to address issues facing women and girls with disabilities. WDDF highlighted the barriers faced by women with visual, speech, and hearing disabilities, whose needs are not accommodated by the police or the judicial system. Misti explains: 'If a girl with a hearing disability is raped, she can't file a report in the police station because the police say they can't understand her. The police deny her the right to file. It is an exercise of power over the victim. The same is true in the courts. Lawyers and judges don't understand sign language and there is no interpretation provided.' WDDF raised the issue with the commission and insisted that a chapter be added

that explicitly required access to justice for women and girls with disabilities. The commission ignored WDDF's recommendation, but the group gained valuable experience in the process.

## **A formidable voice**

A few years later, when the law commission began work on a Domestic Violence Prevention and Protection Act, WDDF was ready with facts and figures about the incidence of domestic violence against women and girls with disabilities. Again, the group urged the commission to explicitly address the needs of women and girls with disabilities. Again, the commission failed to act. But this time, WDDF pursued their struggle to the next stage. Misti explains: 'When the government was in the process of creating the rules for the act, in 2010, we said: If you ignore us, then you cannot claim that the act works successfully. You cannot claim that women get remedy. Because women with disabilities are also women. Girls with disabilities are also girls.' This time, WDDF's message was heard. For the first time ever, the government explicitly included rules about accommodating the needs of women and girls with disabilities.

WDDF eventually developed a good relationship with the Ministry of Women and Children Affairs. By the time the government began preparing a new 'National Policy Related to Women's Advancement', WDDF's recommendations were taken seriously. Five chapters of the new policy specifically addressed issues of women

and girls with disabilities. It included training for court practitioners, police officers, and staff of victim support centres on the needs of women and girls with disabilities, and improvements to police stations to make them ‘disability friendly’. It featured measures to enhance women with disabilities’ engagement in political processes, including by improving accessibility of polling places and reserving two seats in the national parliament specifically for women with disabilities.

### **‘You have to ensure our rights’**

Among other things, WDDF advocates for policies to promote employment for women and girls with disabilities. As part of the 2013 Persons with Disabilities Rights Act, which WDDF helped influence, a certain number of government jobs are reserved for persons with disabilities. Since then, WDDF has urged the government to improve implementation of the law by more actively recruiting persons with disabilities. When the government recently made a move to scrap the quota, WDDF successfully mobilised to ensure that it was kept in place.

Improving accessibility of public buildings and public transportation is another important goal. WDDF recently published a report and guidelines on accessibility of buildings, and successfully lobbied the government to ensure attention to the issue in the new National Building Act 2020. The group has met with government officials to discuss making transportation inclusive, including in its plans for a new metro rail

system. Misti recalls a conversation with the Ministry of Transportation: ‘We told them that there are public buses, foot paths, bridges, underpasses, etc. that are not accessible to women and girls with disabilities. But if you recognise that we are citizens of Bangladesh, then you have to ensure our rights. You have to make transportation accessible.’

One of the challenges WDDF faces is convincing the government that disability issues (and the budget to address them) are relevant to all Ministries. ‘In the national budget, money for disability issues is exclusively in the social safety net budget line of the Ministry of Social Welfare,’ explains Misti. ‘That means there is no budget to cover disability issues in other Ministries, like employment, transportation, health, education, communication. Disability issues are ignored by the other Ministries, because they don’t receive the budget for it.’

### **The next generation of leaders**

Alongside of advocacy, WDDF works to build leadership and expand opportunities for women and girls with disabilities. In seven sub-districts in Bangladesh, the group has organised ‘grassroots committees’ of women and girls with disabilities. It supports the members to develop income-generating activities, access education, and engage in political processes. Some of these women and girls have taken part in WDDF’s intensive training programme, where they have learned about gender, violence against women, sexual and

reproductive health and rights, and other issues at the intersection of feminism and disability rights. (The training is also open to staff of other disability rights organisations.) Graduates of the training programme are playing an important leadership role in their communities, where they bring issues to the attention of decision-makers. Some now serve in Bangladesh's sub-district (upazila) and 'union' (a collection of villages) levels of government.

