

RESEARCH REPORT

**Stigma and discrimination faced by people with disabilities returning to the Federally Administered Tribal Areas in Pakistan**

# Acknowledgements

Islamic Relief would like to thank the people with disabilities (PWD), their caregivers/families, and all the community members, civil society and government stakeholders who so generously contributed their time and knowledge to make this research possible.

We are grateful to the Federally Administered Tribal Areas (FATA) Disaster Management Authority (FDMA) and Malteser International Pakistan for sharing their experiences and information about systems and services for PWD.

The assistance of the Khyber Pakhtunkhwa knowledge, information & management coordinator and media & communications officer with the data collection, analysis and validation was also highly valued.

It is our sincere hope that this report will help the FATA, federal, provincial and district governments in Pakistan, and other allied stakeholders, to substantially improve support for PWD in Pakistan.

**Cover:** *A child with disabilities participating in a focus group discussion held by Islamic Relief Pakistan in the Federally Administered Tribal Areas (FATA) of Pakistan.*

## List of Abbreviations and Acronyms

<b>FATA</b>	Federally Administered Tribal Areas
<b>FDMA</b>	FATA Disaster Management Authority
<b>Agency</b>	An area in FATA (similar to a district in other areas of Pakistan)
<b>FGD</b>	Focus group discussions
<b>PWD</b>	People with disabilities
<b>CWD</b>	Children with disabilities

## Version management

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# Introduction

Islamic Relief has been delivering emergency relief and sustainable development aid in Pakistan since 1992 and is one of the only humanitarian agencies currently permitted to operate in the Federally Administered Tribal Areas (FATA).

There has been a humanitarian crisis in the FATA region over the past ten years, with conflict contributing to the displacement of significant numbers of local people to adjoining areas. As the conflict has subsided in recent years, people have started returning to the FATA and these returnees are the focus of this study.

This report documents research by the organisation to understand stigma and discrimination faced by people with disabilities (PWD) returning to live in the Khyber Agency of the FATA. It sets out the context within which the research was conducted, a summary of the findings, the research project and results, and finally recommendations arising from the research.

# Research aim

## The purpose of the research was to:

- measure the level of knowledge, attitudes and practices by people with no disabilities towards PWD, and
- to understand factors contributing to stigma and discrimination faced by PWD, among people returning to the FATA.

# Key definitions

The definitions of disability and discrimination used for the research have been taken from the CRPD Convention.<sup>1</sup>

## While the Convention does not include a formal definition of disability it provides the following in its preamble and first and second Articles:

*“Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (from the Preamble), and;*

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (from Article one).*

It should be noted that the use of the word “include” in the statement from Article one does not necessarily exclude those with short-term disabilities.<sup>2</sup>

## In relation to discrimination, the CRPD Convention offers the following definition:

*“Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;*

*“Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (from Article 2).*

# Global, national and local context for the research

## International and national data on disability

A lack of data on PWD is one of the main barriers to greater inclusion. The World Health Organization's (WHO's) *World report on disability 2011*<sup>3</sup> is one of the most reliable sources of statistics. According to this report, there are around one billion CWD/PWD worldwide, 15 per cent of the total global population.<sup>4</sup> Using this as a guide, it can be estimated that there are potentially as many as 29 million<sup>5</sup> PWD in Pakistan. The WHO report details why PWD have the lowest health, education, economic and social outcomes of the population. The barriers include: inadequate policies and standards, negative attitudes, lack of services, problems with service delivery, inadequate funding, lack of accessibility, lack of consultation/involvement and lack of data and evidence.<sup>6</sup>

In Pakistan, the most recent official statistics on disability are from 1998, and are considered too outdated to be useful.<sup>7</sup>

Inclusion-focused humanitarian actors and networks in Pakistan, including the Community Based Inclusive Development Network (CBIDN), UN-led clusters, and relevant government departments, agree that more accurate, diverse and up-to-date data about PWD is needed.

## International and national law on disability inclusion

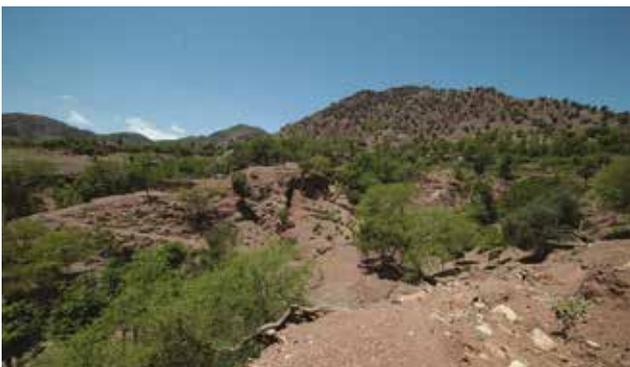
The most significant development in international law relating to disability this century has been the United Nations *Convention on the Rights of Persons with Disability* (CRPD Convention) 2006,<sup>8</sup> which came into effect in 2008. This sets-out the rights of PWD and the obligations on states to promote, protect and ensure those rights. More recently, in 2018, the Committee on the Rights of Persons with Disabilities (which oversees implementation of the CRPD Convention), adopted a new *General Comment*, which provides further guidance on what is meant by inclusive equality for PWD.<sup>9</sup>

On a national level, progress has unfortunately been slow. While Pakistan ratified the CRPD in 2011,<sup>10</sup> little has been done since then to implement it.



The recent conflict in the FATA resulted in significant damage to villages.

There is currently only one law targeted at PWD, the Disabled Persons (Employment and Rehabilitation) Ordinance 1981.<sup>11</sup> The Ordinance requires that employers of more than 100 staff ensure that at least two per cent of their staff are PWD, but according to the British Council its implementation is poorly enforced.<sup>12</sup> The British Council attributes the lack of legislation to the devolution in 2010 of responsibility for relevant policies and draft legislation from the federal level to the provinces, which have not seen this as a priority.<sup>13</sup> However, some provinces are advancing initiatives such as accessible education and employment support.<sup>14</sup>



The rugged mountainous terrain of the Khyber Agency.

## Humanitarian crisis in the FATA

Since 2008, the FATA has experienced large population displacements and a protracted humanitarian situation triggered by conflict and resulting security concerns.

The population of Khyber Agency was displaced to different parts of the adjacent Khyber Pakhtunkhwa province and Afghanistan during these years. As the Pakistan government has now eliminated the threat of conflict from the FATA, people of the agencies have been allowed to return to their homes.

