# Moving from the margins

# Mainstreaming persons with disabilities in Pakistan

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# Foreword

*Moving from the margins: Mainstreaming persons with disabilities in Pakistan* examines the challenges, opportunities and policy issues affecting persons with disabilities in Pakistan. For a country that could have as many as 27m persons with disabilities, only one trained psychologist or psychiatrist for every 230,000 people and a possible cost to the economy of between 4.9% and 6.3% of GDP each year, the cost of inaction is prohibitive.

Persons with disabilities are often overlooked in discussions about Pakistan's future. This is by no means peculiar to Pakistan: discrimination, exclusion and neglect of persons with disabilities are commonplace the world over. Professor Michael Stein from Harvard Law School has been heavily involved in this research and argues that most countries still have a long way to go to fulfil the promise of the UN Convention on the Rights of Persons with Disabilities (CRPD).

In the three years since Pakistan ratified the CRPD, there has been little progress towards achieving its goal for persons with disabilities to participate fully and effectively in society. Some would claim that Pakistan has many priorities it should address before this one, and it can be argued that developed countries, including the UK, should also do more to ensure social inclusion and equal opportunities for persons with disabilities.

*Moving from the margins* is one of the first attempts to consider the social model for persons with disabilities in Pakistan. The report makes strong recommendations for policymakers as well as the corporate sector and others. It advocates a comprehensive strategy through a gradual approach that includes policy intervention, awareness-raising and investment. The attitudinal, social and physical barriers faced by persons with disabilities in Pakistan also need to be challenged.

The report sets out the case for genuinely inclusive education in Pakistan. Recent estimates by UNESCO suggest that as many as 1.4m children with disabilities are left without access to either inclusive or special schools. Just getting registered as a disabled person in Pakistan can be a *disabling* experience. However, there are examples of good practice in Pakistan, from Telenor's Open Minds programme and MCR's inclusive recruitment practices to strong family systems. Marginalising persons with disabilities is more than a social, legal or moral issue—there is also a compelling economic argument for inclusion. Building on a framework developed by the World Bank, The Economist Intelligence Unit estimates that by 2018 the costs to Pakistan's economy of excluding persons with disabilities from employment could reach US\$20bn a year. The current base is US\$12bn, and these costs will continue to rise each year—that's approximately US\$5.5m per day, every day.



*Moving from the margins* provides policymakers and others with clear recommendations that can improve access for those with disabilities and—most important of all—break the vicious cycle of neglect, exclusion and cost. We recognise the difficult challenges ahead for achieving these goals in Pakistan, but the cost of inaction is too high. Pakistan is a developing country with a lot of challenges: energy shortages, persistent inflation, budget deficits and security issues. But this does not mean that we can afford to ignore millions of Pakistanis who are currently out of sight but who, if given a chance, could contribute significantly to the nation as a whole.



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# **Executive summary**

An estimated 1bn people, or 15% of the world's population, are living with disabilities. Left at the margins of society and facing a world steeped in discrimination, pity and shame, persons with disabilities have limited access to quality education and dignified employment. There is not just a human rights argument to inclusion, but also a strong economic one: the International Labour Organisation (ILO) estimates that the economic losses incurred through excluding persons with disabilities from the world of work are as high as 3-7% of global GDP.

In Pakistan, estimates of the number of persons living with disabilities vary between 3.3m and 27m, depending on whether they are based on government statistics (the last census which measured the prevalence rates was taken in 1998) or whether they come from other agencies. Pakistan did, in fact, make early attempts at including persons with disabilities in the 1980s with the introduction of education and employment policies, setting up special schools for persons with disabilities, for example, and mandating businesses to employ persons with disabilities through a quota-based system and levies. But although these were celebrated achievements in the early years, they proved to be ineffective in including persons with disabilities. Persons with disabilities still have difficulty exercising their civil and political rights, attending quality schools and finding gainful employment, among other activities. This ultimately means that they are being excluded as productive members of society, leading to economic losses of as much as US\$11.9bn-15.4bn, or 4.9-6.3% of Pakistan's GDP.<sup>1</sup>

Globally, and in Pakistan, policy approaches to disability have largely been focused on rehabilitation, welfare handouts and related charity. This has been changing since the UN Convention on the Rights of Persons with Disability (CRPD), which became operational in 2008. The CRPD offers a blueprint for a rights-based approach to mainstreaming persons with disabilities. Pakistan ratified the treaty in 2011, but progress around building an inclusive society has been slow.

To better understand the experiences and needs of persons with disabilities in Pakistan, this study by The Economist Intelligence Unit aims to offer an insight into efforts to mainstream persons with disabilities in Pakistan. The research draws on contributions from over 60 interviews conducted with experts in this field in both Pakistan and globally.

The main findings of our research are as follows.

• Pakistan needs to move away from a culture of sympathy and pity. Although there is an overarching culture of sympathy for persons with disabilities and there is a desire

<sup>1</sup> Economist Intelligence Unit estimates based on analysis by Robert L. Metts, "Disability issues, trends and recommendations for the World Bank", World Bank, 2000.



to help, the focus continues to be on a charity or medical approach to disability. What is needed instead is a shift to a rights-based approach, which recognises that persons with disabilities should be empowered. Disability is a diversity that needs to be accepted.

• Negative attitudes in society hamper finding a life partner. Marriage is an important social institution in Pakistan, and marriage prospects are different for men and women with disabilities. Where men with disabilities have better access to education and employment opportunities, they have some marriage prospects. Women, who are seen as caretakers of the household, face a more difficult time in finding a partner.

• The legal framework in Pakistan is weak as far as protecting the rights of persons with disabilities is concerned. There is only one law especially targeted at persons with disabilities, the Disabled Persons (Employment and Rehabilitation) Ordinance 1981. It specifies that employers with 100 workers or more must ensure that at least 2% of their total workforce consists of persons with disabilities, or pay a levy. Unfortunately, the monitoring and implementation of this law has been weak. Several investigations found that many large, private companies and public agencies are not meeting this requirement.

• Pakistan ratified the CRPD in 2011, but little has happened by way of policies and strategies in line with the CRPD framework. Part of this is the result of the 18th Amendment to the Constitution of Pakistan of 2010, which devolved powers to the provinces. Several plans and policy papers, as well as pending legislation that was being drafted and discussed at the federal level, became the responsibility of the provinces and have since been largely ignored. That said, government agencies consulted for this study recognise that changes need to be made, and provinces are making strides in different ways. The Punjab government, for example, is focusing on expanding educational services for persons with disabilities, and the Khyber Pakhtunkhwa government is looking to provide more in the way of employment support.

• Education for persons with disabilities is largely limited to special education schools, which are inadequate and of low quality. According to interviews with government officials, there are 330 special education schools in Islamabad, Punjab, Sindh and Khyber Pakhtunkhwa provinces. Most of these schools are in urban areas, which makes education for persons with disabilities in rural areas a challenge. Some interviewees estimate that as many as 50% of children with disabilities have access to such schools, but even where there is access, quality of education is lacking. The fees for private schools can be up to 15 times higher than for public schools, making them only accessible to wealthier families. With limited primary and secondary school education, few students go on to university. There are vocational institutes run by the government and non-governmental organisations (NGOs), but interviewees suggest that these are insufficient and varying in quality of education. There is a bidirectional link between



disability and poverty, and inclusion of persons with disabilities in schools is key in breaking the vicious cycle.