WDDF is also investing in building 'second-line leadership' within the organisation, helping ensure they have the skills to some day run the organisation. Misti believes that new leaders can benefit from the same opportunities that she had – to travel and participate in international meetings, develop new insights and connections, and see how accessible other countries are.

## **The challenge of funders' restrictions**

The need to invest in leadership and organisational development is a topic of relevance for funders. Conditions of funding, such as limits on or the exclusion of administrative and management salaries, or for infrastructure, can make organisational development difficult. Misti explains:

'One donor would not give us funding for laptops. So we asked: How will we work? How will we write a proposal? How will we write a report?'

There are also limited funding opportunities for small grassroots organisations working with women and girls with disabilities. Most funding goes to large, well-known national and international NGOs. Other donors restrict the types of activities they will support. For example, some focus on advocacy and leadership building, but will not fund direct support to women and girls, such as the provision of assistive devices, like wheelchairs. Misti describes the absurdity of the situation: 'Donors say they want to fund activities for women and girls with disabilities. But if a woman or girl with a disability needs a device and does not have it, how can she come to our activities? This is one of our big challenges.' Moreover, such donor policies conflict with the government's requirement that at least 15% of funding be used as direct support for the organisation's 'target groups' (i.e., women and girls with disabilities). WDDF is raising this issue with donors and the government. But in the meantime, when necessary, the organisation looks to the generosity of friends and family (and sometimes its own staff) to provide assistive devices to the women and girls who may one day lead the organisation.

# 07 The healing power of solidarity

Anjali, India



Anjali builds evidence for advocacy by using activities like crafts sessions to support women in mental hospitals to tell their stories. Photo: Anjali.

**In 1999, Ratnaboli Ray received a fellowship from Ashoka Innovators for the Public to support her pioneering work with women patients of a public mental hospital in Kolkata. At the hospital, Ratnaboli, a trained psychologist, was given a veranda where she would sit with the women, or do yoga or crafts with them. 'The activities were all vehicles to build trust and relationships, and to exchange stories – stories from home, stories from living in the institution, stories of violations, stories of violence,' she explains. 'I just listened and built my bank of insights.' After just one year, 26 women were able to leave the hospital and return home.**

The government soon took notice of Ratnaboli's success and began supporting her programme. In 2001, she founded Anjali, named in honour of the first woman from the programme to return home. Anjali means 'offering' in Sanskrit, which also signifies the mutual offering between the organisation and the women involved in its programmes. 'I was very clear about what needed to change,' recalls Ratnaboli. 'It is the way mental health institutions look and feel. And I was very clear that I wanted to work with women.'

## **Dehumanising women patients**

At the time, there was a stark difference in how men and women patients were treated inside the hospital. The male ward was more open and spacious, with more greenery. The women's ward

was more constricted, with locks and grills on the doors and windows. Men received more food and better clothing. 'It pained me to see what the women were given to wear, just a nightie. It was so dehumanising and desexualising,' recalls Ratnaboli. 'They were not even given underpants or bras.'

The difference in treatment was also reflected in diagnoses. Some women had been given the diagnosis of insanity simply because their husbands wanted to be rid of them: 'At the time, insanity certificates could be bought for 5,000 rupees – about \$50 (US dollars). Women would be incarcerated for life,' explains Ratnaboli. 'Every fragility shown by the women patients would be given a psychiatric label. If a woman cried a lot because she wanted to go home, she was labelled as schizoaffective or severely depressed. Women were treated like they couldn't do anything, they didn't know anything, they couldn't have an opinion.'

## **Stories as evidence**

Anjali, which now has a staff of 42 that includes women who have or have had psychiatric or mental health diagnoses, has worked for twenty years to improve the situation for women living in public mental hospitals by building women's agency and supporting them in driving institutional reform. One key element of the group's decision-making model is regular consultations with women in public mental hospitals to ensure that the constituency is involved in shaping Anjali's activities and also in identifying key issues for advocacy and action

within the hospitals. Anjali's Voices programme, which grew out of the original story-telling group work in the first hospital, has expanded beyond Kolkata and reaches all mental health hospitals across the state of Bengal. 'Our most important achievement is that many women are now themselves mental health champions,' Ratnaboli says. 'Women themselves are championing de-institutionalisation and an end to forced incarceration. They are calling for affordable care and treatment within their community. They are demanding an end to discrimination, child marriage, and domestic violence. They are demanding warm, nutritious food, clean water, recreational activities, and livelihood opportunities within the institutions.'