The United Nations Office of the Coordination of Humanitarian Affairs (UNOCHA) says that up until March 2018 over 330,000 families have so far returned to the FATA, and almost 100,000 of these have gone to Khyber Agency.<sup>15</sup>

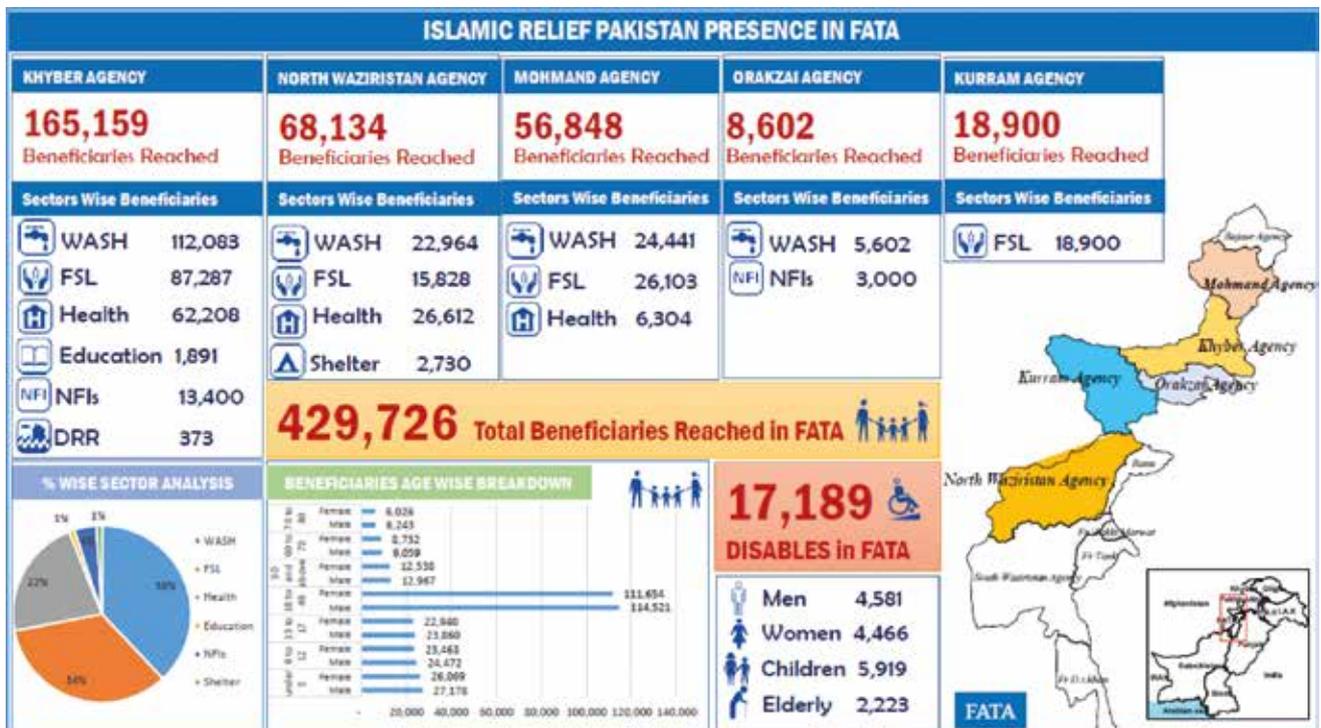
## Islamic Relief's programmes in the FATA

Islamic Relief is one of the few humanitarian agencies providing badly-needed aid and services in the FATA, such as: water and sanitation, food security and livelihoods, health, education, non-food items, and disaster risk reduction. The table below shows the number of beneficiaries Islamic Relief worked with across the FATA from 2010 until May 2018.

Since 2017, the organisation has also distributed food packs and meat under seasonal food programmes.

Specific support to PWD includes assistive devices to address some mobility issues (wheelchairs, walkers and toilet chairs), small cash grants and small-scale business training.

The number of beneficiaries Islamic Relief worked with in the FATA from 2010 until May 2018



# Summary of research findings

The primary research activities consisted of individual interviews with PWD and their caregivers/families and key stakeholders in the community, civil society and government; as well as FGD with PWD and a wider group of stakeholders. Interviews covered the following points:

- demographic information
- levels of disability
- access to services
- understanding of what a disability is
- knowledge and awareness about disability, and
- attitudes towards disability.

The average age of respondents with disabilities was 31 years, of whom around two-thirds were males and a third were females. A trend of disabilities increasing in younger generations was thought by respondents to be due to the popularity of cousin marriages.

All of the respondents had problems with at least one disability relating to hearing, sight, walking, self-care, remembering/concentrating or verbal communication.

Access to education services by CWD/PWD is an acknowledged problem in the FATA. There are no special education schools and 82 per cent of PWD have had no education. This affects job prospects, with 29 per cent of respondents with disabilities unemployed, however 45 per cent are self-employed.

When asked about different types of disabilities, almost all respondents believed that someone with a physical or intellectual impairment has a disability. This is despite the fact that some of the impairments may be able to be managed (with assistive devices), or may not meet the formal definition of a disability.

In terms of knowledge and awareness about disability, this research examined awareness of services, social exclusion, experiences during emergencies (such as humanitarian situations) and economic participation. It found a low level of awareness about services – only four per cent were aware of any services for CWD/PWD in their community, but 34 per cent were aware of organisations supporting CWD/PWD in their community. Eighty per cent of respondents with disabilities agreed that PWD suffer most in emergency situations. Ninety-six per cent of respondents agreed that women and girls with disabilities suffer more social exclusion than men and boys, due to the male-dominated culture in the FATA. Only 26 per cent agreed that most PWD are economically active.

Almost two-thirds of respondents believed that PWD are treated fairly in society and 60 per cent believed attitudes have improved over the past ten years. While 70 per cent would be happy to have a CWD/PWD living next door, a similar percentage would not be happy for their child to marry a PWD. People are particularly against sons marrying a woman with a disability. Sixty per cent agreed that PWD cannot lead as full a life as those without disabilities and less than half agreed that PWD can make a positive contribution to their family or society. Only four per cent agreed that health services are fully accessible to PWD, and only 12 per cent agreed that education services are fully accessible to CWD/PWD.