• Persons with intellectual disabilities are often entirely omitted from policies and strategies. Identification mechanisms are weak and often focused on physical impairments. There is also a shortage of mental health professionals trained to identify and rehabilitate persons with varying degrees of intellectual disorders: according to a 2008 World Health Organisation (WHO) report, there are only 0.49 trained psychologists and psychiatrists for every 100,000 in Pakistan.

• There are limited employment opportunities for persons with disabilities. This stems from several issues: (a) limited access to quality education, which later leads to limited skills for the labour market; (b) limited support for job seekers, from searching for a vacancy to drawing up a résumé and related professional documents; and (c) the attitude of businesses regarding the employment of persons with disabilities. However, there are positive examples in Pakistan of local and international companies that have successfully built an inclusive workforce.

There are several solutions to the problems outlined above. The CRPD provides a framework for the inclusion of persons with disabilities in all aspects of life, but the treaty has only recently been introduced, and changes are slow to arrive. Considering Pakistan's resources, this report suggests several changes that can happen. There is a need for the government to implement better laws and policies, for services (whether led by the government or by civil society) to be efficient and effective, and for disabled people's organisations (DPOs) to adopt a co-ordinated approach to communicating the needs of persons with disabilities. Pakistan also has a unique opportunity to be a leader from a developing country perspective in initiatives to mainstream persons with disabilities. The research recommends the following.

1. Develop a comprehensive set of laws to protect the rights and dignity of persons with disabilities in all aspects of living. This includes laws that protect the rights of persons with disabilities with regard to discrimination, education, employment, communication, infrastructure and transport, and civil rights.

2. Establish a lead government department to develop and monitor the implementation of policies that protect the rights of persons with disabilities. This should be available at both the federal and the provincial level.

3. Where resources are limited in a country such as Pakistan, it is imperative that there is an effective use of government and other stakeholder resources and funds for rehabilitation, health, education and employment services. This can be done with proper strategy development and regular monitoring.



**4. Innovative community-based mechanisms can alleviate the burden on the government.** There are successful examples in Pakistan, such as the Lady Health Worker Programme and similar community-based mechanisms, which can help in building awareness, changing attitudes and driving change.

5. Special education promotes segregation, but inclusive education, where persons with disabilities are in the same classroom as mainstream students, makes educational services more accessible. Studies also show that this has a positive impact on costs and on changing attitudes. This requires changes in school infrastructure and investment in better teacher training.

6. On employment, there is a need to build an effective ecosystem to support the employment of persons with disabilities. This includes anti-discrimination laws, incentives for employers, vocational training services and job-matching support.

7. DPOs need to work together to ensure a united front that communicates change from a rights-based approach. DPOs in Pakistan are sometimes still focused on a charity or medical approach, which are both important services, especially where the government falls short. But there needs to be a better awareness of the need for broader change.

8. Persons with disabilities must be represented in parliament. There are seats currently reserved for various minority groups, but not a single one for persons with disabilities. This will have an impact on policy development and changing society's image of persons with disabilities.

"The most important barrier to persons with disabilities is attitudes. People feel sympathy towards them but do not want to understand their capabilities, and they can be given a job and do it well. Some companies hire a disabled person but tell them to sit at home and they'll be paid a salary because the workplace lacks necessary

facilities."

Dr Shahida Sajjad, dean, Faculty of Education, University of Karachi



# **Chapter 1: Introduction**

# 1. Overview of disability in Pakistan

Persons with disabilities form Pakistan's largest overlooked minority. There are various estimates of the number of persons with disabilities living in Pakistan, ranging from 3.3m to 20m. Since Pakistan's last official count of persons with disabilities was in 1998, quantifying the size of this minority is in many ways anyone's guess.

According to the World Health Organisation (WHO), 15% of the world's population has disabilities (around 1bn people). If we take the world average and apply this to Pakistan, the number of persons with disabilities could be approximately 27m, larger than the total resident population of Sweden, Austria and Switzerland combined. In fact, the number may yet be conservative considering factors particular to the country: high poverty rates, the prevalence of endemic debilitating diseases (including malaria, dengue fever and polio), injuries sustained through natural disasters and conflict, and cultural factors that increase the likelihood of children being born with a disability.

Administrative unit	Total disabled population	Blind	Deaf/Mute	Crippled	Insane	Mentally retarded	Multiple disability	Others
Pakistan	3,286,630	8.06	7.43	18.93	6.39	7.6	8.23	43.37
Rural	2,173,999	7.92	7.53	20.52	5.94	7.32	8.23	42.55
Urban	1,112,631	8.32	7.24	15.81	7.28	8.15	8.22	44.97
Khyber Pakhtunkhwa	375,752	7.24	7.69	31.73	5.9	7.43	8.11	31.9
Rural	327,638	7.46	7.52	32.25	5.81	7.26	8.22	31.48
Urban	48,114	5.71	8.84	28.21	6.55	8.63	7.31	34.75
Punjab	1,826,623	8.48	8.17	20.83	6.75	7.87	8.07	39.84
Rural	1,338,410	8.58	8.16	20.84	6.29	7.63	8.18	40.32
Urban	488,213	8.22	8.2	20.79	7.99	8.51	7.77	38.52
Sindh	929,400	7.48	6.18	10.56	6.13	7.45	8.92	53.29
Rural	385,984	6.24	6.02	11.25	5.34	6.81	9.06	55.28
Urban	543,416	8.36	6.29	10.07	6.69	7.91	8.82	51.86
Baluchistan	146,421	8.42	5.24	14.81	4.6	5.61	6.35	54.96
Rural	117,971	7.11	5.2	14.31	4.25	5.53	6.24	57.36
Urban	28450	13.87	5.42	16.86	6.03	5.97	6.83	45.02
Islamabad	8,434	9.22	12.09	29.89	12.46	8.05	4.55	23.73
Rural	3,996	9.78	12.16	29.65	6.03	8.63	4.02	29.73
Urban	4,438	8.72	12.03	30.1	18.25	7.53	5.05	18.32

#### Persons with disabilities (percentage of total population), 1998

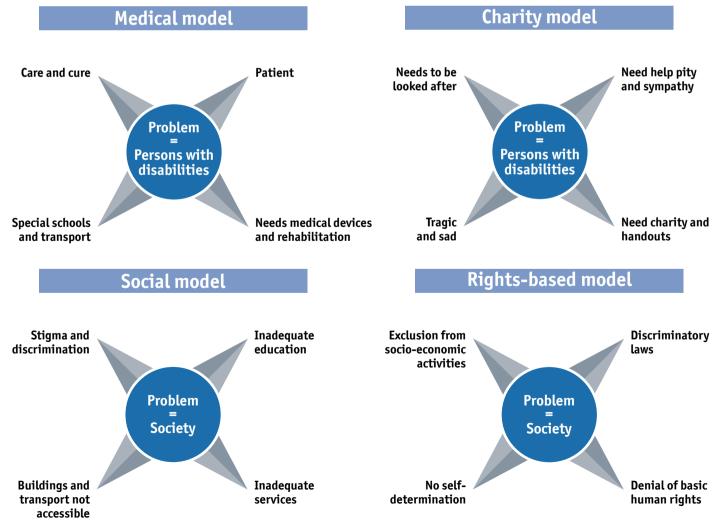
Note: The disability group classification and terminology used in this table is as per the census report.