Listening to and telling women's stories remains a cornerstone of the programme. Using women's stories as evidence to engage in persuasive dialogue with hospitals is one of Anjali's key strategies. In so doing, Anjali is challenging the notion that evidence must be empirical or quantitative or produced by professional experts. 'We are used to looking at evidence in one particular way,' explains Ratnaboli. 'But my feminist training enriched me and taught me the importance of looking at women as persons and capturing their stories. That is very important. Their stories are critical, powerful evidence.' Alongside of dialogue with hospitals, Anjali partners with media and journalists to bring public attention to women's stories. Although this

comes at the risk of antagonising the hospitals with which Anjali partners, the strategy has proved successful. In one case, media coverage helped expose and change the policy of two hospitals where women patients were kept naked.

Anjali works to create housing and livelihood opportunities for recovered patients, both women and men. When recovered women and men have nowhere else to live, the mental hospital serves as temporary housing. For years, Anjali has lobbied and advocated for an assisted living space to accommodate recovered patients as they transition to independent living. In just a few months, the government will open the first such space. Recovered patients will live in the assisted living space and travel independently to their jobs and to the hospital, for out-patient visits. 'This has been one of our major achievements,' says Ratnaboli. 'We were consulted at every stage and the infrastructure of the new living space is beautiful and thoughtful.'

Anjali has also helped develop livelihood initiatives for recovered patients, including a bakery, a tea shop, and a commercial laundry unit. The work enables women to gain a measure of economic autonomy: they receive a bank account, earn a fair wage, and can make their own purchases, mostly food. ('The food in the hospitals is appalling!' says Ratnaboli. 'Having the same food day in and day out is nauseating. This money gives them the freedom to buy their own food.')

## Reframing mental health: from illness to wellness

Anjali also works at the community level, in partnership with municipal governments, to make mental health services more available and accessible. One of the intentions behind this programme, which is called *Janamanas* or 'the mind of the collective', is to shift the focus of the mental health discussion from illness to wellness. As part of this programme, some 350 women have participated in an intensive training programme on mental health, sexuality, gender, and human rights. Following graduation, the women implement diverse activities in their communities, from disseminating information to organising outreach camps to providing lay counselling. Services are open to the entire community, but it is the women who run the programme.

In contrast to Anjali's Voices programme, *Janamanas* does not focus on mental health patients or institutional mental health services. The programme aims to promote community-based wellness. 'We don't diagnose people, and we don't focus on people who already have a diagnosis,' explains Ratnaboli. 'We are trying to break the hegemony of the biomedical model, because there is also a social and human rights model of mental health. Both models can co-exist. So why privilege one model?'

Anjali also engages in research, advocacy, and campaigning. In 2017,

India's mental health advocates won a hard-won victory with the adoption of the landmark Mental Healthcare Act. The law, which Anjali supported, reflects a significant advancement in Indian society's understanding of mental health issues. Ratnaboli describes the shift: 'We have created an environment of disclosure, where people can say that they are suffering from a mental health condition. I think we have been able to get rid of some of the internalised shame of mental illness. People are waking up to the fact that discrimination has to end.' The evolution of the law's name echoes the change: it was first called the Lunacy Act, then the Mental Health Act, and finally the Mental Health Care Act, with the emphasis on care. The law refers to the agency and consent of people with a mental health condition, and prohibits their involuntary admission to a mental health institution. 'Of course we are still struggling to implement the law in its full spirit,' Ratnaboli acknowledges. 'But the law received the President's assent and that's very important. It was a milestone.'