The FGD also looked at understanding of what a disability is; as well as access to services, education, health and economic opportunities. In addition, the groups discussed barriers to disability inclusion and the role of the faith community.

The FGD results were in-line with the results of the individual interviews and provided some richer detail about the challenges faced by PWD and their families in the FATA.

# Research methodology and sample

This research was conducted in the second quarter of 2018 and was built on four approaches, as follows:

a) A desk-based literature review, to understand the current social, economic and political context for PWD in the FATA.

b) Individual interviews with key informants, to understand the perspective of important stakeholders for PWD. These interviews also helped in verifying the information gathered through focus groups. Seven interviews were conducted with the employees of local schools, NGOs, the FATA Disaster Management Authority (FDMA), and Malteser International (another international NGO operating in the FATA).

c) Individual interviews with 50 PWD (17 female and 33 male) and their caregivers/families, to obtain a first-hand perspective on their experiences.

d) FGD with a wide group of important stakeholders for PWD, including PWD, their caregivers/parents, teachers, principals, health workers, community leaders, religious leaders, and local NGO employees. Six focus groups (four male and two female) were held.

In total, 150 respondents aged from 16 to 65 years old participated in the research.

Before the start of field work, the field team was trained on the methodologies and tools of the research. They were divided into groups and practised performing individual interviews and focus group questions, including the Washington Group Short Set questions on disability.<sup>16</sup> The team was also trained on how to collect data using KoBo Toolbox<sup>17</sup> online data collection, and to use the analysis tool. The team training was an important aspect to ensure each member of the research understood the objective and purpose of the research.

The table below shows the villages or sub-tribes included in the research:

## Villages included in the research study (per tribe)

Agency	Administrative division	Tribe	Village/ Sub-tribe
Khyber Agency	Bara	Kamar Khel	Kajoorai
			Ziayarat
			Kalay
			Moira
		Upper Akka Khel	Milward Kalay
		Sipah	Yousaf Talab

# Research constraints

The research team faced a number of challenges, as follows:

**1.**

The security situation and lack of access to Khyber Agency meant that prior permission from the law enforcement agency had to be obtained.

**2.**

The limited availability of communication networks was another hurdle in the areas researched.

**3.**

In some areas, due to cultural traditions, researchers were unable to interview some potential female respondents, as even female interviewers were not allowed to speak to them.

**4.**

Local and international NGOs in the area rarely work with PWD so they had little knowledge about them.

**5.**

There was a lack of secondary data about PWD in Pakistan.

# Results of the individual interviews

## Demographic information

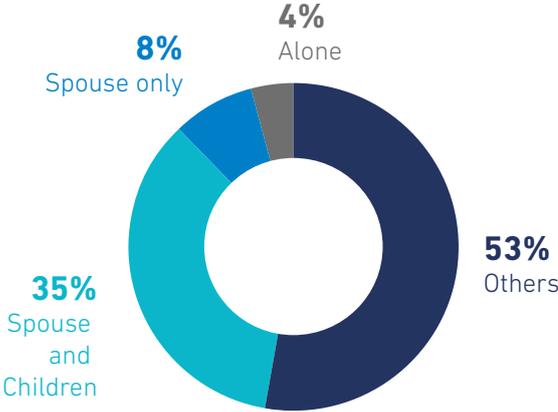
According to research findings, the average age of the respondents is 31 years, with a ratio of 66 per cent males and 34 per cent females, and an average family size of 8.3 people. Respondents advised that approximately 20 per cent of families in the area have a PWD. The majority of PWD are living with others in strong family environments.

Results also show that most disabilities are increasing in the younger generation (55 per cent of the CWD/PWD are sons and 27 per cent are daughters). This was thought by the respondents to be due to the high rate of cousin marriages, and was of concern given the popularity of inter-family marriages in the FATA.

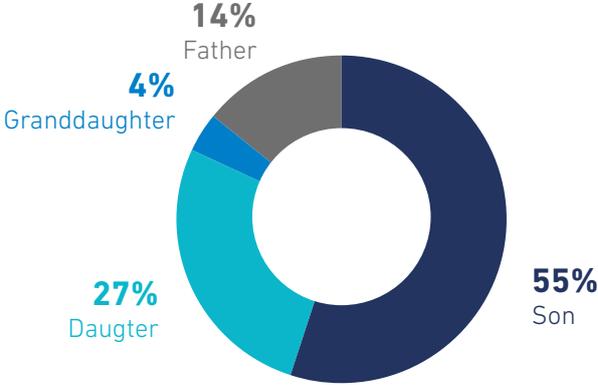


The ratio of children and young people with disabilities in the Khyber Agency is very high.

## Living arrangement of CWD/PWD



## Analysis of CWD/PWD in the family



## Levels of disability

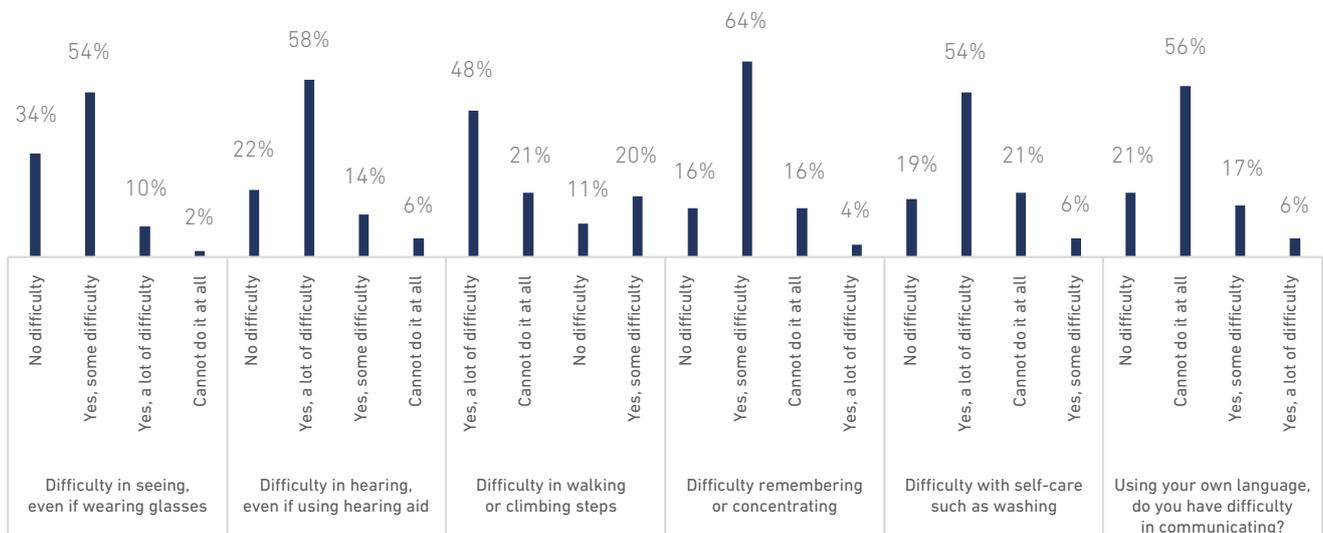
During interviews with the PWD, respondents revealed the extent of their disabilities. Sixty-four per cent have some difficulty seeing, even if wearing glasses (two per cent cannot see at all), and 72 per cent have some difficulty hearing (six per cent cannot hear at all), even if using a hearing aid. Most of the difficulties reported in seeing and hearing were mild to moderate in nature and could be addressed by the greater availability and use of assistive devices (glasses or hearing aids).