Source: Pakistan National Census 1998.



Barriers for persons with disability exist not just in Pakistan, but in every single developed and developing country. The overarching impediment to any form of mainstreaming disability is attitudes, says Michael Stein, visiting professor of law at Harvard University and executive director of the Harvard Law School Project on Disability: "If we really have the attitude of including everyone, whether it is people with disabilities, different nationalities and religions, we can have laws that say everyone is equal and that will be enough." But the reality is that we just don't, he adds. Pakistan's use of classification groups (see table above) reflects such negative attitudes: words like "mentally retarded" to describe persons with intellectual disorders and "crippled" to describe persons with mobility issues underline the grave stigma in society.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is one step towards changing those attitudes. The Convention, which became operational in 2008, is the first human rights treaty of the 21st century and the first UN treaty protecting





the fundamental rights of persons with disability. In line with the general discourse around development-related issues today, the treaty is a move towards viewing disability from a rights-based approach. It embodies the social model of disability, which outlines that the barriers individuals face are not a result of their impairments (that the problem is not the individual), but that the barriers are created by society, attitudes and the physical environment. It goes one step beyond the social model in that it asserts that these are the rights of the individual and should be protected. This is a departure from a purely medical or charity model of simply providing assistive devices and welfare handouts, where the focus is on fixing the individual. Like all individuals, persons with disabilities should be able to lead a life with respect and dignity, as outlined by the UN Convention, and should be entitled to a broad range of life activities, including quality education, accessible spaces and the right to employment.

Pakistan ratified the CRPD in 2011, underlining the government's commitment to protecting the civil, political, social and economic rights of persons with disabilities. However, not much has changed in accordance with the framework set up in the CRPD, and millions of persons with disabilities in Pakistan are still excluded from schools and universities, jobs, healthcare and rehabilitation, and mechanisms for redress. They exist instead as an unheard, and mostly unseen, vulnerable group.

The aim of this report is to look at the challenges faced by persons with disabilities living in Pakistan and to explore solutions that facilitate becoming a mainstream member of society. Underlying all this is creating a barrier-free environment that supports a dignified life for the individual and brings broader economic benefits to the country.

# 2. Challenges around data collection

# It's a (difficult) numbers game

One of the obstacles standing in the way of obtaining accurate statistics on persons with disabilities is the failure of successive governments to carry out an exhaustive national

Study	Prevalence of disability	Note on data
1961 census of Pakistan	0.34%	Survey only for persons who were "completely blind, deaf, dumb and crippled"
1973 Housing, Economic and Demographic (HED) Survey	2.08%	Survey included data on "blind, deaf, dumb, crippled and other disabled". The survey was based on a larger sample size, which is one reason cited for the higher prevalence rate. <sup>2</sup>
1981 census of Pakistan	0.45%	Survey included persons who are "mentally retarded"
1984-85 National survey of disabled persons	4.9%	Survey included mental and physical disabilities
1998 census of Pakistan	2.54%	Survey included mental and physical disabilities

#### Disability prevalence rate in Pakistan

Sources: 1961 census of Pakistan; 1973 Housing, Economic and Demographic (HED) Survey; 1981 census of Pakistan; 1984-85 National survey of disabled persons; 1998 census of Pakistan.



census.<sup>2</sup> In addition, the various surveys that have been taken are not comparable because of their different coverage and sample sizes and because they only capture prevalence rates by gender and administrative unit. "We need more than just prevalence rates of disability," explains Atif Sheikh, president of the Islamabad-based disabled people's organisation (DPO), the Special Talent Exchange Programme (STEP). "We should ask questions around the types of impairment and the types of challenges faced in daily life. This will help define their disability."

In the absence of more recent official data, policies dealing with disability often cite the prevalence rate of the 1998 census, in which persons with disability accounted for 2.54% of the total population of 132m recorded that year. "The prevalence rate is an understatement of the highest order," says Omair Ahmad, CEO of the Network for Organisations Working for People with Disabilities, Pakistan (NOWPDP),<sup>3</sup> a nongovernmental organisation (NGO) based in Karachi. In the 16 years since the census was taken Pakistan's total population has grown to 186m. For persons with disability, this has put them at a double disadvantage: the government data in the 1998 census about the number of persons with disability were small to begin with, and while the population has grown since then, the corresponding rise in the number of persons with disability has not been accounted for.

In 2009 the Special National Identity Card (SNIC) was introduced in response to some data collection issues. The SNIC is a special category of the national identity card which carries no fee and offers modest travel discounts on state transport. By 2011 the National Database and Registration Authority (NADRA), the body which handles personal data for the government and issues the cards, had registered over 600,000 people.<sup>4</sup> Of these, 334,000 had physical disabilities, 125,973 had intellectual disabilities, 85,254 had visual impairments and 93,869 had hearing or speech impairments. This was seen as an achievement, drawing hitherto marginalised people into the system for the first time. But the numbers still fall considerably short of registering most persons with disability in Pakistan, and they do not include children who are too young to apply for an identity card. Registration drives in cities like Karachi have seen spurts of encouraging activity that have come to a halt after changes in government. The registration process is time-consuming, and public buildings at which a person would register are sometimes not accessible, according to Saima Aslam, director of project management at the Saaya Association, a DPO in Islamabad. "One first needs to have a disability certificate, which takes about 3-5 months to process. And then getting the ID card thereafter takes another 1-3 months," she says about the arduous process. Marriyum Aurangzeb, parliamentary secretary for the interior and NADRA, acknowledges some of these challenges. "We have taken some of these issues very seriously, and soon we will build ramps for wheelchairs and have a facilitation desk for persons with disability," she says.

<sup>2</sup> http://www.sdpi.org/ publications/files/W13-Disabled%20Population%20 in%20Pakistan.pdf

<sup>3</sup> Interview with The Economist Intelligence Unit in Karachi on March 19th 2014.

<sup>4</sup> Express Tribune, January 8th 2011, http://tribune. com.pk/story/100682/ nadra-registeredphysically-challengedpeople-top-639096/



# 3. The socio-cultural dimension to disability in Pakistan

### Stigma and shame

Another challenge for data collection and meaningful policy changes is that individuals and families are reluctant to admit disability. "Disability is a stigma in Pakistan, and culture norms are a hindrance to [inclusion]," says Farooq A Rathore, a faculty member at the CMH-Lahore Medical College. In the deeply conservative circles of Pakistani society a person who is born with or develops a disability may be perceived as suffering from an affliction from God. The family can often retreat into a state of shame, fearing that they have been punished for some misdeed or placed in adversity as a test of their faith.