## Feminist movements address mental health

According to Ratnaboli, one of the biggest achievements of the Mental Health Care Act was the decriminalisation of suicide, which was a result of campaigning by feminist groups. Feminist groups focused attention on the fact that many women take their lives or engage in self-harm because of stressful conditions, domestic violence, and rape. 'In the

beginning, it was a challenge for feminist movements to see women with a mental health condition as a legitimate constituency. Reason and rationality were emphasised. But that has now changed,' explains Ratnaboli. 'Feminist movements now recognise mental health as an important intersection. Mental health groups that have a feminist perspective kept talking about the fact that it is OK to be vulnerable. It is OK to be incoherent. It is OK to be fragile. Let's take those things into consideration and extend solidarity, because solidarity and sisterhood are very powerful tools for healing.'

Anjali actively participates in feminist movements in India that are working intersectionally. The group engages in inter-movement dialogue and alliance-building, a strategy that it sees as extremely important. Through its work with CREA, an India-based global feminist organisation which has a long-standing programme on disability, sexuality, and rights, Anjali has learned to incorporate sexual and reproductive health and rights, and affirmative sexuality in its work. Anjali is slowly beginning to broach the subject of pleasure, self-pleasure, intimacy, and romance with women mental health patients. It has been and continues to be very difficult for Anjali to raise these issues with hospital authorities. 'They are still completely taboo,' Ratnaboli says. Raising the issues with the women, however, is a different story. Ratnaboli enthusiastically describes the experience of one such session: 'It was so much fun! The women were tickled to no end that they were asked

questions about self-pleasuring. They also appreciated the safe space to talk about these feelings.'

## **Building cross-movement dialogue and engagement**

Anjali is part of the Women with Disabilities India Network and the disability rights movement. But in Ratnaboli's experience, mental health remains a relatively low priority for the movement. Moreover, some parts of the disability rights movement insist on the complete rejection of the biomedical model and are calling for de-institutionalisation of mental health services. Anjali's vision is of a middle path. Ratnaboli explains: 'The future is community-based care, but institutions remain necessary. Women still lack shelters or safe spaces where they can escape to or rest. We still need institutions, but ones that are smaller in size and driven by a different set of values.'

Feminist funding organisations can play a valuable role by supporting inter-movement dialogue. According to Ratnaboli, there is a great need to bring together mental health, disability, and feminist movements and the trans community, for example. 'Movements are the only solid response to demolish mainstream thinking,' says Ratnaboli. For its part, Anjali has just completed a study on mental health issues among trans persons in West Bengal.

Funders can also amplify the stories of impact of their grantee-partners,

to show the concrete improvements they have on women's lives. Anjali has benefitted from the flexible, core grants of funders like Mama Cash and Oak Foundation, which have enabled the organisation to use its resources as they see fit. 'Feminist funders should talk amongst themselves. They should start a dialogue with others. They need to change the perspective of mainstream funders and encourage them to fund more flexibly.'



*Anjali engages in one-to-one community interactions to raise mental health awareness and shift the focus of discussions from illness to wellness in the Janamanas programme. Photo: Anjali.*

# 08 What security means for women

Women's Security Index  
Coalition, Israel



Assia Istoshina (right), of the Women's Security Index Coalition, interviews a disabled woman for the Index's research on women with disabilities. The Women's Security Index uses interviews to ensure that women's voices and lived experiences are central in defining 'security'. Photo: Women's Security Index Coalition.

**The issue of security dominates the political discussion in Israel. But what does security mean? And for whom? What does it mean for women, especially those from communities that are marginalised in Israeli society? In 2010, a group of radical feminist organisations – united by their feminism as well as their political stance against their country’s occupation of Palestinian territories – set out to answer these questions. The Women’s Security Index Coalition (WSI Coalition) was born. Coalition members represent and work together to promote the security concerns of women from various communities in Israel.**

‘Security in Israel is perceived in militarist terms,’ explains Assia Istoshina, who leads the research for the coalition’s annual Women’s Security Index. ‘We wanted to challenge and expand the understanding of security and show what security means for women.’ The Index is an annual report detailing the situation and security needs of particular groups of women in Israel. Past Indexes have focused on women with disabilities, Russian-speaking immigrant women, and LGBTQ women, among others. Statistics are complemented by in-depth interviews to ensure that women’s voices are at the centre of the report. ‘The concerns and needs of women from marginalised communities are not known,’ says Assia. ‘These women are not heard. They are not seen. And they are not considered in policies.’ In its research, WSI Coalition avoids the common pitfall of starting with research questions that may be based on false assumptions.