Sixty-eight per cent of respondents have some difficulty walking or climbing steps (21 per cent cannot do it at all), and 68 per cent have some difficulty remembering or concentrating (16 per cent cannot do it at all). Intellectual difficulties were thought by respondents to be due to genetic issues arising from cousin marriages.

Difficulty in seeing, hearing and walking is lowest among the youngest respondents and increases gradually with age.

Sixty per cent of PWD have some difficulty in performing self-care, such as washing or dressing themselves (21 per cent cannot do it at all). Twenty-three per cent of PWD have some difficulty communicating verbally (56 per cent cannot do it at all).<sup>18</sup>

**Disability (Functionality)**



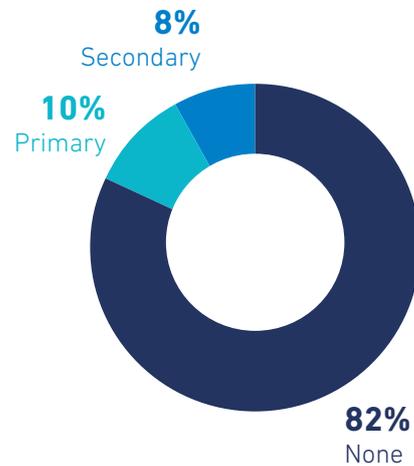
## Access to services

According to interviews with government officials and members of the community, there are no special education schools in the FATA, which makes education for CWD/PWD a significant challenge. The research also shows that 82 per cent of CWD have no access to any schools. This suggests a need to promote inclusive education, where CWD are in the same classroom as mainstream students, to make education services in the FATA more accessible. Currently, with limited or no education, 45 per cent of respondents with disabilities are self-employed and 29 per cent are doing nothing. It was thought by the researchers that the low employment rates are due to the lack of access to quality education, which results in poor skills for the labour market. Combined with minimal support for job seekers with disabilities to perform activities such as searching for a vacancy, and a negative attitude from employers, PWD have very poor job prospects.

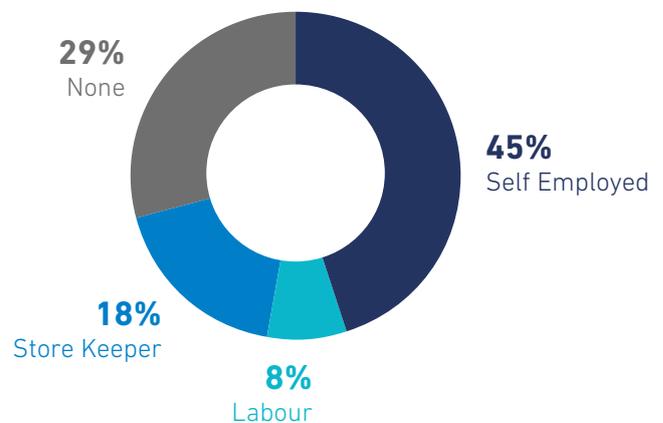


Small businesses are the main type of employment for people with disabilities in the Khyber Agency. Ijaz Ahmed has a speaking disability but has not let this limit him. He is a trained tailor and makes clothes to support his family.

## Educational Level



## Job Status



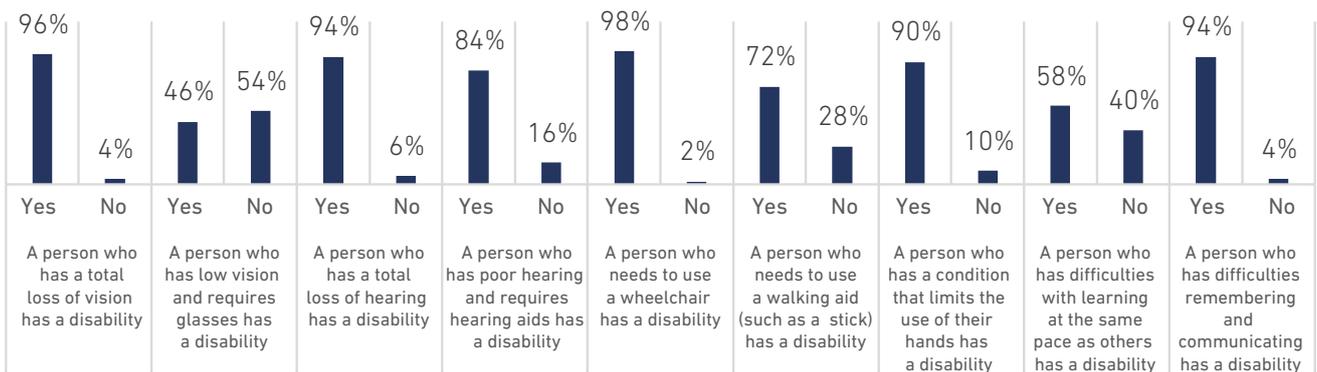
## Understanding of disability

The research explored the knowledge and understanding of the community about disabilities. When asked who a person with a disability is, 96 per cent agreed that a person who has a total loss of vision has a disability. However, only 46 per cent agreed it's a disability if someone has low vision and requires glasses. Ninety-four per cent agreed that a person who has a total loss of hearing has a disability. Eighty-four per cent agreed that a person who has poor hearing and requires hearing aids does.