The stigma is so potent that families can resort to hiding their children, or in cases where the disability is mild or less pronounced, deny that there is any disability at all. Mr Sheikh of STEP recounts an incident where he visited a family in a village and spoke to a father of four children with hearing impairments. "He told me his children were not disabled, which was so confusing to me. And when I asked why, he said 'They're not disabled, they are earning very well!' There is an unwillingness to recognise disability." As Mr Sheikh explains: "We only think a person is disabled when he or she is not economically productive." These factors further compound problems related to data collection.

#### Hidden and forgotten

The grave lack of sensitivity when dealing with persons with disability often means that they are denied access to even the most basic services. It has often been the case that

#### Islam and disability

Religion does influence culture and daily life, and so any discussion about disability in Pakistan is incomplete without also discussing the dominant religion in the country, Islam. According to Mohammed Ghaly, professor of Islam and biomedical ethics at the Hamad Bin Khalifa University in Qatar, Islam outlines that, in principle, persons with disabilities are on an equal footing with able-bodied individuals: "The Quran speaks about the dignity of the children of Adam, and the children of Adam includes Muslims and non-Muslims, rich and poor, healthy and sick, people with disabilities, with no disabilities, etc. It includes every human being. So dignity is conferred upon human beings unconditionally."

He adds that according to Islamic history, there were innovative hospitals created in the first

century which were dedicated exclusively to people with disabilities. And after leaving these hospitals they were given money to help them transition and lead their lives again, he adds. In fact, historical biographies show prominent people with disabilities contributing to society as poets, judges and writers. "They had access to education and were not excluded from society. The Islamic texts are not discriminatory to persons with disabilities."

He adds, however, that religion is not the whole story. These virtues and ideas need to be transposed into the laws of a country. But many of these countries lack the resources and capacity to enact effective laws to protect the rights of individuals.



instead of sending children to the few "special education schools" that exist in Pakistan, they may be kept at home without education or dispatched to a madrasa, where they are given religious instructions by rote learning.

When the disability rights group NOWPDP visited a series of villages in the largest province of Punjab, this was a recurring trend. "There we realised that people don't take their hearing-impaired and intellectually challenged children out of their homes," says Zulqarnain Asghar, a visually impaired clinical psychologist who works with NOWPDP. "Visually impaired children are sent to madrasas and mosques, but hearing-impaired and intellectually challenged children are kept inside the homes." Sadia Mumtaz, a lawyer and founder of the Karachi-based NGO Inclusive Society, echoes similar experiences. While her team was working in Machar Colony, one of the poorest slums in Karachi with a high prevalence of intellectual disorders, children were chained up while parents went out to work.

According to some austere social traditions, children with disabilities are seen principally as objects of pity. "They say we should get prayers from people with disabilities because their prayers will be heard," says Abid Lashari, head of the Nawabshah Disability Forum based in rural Sindh. Even in Pakistan's largest cities, there is a dominant impulse to see persons with disability as deserving of charity rather than equality (this idea is further entrenched because persons with disabilities are often seen working as street beggars). When politicians wish to make a gesture of support for persons with disability, it typically involves the distribution of free wheelchairs or walking canes in front of television cameras. This, in turn, creates a hierarchy of disabilities, where the most visible physical disabilities receive most of what limited attention is available. Persons with hearing, visual or speech impairments get some attention, and persons with mental disorders receive almost no attention at all.<sup>5</sup>

#### The power of language

Stigma is a major reason why barriers in society remain, and changing the language used to describe disability plays a big part in removing those barriers. In Pakistan, persons with disabilities are still referred to in derogatory terms such as "crippled" and "mentally retarded". There are also learning institutions using these terms in their names. Globally, the nomenclature around persons with disabilities has shifted from "disabled person" or "handicapped person" to "person with disability". Dr Maryam Mallick, technical adviser on disabilities and rehabilitation, WHO Pakistan, explains that using the word "person" acknowledges that he or she is first a human being and then a person who has an impairment. The term "persons with disabilities" is also used in the CRPD. However, in rural areas, and even in cities, people still use extremely derogatory terms. The government is also using archaic terms such as "disabled persons" and "special persons".

<sup>5</sup> James I Charlton, Nothing About Us Without Us: Disability Oppression And Empowerment. University of California Press, August 2000.



In some societies, the negative words used to describe persons with disabilities have been the driving force reducing the stigma. Professor Stein of Harvard University recounts his experience in drafting a disability law in Vietnam. "The community there said: 'We know we are not going to get all these rights for ages and ages, but we're tired of being called this horrible word. We'd like a word that has dignity in it and that will mean more to us on a daily basis'." In Pakistan, persons with disability experience similar derogatory words, but with no credible mechanism to voice their concerns, they only suffer in silence. One Peshawar resident interviewed for this study could not even utter the words he had been called. "As a child, the names were very painful. And as you grow older, things change, but not because the perception has changed, but maybe they are scared of you. These days, kids on the streets call me the one-legged man, and others call me 'good for nothing'."

### Marriage is a challenge

Attitudinal barriers also play a role in marriage, but the experience is different for men and women. For the few men with disabilities who successfully complete school and university, their families accept that they will pursue a career and, alongside it, marriage. In a culture where arranged marriages are common, family background and job status are of paramount importance. Muhammad Ameen Memon, examinations operations officer at the British Council, for example, managed to convince his future parents-in-law that he was worthy of taking their daughter's hand only after he had graduated and had secured a job as cultural ambassador for Pakistan to the US. Mr Memon has a slight squint in his eye and is unable to read small print. In many ways, he admits, this is not a major impairment, but there was still hesitation from the family: "If you have any type of shortcoming, the culture here is that you have to prove yourself before you get something."

But even when men with disabilities have impressive credentials, the broader social stigma is difficult to overcome. "My father-in-law asked: What would people think about me if I allowed my daughter to marry visually impaired person?" says Mr Asghar of NOWPDP, a visually impaired clinical psychologist who married another clinical psychologist.

In rural areas, the story is bleaker. Ghulam Nabi Nizamani, chairman of CBR Asia Pacific Network and head of the All Sanghar Handicaps Association (ASHA), explains that with fewer schools educational attainment is lower, and economic opportunities, which are already limited in villages, are even slimmer. Individuals with disabilities tend to marry someone with the same disability. "I got married at 16, when child marriages were still common. At that time, living in a rural area, persons with disabilities had marriage prospects. But today, as rural people have gained some knowledge about disability and that marrying someone with a disability might result in children with disabilities,



marriage for persons with disabilities living in rural areas is difficult. They tend to marry each other, or not at all."

For women, there is double discrimination. It could be said that the only thing tougher than being a girl in Pakistan is being a girl with a disability in Pakistan. They have limited access to education, employment and face challenges in finding a life partner. Abia Akram, chair of Pakistan's National Forum of Women with Disabilities, explains that parents tend not to send a daughter with a disability to school for fear of harassment (especially when she requires someone to help her when moving from a wheelchair to a seat, for example). With limited education, there are even fewer options for gainful employment. As a result, these women remain in the family as caretakers of the household, and depending on the nature of their impairment, housework can be difficult.