Instead, the Coalition gives women the lead in articulating the issues they find most important.

## **More than a seat at the table**

The Women’s Security Index Coalition has involved Isha L’Isha (Woman to Woman)-Haifa Feminist Center, Women Against Violence, Kayan, Aswat (Palestinian Gay Women), Coalition of Women for Peace, and New Profile-Movement for the Demilitarization of Israeli Society. The Coalition collaborates with other partners and stakeholders to identify and address important gaps in knowledge and awareness. The Index serves as a resource for diverse movements, organisations and government bodies – those who are in the position to take WSI Coalition’s findings and recommendations further in their programming and advocacy work. ‘Organisations that are working directly with women tell us they don’t have the time for detailed analysis. They often don’t have the time, or the necessary skills and expertise, to conduct research. One of the main goals of the Index is to respond to their need for this kind of analysis. We get in touch with existing organisations and see where there is potential for change. We see it as our mandate to provide information and partner with other organisations working for social change.’

For many stakeholders, considering women as a separate category with unique needs is itself novel. But WSI Coalition asks them to go deeper. The Index uses an intersectional approach,

zeroing in on the needs and experiences of women who face interconnected forms of oppression and discrimination in Israeli society. The aim is not only to increase understanding about women's specific needs, but also to improve their participation in decision-making bodies and show society what can be learned from women's unique knowledge and perspectives. 'It's not just about securing a seat at the table for women from marginalised communities,' explains Assia. 'It's about showcasing their uplifting, inspiring, and thought-provoking perspectives, such as those on gender, on the family, on the role of the state.'

## **Women with disabilities**

Each year, the Women's Security Index focuses on a particular group. One of the earliest editions of the Index, in 2013, focused attention on women with disabilities. WSI Coalition had identified a gap in the work of feminist movements on the one hand and disability rights movements on the other. Neither seemed to be paying sufficient attention to the particular situation of women with disabilities. 'We chose the topic of women with disabilities because they are a particularly marginalised and over-looked group of women. Their needs were under-researched, and there was an opportunity to collaborate with an existing group of women with and without disabilities that is part of Isha L'Isha, one of the Coalition members.'

Disability rights issues also featured in last year's Index, which focused on elderly women, many of whom have disabilities. There is a lot of attention on

the elderly in Israel, but little is known about the specific situation and needs of elderly women from marginalised communities, including women from Israel's large Russian, Ethiopian, and Palestinian communities, many of whom speak little or no Hebrew.

## **Violence is a key issue**

WSI Coalition has succeeded in shedding light on key challenges that women with disabilities face. Indeed, by looking at the issue of how disabled women experience security, the Index helped to illustrate that disablism itself is a security concern for women. Among other things, the 2013 Index revealed that women with disabilities commonly faced abuse, humiliation, and harassment by the state and by family members. In comparison to women without disabilities, women with disabilities were nearly three times more likely to experience physical violence from a family member. The reasons for this are complex and include many factors, one of which is economic insecurity. 'Women with disabilities are often financially dependent on their families. They have nowhere else to go,' explains Assia. 'Abusers think there will be no repercussions. They do it because they know they can get away with it.' In interviews for the Index, many women revealed their fears of leaving an abusive husband, losing their homes, and being put in an institution. Up until 2017, people with disabilities in Israel received social assistance that amounted to just half of the minimum wage. It was not nearly enough money to cover the basic cost of living, let alone the costs of living with a disability,

which is often more expensive (as it is left to individuals to absorb the cost of most accommodations needed, rather than treat barriers to participation as social issues, the costs of which should be born by society). Disability rights activists protested the situation under the slogan, 'People with disabilities are not half people.' Their struggle led to an increase in the amount, but it is still significantly less than the minimum wage.

The Index also revealed that women with disabilities experienced a much higher rate of sexual violence perpetrated by strangers. They were also four times more likely than other women to have experienced harassment or rude and humiliating treatment from government institutions. 'One of every three women with disabilities has experienced some sort of harassment by the state,' says Assia. 'The state institutions are there to provide services and protect the rights of women with disabilities. Instead, they themselves are perpetrating abuse.'