Ninety-eight per cent agreed that a person who needs to use a wheelchair has a disability. Seventy-two per cent agreed that a person who needs to use a walking aid (such as a stick) does. A person who has a condition that limits the use of their hands has a disability according to 90 per cent of respondents. In terms of intellectual difficulties, 58 per cent agreed that a person who has difficulties with learning at the same pace as others has a disability. Ninety-four per cent agreed that a person who has difficulties remembering and communicating does.

These results indicate that people have limited knowledge about different types of disabilities and their complications. They considered that any physical or intellectual impairment is a disability, even though it may be relatively minor, or may not meet the CPRD Convention's description of a disability.

### Disability



## Knowledge and awareness about disability

In the FATA stigma and discrimination are highly associated with the lack of awareness about disabilities and the rights of CWD/PWD. The research examined awareness of services for CWD/PWD; social exclusion among CWD/PWD; hardship experienced by PWD during emergencies (such as humanitarian situations); and whether PWDs are economically active or not.

Ninety-six per cent of respondents with disabilities were not aware of any services for CWD/PWD in their community, but 70 per cent were aware of services at a national level. Only 34 per cent were aware of organisations supporting CWD/PWD in their communities, and only eight per cent were aware of religious institutions/mosques providing support. This result is in-line with the researchers' expectations, given there's currently very few services for CWD/PWD in the FATA.

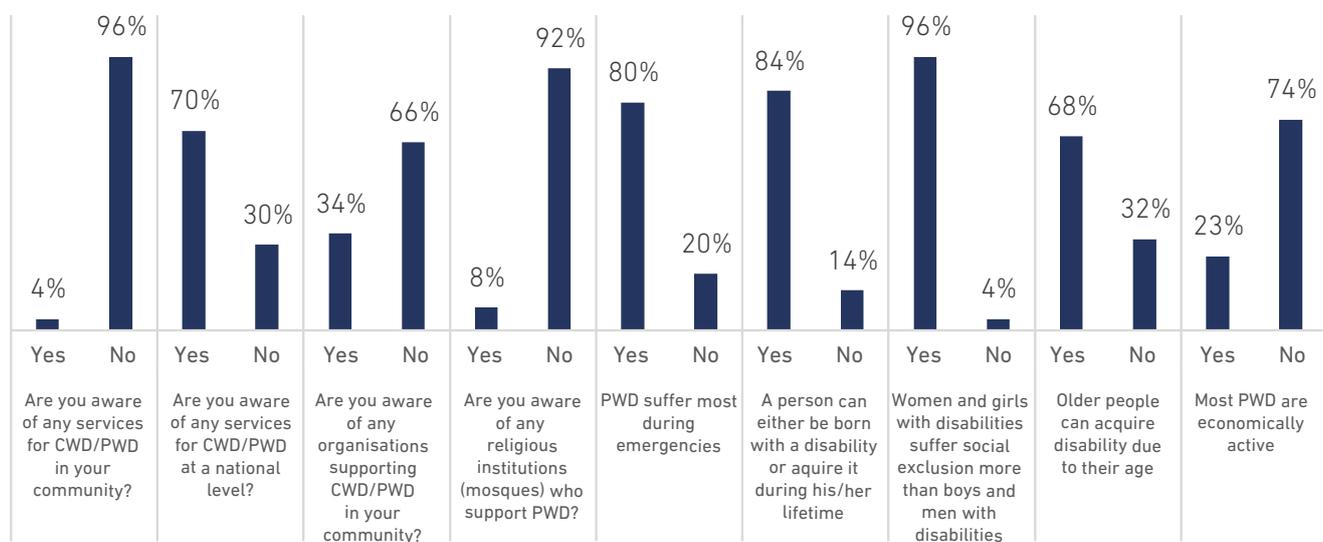
Eighty per cent of respondents with disabilities agreed that PWD suffer most during emergencies. For example, 25-year-old Abdul Salam recently returned to the remote area of Bara in Khyber Agency and is sadly living a miserable life. His whole body is paralysed, and he communicates through signs and gestures as his speech is impaired. Mr Salam is part of a big family with seven sisters and nine brothers. His father Mr Wajid Khan said, *"We want organisations to work for disabled people as there is a high ratio of such people in our area"*.

When asked if women and girls with disabilities suffer social exclusion more than men and boys, 96 per cent of respondents agreed with this, due to the male-dominant culture. This gender bias was also reflected in their understanding of the economic capabilities of PWD. Seventy-four per cent disagreed with the statement that most PWD are economically active, and said this is due to poor educational and job opportunities for PWD. The lack of opportunities for PWD has been worsened by the humanitarian crisis in the FATA, and is a major cause of stigma towards PWD.

The research also looked into the correlation between disability and age, and 68 per cent agreed that older people can acquire disability due to their age.

Results show that a lack of knowledge about disabilities, and a lack of services for CWD/PWD in the FATA, are major causes of why CWD/PWD are marginalised and excluded from their own communities.

### Disability Knowledge



## Attitudes towards disability

According to the research findings, 64 per cent of respondents agreed that PWD are treated fairly in society. Sixty per cent agreed that attitudes towards PWD are better than they were ten years ago.

Seventy per cent of respondents would be happy to have a CWD/PWD living next door, and 76 per cent would be happy to have a CWD attending the same class as their own child. But despite this, only 24 per cent would be happy for their child to marry a PWD. The researchers observed that people are particularly against sons marrying a woman with a disability, due to the male-dominated society in the FATA.

CWD and their families face social stigma, as 22 per cent of respondents agreed that disabilities are the result of the past deeds of parents. As mentioned, there is a common belief that disabilities are due to cousin marriages. On the other hand, 78 per cent of the respondents agreed that CWD are a blessing given to families by God (Allah).

Sixty per cent of respondents agreed that PWD cannot lead as full a life as those without disabilities, and less than half agreed that PWD can make a positive contribution to their family or society.

The research explored attitudes towards CWD in education and their general treatment.

Fifty-six per cent of respondents agreed that CWD should attend the same schools as other children, but only 44 per cent agreed that CWD benefit from attending school. Sixty per cent of respondents agreed that CWD should be encouraged and supported to play with other children. Sixty-eight per cent agreed that it is sometimes alright to treat CWD more favorably than other children.