Marriage is especially difficult for women with disabilities: "Culturally, marriage is seen as an important life goal for women in Pakistan, and women are important in keeping the house together, handling the chores and cooking. But when women have a disability, whether it is physical, hearing, speech or intellectual, she is seen as unable to fulfil these duties and a burden," explains Ms Akram. There are no official estimates of the number of women with disability who are employed or married, but she admits that both marriage and employment prospects are significantly better for men who have disabilities. Muniba Khurram, an artist who lost the use of her legs after a car accident six years ago, admits that if she had not been married before her accident, she would have remained a spinster all her life. There is a fear that children born to women with disabilities may also have disabilities, and her other siblings could face a similar stigma: "If somebody is bringing a proposal for a sibling, the matchmaker woman will usually tell the disabled woman to go inside the room and don't come out or people will see her and her sisters won't get married," Ms Akram explains.

When they do find life partners, it is more common that women marry partners who also have a disability. For some types of disabilities, such as speech or hearing impairments, marrying someone with a similar disability makes for a more harmonious partnership. Mushtaq Butt, president of the Sir Syed Deaf Association who is himself hearing-impaired, says that he has seen many marriages fail where a hearing-impaired individual married someone with normal hearing. "In Pakistan, if I am deaf, my parents would love it if I married a 'normal' girl, but they don't understand that communication will be a very big issue." Mr Butt is now over 50 years old and married to his university sweetheart, who is also hearing-impaired. Besides running vocational training programmes at the Sir Syed Deaf Association, he helps to arrange marriages. He recounts several stories where his friends with hearing impairments married "normal" girls, only to get divorced. "Now they are married to girls with similar impairments and they are so happy," he adds.



However, there are also problems when two people who both have disabilities get married, says Mr Nizamani, who works in rural areas of Sindh province: "I know of many men and women with disabilities who do not find a partner. And when they find a partner without a disability, they somehow feel less secure, that their marriage is less sustainable. So they marry each other, but then you do not have an inclusive society." These unions are often arranged, and since marriage is an important cultural institution in Pakistan, families believe that any marriage is better than no marriage at all.

# It's about the culture

Many challenges facing persons with disabilities in Pakistan are rooted in social stigma and negative attitudes. Muniba Khurram, for example, often gets stares in public as she moves around the streets of Islamabad in a wheelchair, doing her shopping with her threeyear-old son on her lap. "I wear a shirt, jeans, lipstick. I do my nails. This is my life, and I'm here to prove people's misconceptions about disability wrong. I look so different [for a person with a disability] that people often ask if I am from Pakistan or the US."

Changing attitudes is difficult and will take a long time. But experts agree that change is already happening. "If you had asked me ten years ago how optimistic I was about change, I would have said not optimistic at all. But today I am very optimistic. There is still a lot that needs to be changed, but it is happening," says Dr Mallick of the WHO.

"The willingness is not there. We have five star hotels that are bound to have arrangements but do not have facilities for persons with disability—why? They can afford it, they have the exposure and there is an obligation to do it, but they do not."

Marriyum Aurangzeb, parliamentary secretary, Ministry of Interior, Pakistan



# Chapter 2: Legal and policy framework

The social model of disability explains that persons with disabilities are excluded from society not because of their impairments, but as a result of attitudinal and environmental barriers that impede their ability to participate in the economic, social and cultural activities of daily life. Fundamental to removing these barriers is enacting laws and effective policies that protect the rights of persons with disabilities. The legal framework—from education, employment, healthcare and communication to transport—needs amendments by way of adding specific articles that protect the rights of persons with disabilities. States often take charity or medical approaches to disability by providing piecemeal facilities and relief through policies and initiatives, instead of adopting a comprehensive and holistic rights-based approach to integrating persons with disabilities into mainstream society.

In Pakistan, there is no comprehensive law protecting the rights of persons with disabilities. The one and only piece of legislation that exists for persons with disability was passed in 1981 and focuses on employment and segregated education (in the form of special education schools). In the 33 years since then only minor adjustments have been made to the law, and it continues to be poorly implemented. Meanwhile, a number of policies and plans have been drafted, but once again, they remain only on paper. The law, policies and plans squarely underline a medical and charity approach to disability.

This chapter will outline an overview of the legal and policy apparatus related to disability in Pakistan, and specify the gaps in the country's laws by analysing the framework outlined by the CRPD.

# **1.** History of legal and regulatory framework for persons with disabilities in Pakistan

# 1981 and beyond: A historical review of disability in Pakistan

The year 1981 was proclaimed by the United Nations as the International Year of Disability. It called for equal rights and opportunities for persons with disability and in many ways was a prelude to the CRPD. "Back then, Pakistan was almost at the top of the table in terms of efforts around the rights of persons with disabilities," explains Mr Sheikh of STEP. Under the leadership of Pakistan's military ruler, General Muhammad Zia-ul-Haq, who himself had a daughter with a disability, the country established a Ministry of Social Welfare and Special Education, which opened over 100 schools offering special education to children, and a National Council for the Rehabilitation of Disabled Persons, which was tasked with designing policies for the rehabilitation of persons with disabilities. The government also introduced national vocational training centres for disabled persons and a National Trust for the Disabled.



The first law dealing specifically with disability in Pakistan was also passed that year: the Disabled Persons (Employment and Rehabilitation) Ordinance 1981 (or Employment and Rehabilitation Ordinance 1981). Under this ordinance, all government agencies and companies employing at least 100 individuals were required to ensure at least 1% of their workforce were persons with disabilities (today this is 2%), or pay a penalty of Rs1,000 (US\$10) per month. There are, however, gaps.

Ms Mumtaz of the Inclusive Society explains that jobseekers have to go through several tiresome procedures: "They are first required to register with their local employment exchange office and then undergo a medical assessment to determine their fitness for employment. The medical board can also prescribe the types of jobs persons with disabilities may undertake, which limits their right to the freedom of choice." Further to this, the medical board was focused on physical disabilities, which left persons with intellectual disabilities excluded from the legal provisions, she adds.

The activity and enthusiasm of the early 1980s, however, was followed by a long spell of inertia: "There was complete silence for the next 20 years. All we had were these special education centres and a quota for employment," according to Mr Sheikh. This was the

#### In Brief: The National Plan of Action of 2006

Some of the short-term objectives of the National Plan of Action for persons with disabilities included:

- Establishment of a data bank
- Sample surveys of persons with disabilities in selected districts
- Reduction in incidence of disabilities through primary and secondary preventive care
- Strengthening of disability prevention programmes
- Arrangements for early detection and institutional interventions
- Escalating medical rehabilitation services
- Promoting inclusive education
- Expanding and reinforcing vocational training
- Employment, including self-employment
- Legislative support to persons with disabilities
- Boosting public opinion and increasing support to non-governmental organisations.

Long-term objectives included:

• Creation of barrier-free physical environment for persons with disabilities in all public, private and commercial buildings and public places and revision of construction by-laws.

• More effective enforcement and expansion of social assistance and social security programme under the provisions of existing laws would be beneficial.



time, however, when Pakistan's disabled people's organisations (DPOs) were at their most active, and the strong disability movement in Pakistan led to the first National Policy for Persons with Disabilities in 2002. The policy was a comprehensive document with guiding principles and strategies, with the focus on empowering persons with disability. The policy was prepared in consultation with the health, education, labour, housing and science and technology ministries, as well as relevant NGOs and DPOs.