The Index contributed to improved knowledge and awareness among feminist and disability justice activist groups, and challenged some common assumptions in Israeli society about the priorities, problems, and needs of women with disabilities. 'Most people assumed that women with disabilities were mainly concerned about difficulties in accessing work or in finding a romantic partner or having children,' explains Assia. 'So if you designed a programme that was supposed to answer the needs of women with disabilities based on those assumptions,

you would be missing some very important issues'.

WSI Coalition's intersectional analysis has generated some important new insights. For example, while only 8.8 per cent of Jewish women described themselves as women with disabilities, the figure was 19 per cent for Palestinian women. Among other things, the difference reflects a disparity in access to health services and in health outcomes. Palestinian women in general, and Palestinian women with disabilities in particular, have more limited access to transportation, and thus to hospitals and doctors, which contributes to a higher proportion of Palestinian women self-reporting as being disabled.

The lack of accessible transportation was also a key finding in the Coalition's recent report on elderly women, about half of whom have disabilities. Elderly women from marginalised communities often do not have a driver's licence, so they need to rely on public transportation, which can be inaccessible or unsuitable. Another issue raised was the lack of language accessibility of public services, a problem that affects many women in Israel, including women with disabilities and elderly women who are not Hebrew-speaking. The WSI Coalition is part of a new coalition that is pushing this issue, advocating for improved language accessibility of public services. Housing is another key issue raised in the 2020 Index: many elderly women cannot afford to live on the ground floor and are forced to live in houses without lifts. 'If you're elderly, disabled, and non-

Hebrew speaking, you're stuck,' says Assia.

The Women's Security Index Coalition specialises in research, putting crucial information in the hands of partners and stakeholders who can advocate for social change. An example is Isha L'Isha, which has a project involving both women with and without disabilities aimed at promoting the rights of women with disabilities. The Isha L'Isha group has used the Index findings in their consciousness-raising and policy-influencing work. The group is currently developing a leadership course for women with disabilities to increase their participation in political decision-making. The group aims to challenge the portrayal of women with disabilities as passive recipients of social assistance and to highlight their contribution to society, such as their efforts to improve the accessibility of urban spaces to the benefit of many, including children, cyclists, and the elderly, among others.

## **Consensus takes time**

WSI Coalition has learned many lessons in relation to its intersectional work. For one thing, a lot must be taken into account for organisations, and society in general, to be truly inclusive and ensure full equality and accessibility for all, including women with disabilities as well as other marginalised groups. Given the scope of the problem, there is always the risk of compromising in ways that may benefit one group but not another. There is always the argument that there is not enough money to make the

necessary changes to accommodate everyone. As feminists, WSI Coalition sees consensus-building as key to dealing with this challenge.

'Cooperation between groups with different agendas is very important,' says Assia. 'The more you try to create an intersectional approach, the more time it takes to come to consensus.' This fact is very relevant for donors. 'Donors need transparency, numbers, and reporting, but there is a risk that the number becomes the goal and not the means. It can be like you are running on a treadmill, constantly trying to keep up with the demands of donors.' Another problem is that organisations are forced to compete for resources by staking their claim as the 'best' group working on a particular issue or with a certain constituency. 'It creates a lot of tension,' explains Assia. Donors can play a role in changing the situation by being more flexible and open, and supporting groups to work together. 'Support for movements, for collaboration and building relationships is crucial.'

# Conclusions

In these final pages, Mama Cash shares our reflections about what we are learning from our disability rights partners about their work and about how to be better funder allies in supporting them.

## Learning from feminist disability rights activists

### *Working at the intersections of movements*

Despite the various contexts in which they work and the particular strategies that they use, these groups all recognise that working at the intersections of identities is an urgent necessity. A common thread through most of these stories is that both feminist and disability rights movements often fail to recognise the particular oppression and discrimination experienced by disabled women, girls, trans people, and intersex people. These movements frequently do not take into account the particular needs of disabled women and girls. Indeed, most of the groups profiled in this publication came together in the first place because of gaps in the agendas of feminist and disability rights movements. These feminist disability rights activists are refusing invisibility and demanding attention for their lived experiences and needs.