Sixty-eight per cent agreed that CWD are more vulnerable to physical and sexual abuse, and 52 per cent that they are more likely to be neglected. Fifty per cent of respondents believe that sometimes it is necessary to punish a CWD for misbehavior but only 26 per cent agreed that it is sometimes necessary to leave a CWD in the house alone. The researchers observed that raising awareness within communities about the rights of CWD is very important.

Fifty per cent of respondents agreed that PWD should have full access to economic opportunities, but 64 per cent agreed that only men and boys with disabilities should work (and that women and girls with disabilities can't work).

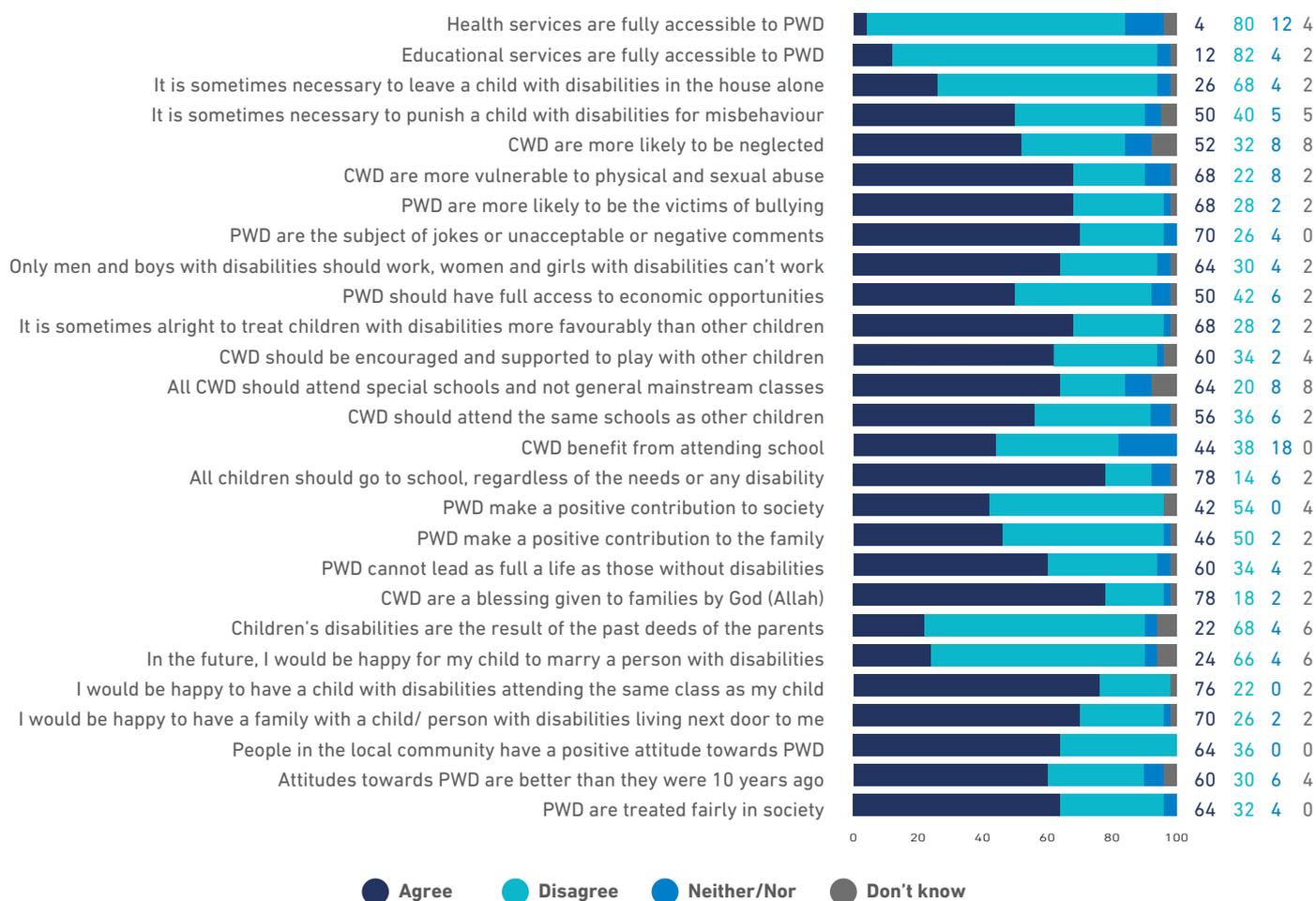
The research also showed that 70 per cent of respondents agreed that PWD are the subject of jokes or unacceptable or negative comments. Sixty-eight per cent agreed that PWD are more likely to be the victims of bullying. Cultural norms in the FATA mean that care and safety-related issues within families, such as gender-based violence, are not reported, especially about girls and women with disabilities. Reporting such problems is against the family code of conduct.

In relation to access to services, only four per cent of respondents agreed that health services are fully accessible to PWD and only 12 per cent agreed that education services are fully accessible to PWD.



[Islamic Relief Pakistan consulting with a person with disabilities in the Khyber Agency.](#)

## Attitudes



# Results of the focus group discussions

The FGD explored similar questions to the interviews, as follows.

## Understanding of disability

Participants were asked about their understanding of disability and what it means to be living with a disability.

They believed that a person who can't function in a normal way, or who has incomplete growth of some body parts that affect their ability to live a normal life, has a disability. They also discussed that PWD who have difficulty performing (or who cannot perform), daily routine activities such as washing and dressing themselves, have more challenges than others with less severe disabilities.

Participants were asked about types of disabilities, and they shared their concerns about different types of disabilities in their local areas. Physical disabilities present from birth or from paralysis during a polio attack are more prevalent than others, but other common disabilities are visual, hearing and speech impairments, and intellectual disabilities.

They also stated that during the conflict era, displacement from their home towns psychologically traumatised people including PWD. The participants believed that all disabilities are challenging as they limit the ability of the person to function and perform daily activities. However, they considered that the worst types are intellectual disabilities and severe physical disabilities. Minor physical limitations where the person concerned can still do something to fulfil their economic needs were viewed more positively. Caregivers/families and communities only tend to interact with PWD when they have a direct or indirect relationship with them.