Four years later the National Plan of Action of 2006 was introduced to provide a roadmap for implementing the policy. It identified "17 critical areas of intervention from assessment of the magnitude of the problem to service delivery systems" and spelt out "short-term steps to be taken by the end of June 2009 and long-term measures to be adopted by July 2025".<sup>6</sup>

Unfortunately, the Plan of Action never took root because the 18th Amendment to the Constitution devolved power from the federal government to the provinces soon after.

### The impact of the 18th Amendment

The 18th Amendment to the Constitution in 2010 fundamentally altered the division of legislative powers, granting provincial assemblies exclusive legislative powers on a variety of issues, including social welfare, mental illness, workers' welfare, employer liability and education. As legislative power and administrative control became more dispersed, ministerial departments and responsibility became a murky area. Before devolution, many issues relating to disability were dealt with by the Ministry of Social Welfare and Special Education at the federal level.<sup>7</sup> After devolution this became a confusing patchwork, with each province working through different agencies. In Punjab, for example, the Special Education Department was given general responsibility for matters relating to special education, including the formulation of policy and law, teacher training, social integration, education, curriculum development and vocational training of children with special needs. But because disability is a cross-cutting issue, some functions were also shared with departments of human rights and women's development. The Social Welfare Department oversees the registration, assessment, training and employment of persons with disabilities and financial assistance to the poor and disabled, while the Department of Human Rights is responsible for human rights violations, including violations faced by persons with disabilities. Administrative functions were also shared: the Punjab Fund for the Rehabilitation of Special Persons was established under the Special Education Department, while the Punjab Welfare Trust for the Disabled operates under the Social Welfare Department. Responsibility for the implementation of the Employment and Rehabilitation Ordinance of 1981 is therefore shared between the labour, special education and social welfare departments in various ministries.

<sup>6</sup> Network of Organisations Working for Persons with Disabilities, Pakistan (2008); A report on the status of persons with disabilities and the way forward.

<sup>7</sup> The Ministry of Social Welfare and Special Education at the federal level was not exclusively in charge, but it influenced policy more than any other government agency.



# 2. Overview of legal provisions for persons with disabilities

# No will, no clue

Part of the problem is a lack of political will to have a department that specifically handles disability affairs. With shared responsibilities, there is confusion among persons with disabilities about where they can seek redress. If they approach the Department of Special Education, they are told that it only deals with education for children with disabilities, says Mr Lashari of the Nawabshah Disability Forum. And when they approach the Department of Social Welfare, they are told certain issues and complaints do not fall under its jurisdiction. There is an official redress mechanism in each province – the Provincial Council for the Rehabilitation of the Disabled Persons - but many find it ineffective. Ayaz Khan, president of Special Life Foundation, estimates that as many 85% of people who lodge a complaint via these channels in Khyber Pakhtunkhwa province do not even get a response. And when they do, says Qari Saad Noor of the Peshawar-based Pakistan Association of the Blind, all they get is Rs5,000 (US\$50) at the end of the year. "I told them that Rs5,000 is not just injustice, it is insanity!" he adds.

Capacity is lacking in Pakistan. Government departments are understaffed, and where there are bureaucrats, individuals working on disability affairs are not well trained. "We've only introduced special university courses in education some 20 years ago. Before this, earlier bureaucrats came from general education or social welfare backgrounds. In other countries, governments employ qualified people and experts for each department," explains Shahid Ahmed Memon, chairman of the Pakistan Disabled Foundation, speaking about bureaucrats in the special education departments. As a result, many of the current top bureaucrats are still clueless about the specific needs of persons with disabilities.

For individuals who have resources, they take the matter to court. "The courts are open, but you need a lot of money, and the procedure is very long. A visually impaired person I know has been fighting for three years in the courts because he was discriminated against on the basis of his disability for a job he was qualified for," explains Mr Memon. There is no anti-discrimination law in Pakistan, which makes cases such as these more difficult to fight in the courts.

Another reason for the lack of access to redress and real progress towards enacting a comprehensive law is the absence of parliamentary representation. Although women and ethnic minorities are represented in parliament, there is not one seat reserved for persons with disabilities. Uganda is often described as a role model as a developing country in this regard, although the implementation of many of its laws and policies continues to be a problem. There are five seats in the Ugandan parliament which are reserved for persons with disability,<sup>8</sup> and the rights of persons with disabilities are explicitly enshrined in the 1995 Constitution of Uganda and in the Persons with Disabilities Act 2006. Sign language

<sup>8</sup> http://www.parliament. go.ug/new/index.php/ about-parliament/ composition-of-parliament



and braille are recognised as official languages in parliament, the courts of law and official documents.

# Limited in scope

The scope of coverage for persons with disabilities is not broad. Different pieces of legislation provide for rehabilitation, training and employment, financial assistance, the manner of detention in psychiatric or other facilities, protection from abuse and inhuman treatment, and compensation for injuries. Anti-discriminatory legislation mandating equal treatment for persons with disabilities, laws on early detection and intervention services for children with disabilities and standards in special education are missing.

#### Education

The Constitution declares primary education to be a fundamental right. Provincial laws, such as the Punjab Compulsory Primary Education Act 1994 and the recently enacted Sindh Right of Children to Free and Compulsory Education Act 2013, provide for the education of young children but make no reference to the educational needs of children with disabilities. The Sindh Right of Children to Free and Compulsory Education Act is probably the first statute to define special education as "educational programmes and practices designed for students, as handicapped or gifted students, whose mental ability, physical ability, emotional functioning, require special teaching approaches, equipment, or care within or outside a regular classroom". The definition is progressive in that it recognises that differentiated teaching approaches may be required either within or outside a regular classroom for children with disabilities. Unfortunately, this is not incorporated in any other provision of the statute, rendering it meaningless.

#### Financial assistance

Financial assistance for persons with disabilities and the poor is the focus of several social welfare laws. The Zakat and Ushr ordinances offer assistance for medical and educational expenditure, and the Pakistan Bait ul Maal Act provides medical, educational, housing and general assistance to the poor or persons with disabilities. The recently introduced Benazir Income Support Programme (BISP) Ordinance aims to enhance the financial capacity of the poor and persons with disabilities through a variety of schemes covering health, microfinance, education and general assistance.

#### Rehabilitation, training and employment

The Employment Ordinance governs the rehabilitation, training, employment and financial support for persons with disabilities. As discussed, this is broadly a quota system of employment, and where employers do not meet the 2% quota (the original 1981 ordinance stipulated 1%), they pay a penalty of Rs1,000 (US\$10) into a Rehabilitation Fund. The quota system, however, is not well implemented. This is discussed in further detail in Chapter 4.



#### Workmen's Compensation Act 1923

The Workmen's Compensation Act 1923 governs the payment of compensation to employees injured in the workplace. The law provides for compensation for partial or total disablement where an injury temporarily or permanently reduces the workman's earning capacity in any employment in which he was engaged at the time of the accident. Compensation is also provided where total disablement incapacitates a workman, temporarily or permanently, for all work which he was capable of. The law is outdated and in need of revision to cover a broader range of employers and employees and to provide compensation for injuries that are not of a physical nature.