According to these activists, disability rights movements often focus on issues of access to education and work, considering issues like gender-based violence and sexual and reproductive health and rights – core issues for disabled women and girls – to be less important. At the same time, feminist movements are often disablist and do not see the needs and realities of disabled women and girls. The experience of the Women with Disabilities Development Foundation in Bangladesh made this clear: after attending meetings *for a year* to ensure that their perspectives would be included, a feminist platform's CEDAW shadow report completely left out the perspectives and experiences of disabled women. As the work of Anjali in India shows, mental health issues need to be elevated on the agendas of both disability rights and feminist movements.

### *Confronting heightened gender-based violence*

Failing to recognise the existence, experiences, and needs of disabled women, girls, trans people, and

intersex people both causes and perpetuates injustice. It makes these communities more vulnerable to violence and violations of their sexual and reproductive rights. Every group in this collection identified violence as a central and pressing issue in the lives of disabled women and girls. A 2018 global study by United Nations Population Fund, for instance, showed that disabled girls and young women face up to ten times more gender-based violence than their non-disabled peers and that this violence often occurs in the family and at the hands of care-givers.

As the stories in this collection underscore, domestic and family violence is common for disabled women and girls, indeed more likely than for non-disabled women and girls. Insidious messages that they are 'worthless' or 'burdensome' normalise this violence. Disabled women and girls often feel dependent on partners and/or families for financial support, also making them less likely to name the violence. As research conducted in Israel by the WSI Coalition showed, disabled women had a significantly greater likelihood than those without disabilities of experiencing family violence.

### ***Challenging barriers to accessibility***

The activists with whom we spoke also stressed the many barriers that disabled women and girls face to their full participation in their communities and in society. They encounter, for example, barriers to accessing social, public, and health services, education, and

employment. Sometimes these barriers are literal: buildings, transportation, technology, and information are not accessible. In other situations, the barriers may be less tangible, but no less limiting. Disablist stigma and attitudes also exclude disabled people from community and social connection. This is what Ana, from the group Sisters, captured so well when she spoke of the distinction between physical accessibility and 'soft' accessibility. Both physical and 'softer' barriers affect the organising work of feminist disability activists. Indeed, several of the activists spoke of the important work that groups undertake to bridge accessibility gaps in order to facilitate activism. Misti from WDDF in Bangladesh spoke of friends, family, and staff members sometimes covering the costs of assistive devices, like wheelchairs, when donors will not fund them. As the activists from Colectiva Polimorfias in Colombia noted, 'our very existence as an activist group is an achievement'.

### ***Implementing a variety of strategies***

The eight groups profiled in this collection draw from a toolbox of many strategies. All of them use **lobbying and advocacy with stakeholders** to ensure that laws and policies, but also norms and mind-sets, take into account the needs of disabled women and girls. Health care providers, teachers and educational institutions, employers, police, elected officials, policy-makers, family members, and care-givers – these stakeholders are all targets of awareness-raising and advocacy work.

Another key strategy used by most groups is community **building** and **awareness raising** with disabled women and girls. One of the first steps in awareness raising is for disabled women and girls to change negative internalised attitudes about themselves and come out ‘into the light’, as Fela of AFHAM emphasised. Support groups, safe spaces for sharing personal stories, and learning spaces like Nazyk Kyz’s School of Independent Life, create the possibility for women and girls to come together to build connections and personal strength and resilience, to develop their understanding of ‘disability’ as a group and societal (not individual) issue, and to become politicised.

**Creating art and stories**, as well as developing **knowledge, research, and documentation**, are strategies used to build the evidence base about the needs of disabled women and girls. Documentary material is crucial in the advocacy work of feminist disability rights activists. For example, Anjali articulated the feminist argument that women’s personal stories count as evidence and that writing women’s lived experience into history is a powerful strategy for making public institutions, such as mental health care facilities and hospitals, responsive to women’s needs and lives. Working with the **press** and creating **media strategies** also contribute to ensuring that these stories and knowledge are widely disseminated and can contribute to activism to change laws, policies, norms, and attitudes related to disability.