In terms of what it means to be living with a disability, the lack of accessible roads/pathways, and special education schools for CWD is challenging. Teachers accept children with physical limitations in some schools, but children who have visual, hearing or speech impairments are not accepted due to a lack of inclusive education facilities. Parents of CWD want to enroll them in school, but due to poverty, the lack of services, lack of information about how to access any services available, and inaccessible roads, are unable to do so. For example, they don't have enough money to arrange private transportation to take their CWD to school.

Poverty and a lack of services has therefore increased CWD/PWD exclusion and isolation, which is having a very negative impact on them.

Participants believed that existing support schemes from the government, such as Bait-ul-Mal, Health Card, and the Benazir Income Support Programme, are not accessible to PWD.

They thought that providing inclusive technical training in specific fields to PWD, along with financial support, would enable them to become self-reliant – able to help their families and be good members of society. Participants also believed that free medical camps for PWD, including rehabilitation centers, are badly needed in their areas.



The lack of sealed roads and infrastructure in villages in the Khyber Agency makes it difficult for people with disabilities to move around independently.

## Barriers to disability inclusion

Participants were asked what challenges they think a family face if they have a PWD, and whether these challenges are the same for males and females.

They identified several barriers faced by PWD and their families, as follows.

### The inaccessible physical environment

Inaccessible, unlevelled roads, unpaved streets and even house yards full of pebbles and stones block the movement of those with physical disabilities. These challenges hinder the ability of PWD to take-up any educational or economic opportunities. The same challenges were also a problem at times of displacement, when people were evacuated from their homes to safer places in Peshawar, Jalozai, and Bannu.

Female participants indicated that girls and women with disabilities, along with their caregivers/parents, faced many problems during displacement as their care and safety (in-line with cultural norms) was even more difficult. All participants agreed that the lack of assistive and mobility devices presented a significant challenge during displacement for all PWD.

### **Care and safety-related problems**

Participants shared that CWD seem to have greater sexual desires compared to children without disabilities. Female participants said that families of girls with disabilities face more difficulties as they require an attendant all the time, and especially during their menstrual cycle. Failing to maintain cleanliness and privacy during the menstrual cycle is considered shameful. Mothers find this particularly hard as they are the main caregiver, and can sometimes become frustrated and violent against their daughters as a result. Daughters with disabilities represent a burden for life to their families as they are not marriageable.

### **Negative attitudes**

People with physical disabilities, especially boys, experience barriers to education and later to economic opportunities, due to an inaccessible physical environment and the negative attitudes of family and the community. Boys with disabilities are habitually shy and don't typically like to participate in games with peers or go to school. Some of the participants were of the view that boys face more challenges compared to girls, as girls generally stay at their homes, but boys are expected to go out. Cultural norms combined with stigma about disabilities almost completely restricts the movement of girls with disabilities. They don't participate in communal activities, attend schools, play or even walk outside of their homes.

### **Gender roles within families**

Participants noted that the responsibility of caring for CWD is mostly the responsibility of their mothers, who feed, dress, and wash them. Mothers must also perform multiple domestic tasks for the remaining family members, and they find it difficult to spare enough time to care properly for their CWD. The care of CWD becomes worse if their mothers get sick. The mothers are therefore stressed and struggle to manage these challenges.

Fathers of CWD are burdened with the need to arrange financial support for their families to cover the cost of food and other expenses like medical treatment costs for CWD. They find it difficult to spend sufficient time with their families including the CWD. Fathers are mainly responsible for earning for the whole family (due to cultural norms women are not allowed to work outside of their houses). Another major stress for fathers is the problem of arranging a marriage for their CWD. Most people don't accept PWD marrying, especially if they have no income, and parents don't allow their sons to marry women with disabilities. This is because at a family level taking care of women with disabilities is solely the responsibility of the mother or elder sisters of the family. Men who have a minor disability can potentially get married, as they are more accepted, while girls

with a minor disability are still not marriageable. The inability to arrange a marriage is stressful for the family, and causes stigma and subsequently discrimination against the PWD.

PWD are generally treated with respect in the FATA though, particularly those who can work despite their limitations. Approximately 70 per cent of PWD who work have the chance to get married. PWD work is almost always based in the house, such as tailoring and shop-keeping.

### **Access to services**

The participants were asked about any services provided to PWD and their families by any organisations. They confirmed that due to the current situation in the FATA it's not easy for local or international NGOs to operate there. NGOs have to obtain permission from the relevant authorities for any humanitarian or development operations, which is a lengthy process. There are very few organisations working to provide a humanitarian response to the people returning to the FATA, and there are no organisations supporting PWD.

Participants advised that the political administration of Khyber Agency provides a small amount of financial support to families who have a PWD. Also, a small local organisation, Karwan-e Nawjawan, is raising awareness among communities about treating PWD in a dignified manner.

Islamic Relief is one of the few humanitarian organisations operating in the FATA, and providing some support to PWD.

### **Access to education**

Participants were asked if CWDs should go to school, and what is needed to ensure greater inclusion. The participants all agreed that CWD should go to school and should have equal rights to inclusive education. They suggested that teaching methods should include both audio and video formats; teachers should give CWD desks at the front of the classroom and extra attention; and transportation and assistive devices should be provided.

Participants thought that CWD who have physical limitations and mobility issues can go to existing schools, if they are provided with support by their families and government. Children with vision, hearing and speech impairments cannot go to existing schools, however, because learning facilities are not able to cater to their needs.

Support to attend school should ideally be provided to the poorest and most vulnerable children of the FATA, but it requires continuous efforts and funding.

## Access to health

When participants discussed access to health services they said that such facilities and services are not available for PWD. Participants believed that PWD should be provided with proper access to health services and care units in hospitals, and should receive maximum discounts for treatments, consultation fees and medicines. Transportation services are also needed to support access to health services.

## Access to economic opportunities

The participants pointed out that economic opportunities are not available in the area, but it's worth mentioning that even before displacement PWD didn't have such opportunities. Participants stressed that PWD should have access to economic opportunities. They suggested that they should be provided with capacity-building/skills training according to their needs and interest. PWD should also be provided cash grants support to start small businesses.

As an example, Muhammad Ayaz, who has a physical impairment, has started a small grocery shop through the support of an Islamic Relief and SIDA-funded project. This small-scale business is operational, and he is earning income to support himself and his family. He is not dependent on others, and he is an example to other PWD and the community that PWD can earn an income.



A focus group discussion held by Islamic Relief Pakistan with a community in the Khyber Agency.