#### Care, treatment and detention of persons with intellectual disabilities

The Mental Health Act is no longer in force in Punjab, Baluchistan and Khyber Pakhtunkhwa. The Sindh provincial assembly enacted the Mental Health Ordinance in 2013 with revisions included after lobbying by the Pakistan Association of Mental Health. Unfortunately, the Sindh Ordinance redefines mental disorders narrowly and excludes mental impairment from the scope of the law. The revision marks a major shift from the Mental Health Act in the UK, on which Pakistan's Mental Health Act was based. This means that persons with intellectual disabilities have no legal protection against inhumane treatment inside and outside treatment facilities in Sindh, and healthcare professionals are free from liability if they provide inadequate treatment.

#### Healthcare

In Pakistan, accessibility and quality of healthcare services are largely determined by an individual's socio-economic and geographical conditions. Persons with disabilities in rural areas and without the financial means to pay for disability-related services, which are often required on a long-term basis, are not protected by the law to receive state-funded disability-related quality services. Since the prevalence of disability is higher in rural communities, a significant demand for service delivery remains unmet. Government healthcare policies demonstrate a gap in recognising the general or disability-related healthcare needs of persons with disabilities. For instance, the Health Sector Strategy 2012-20 for Sindh recognises mental health as a special area of focus, but it does not address the healthcare needs of persons with disabilities. This situation is similar in Punjab. Such exclusion of the identification, prevention and treatment of disabilities and service delivery for persons with disabilities goes against some of the objectives of the National Policy for Persons with Disabilities of 2002.

This, once again, underlines the lack of co-ordination between various ministries. Persons with disabilities may receive financial assistance to cover healthcare costs through the Rehabilitation Fund established under the Employment Ordinance, and this is geared towards assisting persons with disabilities with assistive technologies and



medical treatment. However, it has limited capacity and cannot accommodate the large demand for support.

### Welfare in Pakistan: A two-track system

In the absence of a strong legal framework there exists a parallel system that offers an alternative protection programme: the family. Persons with disabilities are often cared for by their parents, siblings and the wider family network. It's a very strong system, according to Mr Sheikh, but he adds that the attitude is "overly sympathetic". "Parents would often say: I hope I die before my child dies. If I go, who will look after him?"

Part of this is a culture heavily based on kinship: "People support each other, and this is called the maintenance system in Arabic, which is obligatory. In that sense, one can say that the state remains largely out of the picture," explains Mohammed Ghaly, professor of Islam and biomedical ethics at Hamad Bin Khalifa University in Qatar. However, when Muslim-majority countries embraced the idea of modern statehood, they failed to embrace the welfare role that states now play, Professor Ghaly adds. This has created a gap in provision by the state. Part of the problem is, of course, that many of these countries also happen to be low-resource countries that simply do not have the means to offer the same social welfare protection that rich-world countries afford their citizens. However, the focus should not be solely on a social welfare protection programme, which again is based on the charity approach to disability; the focus should be on developing a rightsbased approach to empowering individuals and removing barriers and discrimination. Welfare programmes are important, but should still be viewed in terms of a rights-based approach of "what comes next". Beyond simply giving money or a wheelchair, countries need to be thinking about general accessibility and access to education and employment. The CRPD outlines a framework for thinking along the lines of a holistic approach that views inclusion throughout the lifecycle.

# 3. The CRPD and its implementation in Pakistan

The CRPD was adopted by consensus by the General Assembly in December 2006 and entered into force in 2008. Pakistan ratified the Convention in 2011. The CRPD is a comprehensive, detailed and overarching framework that promotes and protects the "full and equal enjoyment of all human rights and fundamental freedoms" by persons with disabilities and "respect for their inherent dignity".

On ratification, the obligation is to implement the treaty in two ways. The first is to ensure that the civil and political rights, such as the right to vote, the right to liberty of a person and the right not to be tortured are immediately protected. In Pakistan, some of these rights are still missing. On voting, for example, Khurram

#### Ratification of CRPD, selected countries

Country	Ratification date
India	1 October 2007
Bangladesh	20 November 2007
Maldives	5 April 2010
Nepal	7 May 2010
Pakistan	5 July 2011
Afghanistan	18 September 2012
Sri Lanka	Not ratified
Source: UN Enable.	



Badar Alam, project officer, voter education at the International Foundation of Electoral Systems (IFES), an international NGO, says that persons with disabilities are excluded: "Persons with physical impairments sometimes have difficulties coming to the polling stations." But the bigger problem, he says, is a lack of information about their electoral rights that keeps them from exercising their right to vote. "In urban areas, people have access to information. But in rural areas, where the means of communication are not that advanced, persons with disabilities lack the right information. Also, their low levels of good education keep them at the margins."

The second type of rights, which are economic and social in nature, are subject to progressive implementation. "The state must do as much as it can, as soon as it can on issues related to education, sanitation, standard of living and employment. It needs to have timelines and action plans on how to put this into effect," explains Professor Stein of Harvard University. States are then required to submit a report three years from the time of their ratification, and reflect on where they have made positive strides and identify areas where they have yet to improve. "But the treaty went into operation in 2008, and it is honestly too soon to say that something is moving this big social structure. We just haven't had time to assess it."

The CRPD is nonetheless a critical document—a blueprint for applying the human rights approach to disability. Unfortunately, not much has materialised in Pakistan since the ratification of the Convention. Interviewees lament that the government seems to consider the CRPD as a law in itself, instead of using the framework to amend laws and implement strategies.

With lack of progress by the government, civil society leaders have tried to drive positive change, but the changes since devolution have made that difficult. "After the 18th Amendment there was no ministry at the federal level in charge of disability. So we tried to work with the Ministry of Human Rights, because they were working on several labour, women and child conventions. But after the elections we had a new government that merged human rights with law and justice. So now we have to start work all over again with the Ministry of Law and Justice," says Asim Zafar, president of the Saaya Association. Some civil society groups have made better headway in Khyber Pakhtunkhwa, where the government recently passed an ordinance to set up a board on disability that will oversee the use of a disability fund. The main use of the fund will be to provide assistive devices and also create employment opportunities. On the latter, however, experts say the government does not have a clear strategy.

# 4. Applying the Convention in Pakistan: Exploring the gaps

The CRPD offers a comprehensive framework for thinking about integrating persons with disabilities into mainstream society. In this section, we analyse some of the Convention's main articles and highlight gaps evident in Pakistan.



# Defining disability: "I'm not special"

The CRPD does not define disability, but recognises it as an "evolving concept" that "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."<sup>9</sup> This is squarely in the social model of disability that does not see the problem with the individual. The Employment and Rehabilitation Ordinance of 1981, however, defines disability as an impairment, and also fails to consider psycho-social disabilities and intellectual disorders such as autism. Moving towards the social model of disability would thus first require using the right definitions, including moving away from terms such as "special persons", which perpetuate discrimination and enforce sympathy. In fact, individuals interviewed for this study were especially offended by always being called "special". "Why do you refer to us as special people? Do we have horns on our head? At least give us equal rights. You don't give me equal rights and representation, and all you give me is a wheelchair, and that makes me special?" asks Mr Saad Noor of the Pakistan Association of the Blind.