Finally, providing **direct health and social services** to their constituents is an important part of the work of feminist disability justice activists. These services range from support hotlines and shelters for people leaving violent situations, to services that support access to education, legal support, and respectful, responsive health care. During the COVID-19 pandemic, feminist disability rights groups have provided shelter, food packages, and hygiene products to constituents in need.

### ***Reframing the conversation***

Many activists speak of the importance of reframing disability narratives. Dominant narratives often focus on notions of ‘illness’ or ‘impairment’, defining the ‘able’ body as normative. Some feminist disability right activists, like Colectiva Polimorfias, embrace a concept of ‘functional diversity’, which normalises the diversity of human abilities, bodies, and minds. This reframing is urgently important: naming and normalising the diversity of bodies, minds, and capacities creates space for all bodies and minds, for all of us; this is crucial as we work to shift and transform power and secure a more just and joyous world. Many groups in this collection also reflected on the importance of reframing disability not as an individual issue, but rather a social issue. Coming to understand that it is society that creates disability by failing to take the breadth of all people’s needs and realities into account led many of the activists in this collection to organise

with others, like the story that Svjetlana told about how Iz Kruga Vojvodina came into being. It is society that is disabling because of how it is designed and for whom (e.g., when a public building has a lot of stairs and no lift, someone using a walker to walk cannot access it as easily as someone who doesn't use a walker). This makes disability a political issue – since what is at stake is the distribution of rights and resources – one that can only be addressed by society, by all of us together.

## Becoming better funder allies

The activist groups featured in this collection are doing ground-breaking work – often with relatively limited resources. Many of them depended on volunteer labour and worked from their homes before they received their first funding. Sufficient and good quality financial and other resources are crucial for sustained activism. This is a key recommendation that most of the activists in this collection made, and one that we feel strongly about emphasising and amplifying. Funders need to provide **consistent, long-term, core support** so that feminist disability rights groups can strengthen themselves and sustain their work. 'Core funding' is funding without restrictions, allowing activists to decide how best to deploy their resources. This means that they can use their funding to implement the strategies and activities that they choose, and that they can use it to address any of the hard or soft barriers they encounter in their activism. As the activists we spoke with made clear: it is core funding that

allows them to get their work done and to make change happen.

Another lesson we take away is that disability justice activists may be using different frames than some funders are used to; for example, their organising may not explicitly use human rights language, yet their agendas are relevant and their work is clearly about expanding access to human rights. Funders need to develop ways to ensure that both stand-alone, dedicated funding, as well as 'mainstreamed' funding, is available to groups working at the intersections of movements. For example, it is necessary to ensure that gender-focused funding, LGBTQI funding, etc., is appropriate and accessible to disability rights groups, while disability-focused funding is accessible to feminist groups. Funders need to make their awareness of these intersections visible and to clearly signal an active intention to fund at these intersections. And we need to adapt our procedures and processes so that funding is actually accessible for the groups we want to support. We also need to be accessible in more languages, and to cover the costs of translations so that we can communicate with and understand the activists with whom we seek to work.

As funders, we can also support **cross-movement organising and** inter-movement dialogues, activities that are particularly important for feminist disability rights activists working at the crossroads of different movements, including not only feminist and disability rights movements, but also movements

focused on sexual and reproductive health and rights, economic and workers' rights, and environmental justice.

Activists also ask funders to **amplify disabled activists' voices**, letting them tell their own stories and show how their activism has secured change for disabled people, and, indeed, all people. We hope that this collection of articles makes a contribution in this area.

We can also **change the language** we use, be aware of how disablist language and imagery creeps into our speech and minds, and **reframe the narratives** that we use. This work is key to envisioning truly just and inclusive societies.

Similarly, we can **listen** and cultivate empathy. Listening also contributes to our understanding that 'disabled people' are not monolithic and that there are many ways that a person can be disabled and that a society can be disabling; funders and allies need to be aware of this range.

Finally, disability rights activists call on funders to **respect the principle of nothing about us, without us**, which has long been a refrain of the disability rights movement. This mantra calls on us to follow the leadership of disabled women, girls, trans people, and intersex people, to make our funding, spaces, and events accessible, and to include disabled people in everything that we do.

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