## The role of the faith community

Participants were asked if faith organisations provide support for PWD and their families, and if so, what kind of support. Participants confirmed that, unfortunately, religious institutions such as mosques or seminaries (madrassa) do not have support mechanisms in place for the wellbeing of PWD. This will take time and resources to develop, particularly given the current humanitarian situation. In addition, the religious leaders and community elders are lacking awareness about how to support PWD and how to change people's attitudes to create a more inclusive society. They preach and deliver speeches about kindness, peoples' rights, and compassion to other Muslims, but don't highlight the issues and challenges of PWD.

Due to the lack of resources and poverty, most community and faith leaders are not in a position to support these types of initiatives by themselves.

# Recommendations

Following are the key recommendations resulting from this research to help overcome stigma and discrimination towards CWD/PWD and improve social and economic inclusion. We have sought to identify priority areas where interventions are required at family, community and state level, to respond to the immediate needs of CWD/PWD.

The recommendations cover: further research to better understand the problems to be addressed; the creation of community champions and support organisations to work closely with CWD/PWD; the provision of assistive devices, and home-based rehabilitation and care services; training on disability inclusion for humanitarian and government staff, as well as campaigns to combat negative attitudes about PWD; and more specific laws, policies and services to increase education, recreation, employment and social services for CWD/PWD.

## **Further research and mapping:**

- A more detailed baseline survey (by age, gender and disability at a minimum) is needed to understand the needs of PWD in the FATA. Mapping of existing services and contact people at service providers also needs to be performed and communicated to PWD and their families and communities.

## **Community disability champions, and dedicated disabled persons support organisations:**

- A referral mechanism for PWD needs to be developed and delivered by trained community disability champions, who can identify and refer cases to service providers. Champions should reside among the target population, and be capable of mobilising PWD and their families to share their needs and possible solutions with the community. These champions should network with service providers, to improve communication and information sharing, and ensure a degree of sustainability.
- Disabled persons support organisations should be established, and staff trained and supported to work closely with PWD and to establish networks with government, service providers and donors. The formation of such organisations is essential to increase the ability of PWD and their families and communities to elevate disability-related problems to decision-makers.

## **Assistive devices, rehabilitation and care services:**

- Assistive devices need to be provided to PWD based on individual needs-based assessments, along with training for PWD and their caregivers/family members on how to use them. This will enable PWD to increase their mobility to access services and reduce exclusion.

- Home-based rehabilitation exercise sessions by qualified physiotherapists are needed to complement the distribution of assistive devices. Rehabilitation exercises would help improve the motor skills of PWD and facilitate increased mobility and independence.

- Home-based preventative care support (such as training on hygiene) should also be provided to high-risk PWD to avoid any worsening of their disability, and the associated risk of increased dependency on others.

## **Training, raising awareness and advocacy:**

- Training for humanitarian and government staff on identifying and meeting the needs of PWD is needed, to increase inclusion of PWD in humanitarian and development projects.
- Positive success stories about PWD in employment need to be developed and promoted (they do exist, but are limited).
- Comprehensive awareness and advocacy initiatives about PWD rights should be launched in co-operation with faith and community leaders to help combat stigma and discrimination.

## **Better laws, policies and services for education, recreation, employment and social services:**

- There is a need for effective new laws, policies and services to support the employment of PWD. This includes stigma and anti-discrimination laws, incentives for employers, vocational training services, job-matching support, and inclusive education and health services.
- PWD should be provided with economic opportunities including capacity-building/skills training according to their needs and interests, along with cash grants and support to start small-scale businesses.
- PWD should have access to existing social protection schemes available from the government, such as Bait-Ul-Mal support, Health Card, and the Benazir Income Support Programme.
- CWD should be provided with inclusive recreational facilities, games and activities, to help them socialise and address the effects of shyness and isolation.
- Specific policies to mainstream PWD in humanitarian and development projects are needed to ensure PWD receive appropriate assistance.

# End Notes

- <sup>1</sup> [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)
- <sup>2</sup> [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/frequently-asked-questions-regarding-the-convention-on-the-rights-of-persons-with-disabilities.html#sqc3](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/frequently-asked-questions-regarding-the-convention-on-the-rights-of-persons-with-disabilities.html#sqc3)
- <sup>3</sup> The World Health Organization, *World Report on Disability*, (2011)
- <sup>4</sup> Ibid., page 29
- <sup>5</sup> Based on a total population estimated by the WHO at 193 million in 2016 <http://www.who.int/countries/pak/en/>
- <sup>6</sup> The World Health Organization, *World Report on Disability*, (2011), pages 144 - 147
- <sup>7</sup> Population Census Organization, Government of Pakistan, *Report on National Census of Pakistan*, (1998)
- <sup>8</sup> [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)
- <sup>9</sup> *General Comment No.6 on Equality and Non-Discrimination* <http://ohrh.law.ox.ac.uk/crpd-committee-adopts-new-general-comment-on-equality-and-non-discrimination/>
- <sup>10</sup> [www.mofa.gov.pk/contentlist.php](http://www.mofa.gov.pk/contentlist.php)
- <sup>11</sup> [www.ilo.org/dyn/natlex/docs/ELECTRONIC/50075/97325/F1697756412/PAK50075.pdf](http://www.ilo.org/dyn/natlex/docs/ELECTRONIC/50075/97325/F1697756412/PAK50075.pdf)
- <sup>12</sup> The British Council, *Moving from the Margins: Mainstreaming Persons with Disabilities in Pakistan*, (2014), page 5
- <sup>13</sup> Ibid.
- <sup>14</sup> Ibid.
- <sup>15</sup> [https://reliefweb.int/sites/reliefweb.int/files/resources/pak708\\_conflict\\_idps\\_fatakp\\_v66\\_a3\\_p\\_20180413.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/pak708_conflict_idps_fatakp_v66_a3_p_20180413.pdf)
- <sup>16</sup> CWD/PWD were asked if they experienced difficulties with walking, seeing, hearing, self-care, communication or remembering/concentrating. Response categories were 'no difficulty', 'some difficulty', 'a lot of difficulty' and 'cannot do' for each question. [www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/](http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/).
- <sup>17</sup> [www.kobotoolbox.org/](http://www.kobotoolbox.org/)
- <sup>18</sup> Disability was assessed using the six Washington Group Short Set questions.





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