### Women and children need protection

The Convention requires governments to adopt specific measures to advance and empower women and children with disabilities. It converges with other international treaties affecting women and children, such as the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child. Pakistan has recently enacted laws protecting women against acid crimes and their rights in the workplace in light of the CEDAW. These, however, need to be revised to afford specific protection to women with disabilities in Pakistan.

Ms Akram from the National Forum of Women with Disabilities points out that the 2002 National Policy does not contain a single word about women with disabilities. She regularly has conversations with DPOs, national and international NGOs and the government on the subject of including women with disabilities in these policies and laws. "We are not asking them to start specific policies for women with disabilities, we are just asking them to consider women with disabilities as a mandatory part of all activities. This means thinking about women with disabilities in any proposal or policy they are drafting." She admits that it has been difficult, especially when most representatives of DPOs in Pakistan are men. "Step by step we are doing more work, and change will happen."

For children with disabilities, the CRPD outlines that state parties should ensure that such children are educated through an "inclusive education system at all levels" that is non-discriminatory and based on equal opportunity to "develop the personality, talents and creativity … mental and physical abilities, to their fullest potential."<sup>10</sup> In Pakistan, there is a separation between mainstream education and special education, which goes against the framework set out in the Convention. While some ideas of inclusive education

<sup>9</sup> Preamble to the CRPD.

<sup>10</sup> CRPD, Article 24.



were articulated in the National Policy of 2002 and the Plan of Action of 2006, such as formulating an inclusive education policy and establishing a National Curriculum Committee on Disability to standardise specific curriculums for education and diploma courses, the 2006 Plan of Action assumes that children who are "severely handicapped" and "moderately severely handicapped" will require special schools. A disability spectrum for the purpose of education runs counter to the concept of inclusion, explains Ms Mumtaz of the Inclusive Society. "The terms 'severely' and 'moderately severely handicapped' are also left undefined in the 2006 Plan and endorse the medical model of disability," she adds. As the physical and intellectual disorders children face are wide-ranging and assessment costs prohibitive, there is a good chance that a large number of children are incorrectly diagnosed.

### Not just any employment

The right to work transcends the right to simply getting a job; it should encompass the right to have a meaningful and gainful occupation. According to Article 27 of the CRPD, a person with a disability should have the opportunity to freely choose an occupation based on his or her capabilities. Parts of Pakistan's National Policy for Persons with Disabilities 2002, however, are discriminatory: the sheltered workshops it identifies for the employment of persons with disabilities are isolating, the pay is poor and there are no opportunities for promotion.

In accordance with the CRPD, the Rehabilitation and Employment Ordinance of 1981 needs significant and extensive changes to address discrimination in various aspects of employment, including hiring, salaries, promotional opportunities and retirement, as well as other conditions of employment, including health and safety and the exercise of labour and trade union rights on an equal basis with others. These concepts are currently missing in the law.

# Still inaccessible

The CRPD outlines that persons with disabilities should be able to access, on an equal basis with others, the physical environment, transport, information and communications. This means an unrestricted environment where assistive technology, interpreters, ramps, placement of door handles and other means of support make public and work places accessible.

Pakistan embraced the principle of accessibility in the Special Citizens Act 2008 (currently pending), which seeks to make public places and transport accessible for persons with disabilities. The act makes no reference to access to information and communications technology (ICT), but requires buildings in public or private sectors to be wheelchair-accessible and reserved seats for persons with disabilities on public transport. Compliance has so far been limited. Shafiq Ur Rehman, president of the Lahore-



based DPO Milestone Society, explains that the Punjab government, for example, while building the new metro bus system, could have made buses accessible for persons with disabilities. "But now that they have built it, it's very difficult to make it accessible again," he laments. Political will is, thus, still lacking. Milestone Society regularly conducts audits for companies looking to make their workplace more accessible, but reports that most of its clients are international NGOs and the Pakistan Civil Aviation Authority. "We are trying to make airports more accessible. In Karachi and Islamabad we failed. But in Lahore we managed to make some progress on accessibility".

#### Humanitarian responses

The Convention outlines that states will take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, humanitarian emergencies and natural disasters. This includes refugees and internally displaced persons. Pakistan is susceptible to natural disasters, and the protection of persons with disabilities in such humanitarian responses is immensely critical. The floods of 2010, for example, affected 20m people, and the Kashmir earthquake in 2005 affected 2.5m. There is no official count of the number of persons with disabilities who were affected or displaced, but applying an average disability prevalence rate of 10% or 15% means that as many as 3m persons with disabilities were affected by the 2010 floods.

The National Disaster Management Authority, under the Prime Minister's Secretariat, is responsible for disaster management and recently introduced a Gender and Child Cell to oversee responses for vulnerable groups. "But as you can see, the name is 'gender' and 'child', it does not talk about older people or persons with disability," explains Talal Waheed, Ageing and Disability Taskforce (ADTF) co-ordinator for HelpAge International. The ADTF is a one-of-kind agency that works closely with national and international NGOs and government agencies offering training and guidance on policy formulation to include persons with disabilities. It has developed technical guidelines on risk reduction, war and shelter, and rescuing people with disabilities from emergency situations.

Working with government agencies anywhere is a slow process, explains Mr Waheed, but some positive developments can already be seen. For example, agencies have started using appropriate terminologies: "Globally, we use the term 'persons with disabilities', but they were using 'disabled people' and 'special people'. So that has now changed. Second, they accepted our changes to have a separate column for persons with disabilities in their framework of preparedness in emergencies. Also, in the social protection policy, they have a separate section for persons with disabilities and older people." Mr Waheed is optimistic about positive change ahead, but admits that a comprehensive law is much needed to protect persons with disabilities and their rights. "The lack of trained teachers with reference to special education is one of the biggest problems we have. The hindrance to special education is lack of funds and resources. Wherever there is a school, there needs to transport facilities for students."

Motasim Billah, Director, Social Welfare Department, Government of Khyber Pakhtunkhwa, Pakistan



# **Chapter 3: Education**

Education is a fundamental right of every human being, but this is often denied to children with disabilities. "It is difficult to overstate the importance of the nation's education system for children with disabilities and their families. Education is important for all children, of course," say Laudan Aron and Pamela Loprest of the Urban Institute, a policy research organisation, "but for those with disabilities ... it can mean the difference between a socially fulfilling, intellectually stimulating and economically productive life and a future with few of these qualities."<sup>11</sup> Education is also a means to reducing the discrimination and stigma faced by persons with disabilities.

Despite the positive benefits, persons with disabilities are often excluded from education early in life. According to the WHO's *World Health Survey*, which studied 51 countries, found that only 50.6% of males with disability completed primary school, compared with 61.3% of males without a disability.<sup>12</sup> The results for females were even worse: only 41.7% were found to complete primary education, compared with 52.9% for females without a disability. There are no dedicated studies in Pakistan that estimate education completion rates among persons with disabilities, but a World Bank study of persons in employment found that among employed individuals aged 18-65 in Pakistan only 27% had completed primary school, compared with 42% without disabilities.<sup>13</sup>

		Low-income	countries	High-income	countries	All count	ries
		Not disabled	Disabled	Not disabled	Disabled	Not disabled	Disabled
Male	Primary school completion	55.6%	45.6%	72.3%	61.7%	61.3%	50.6%
	Mean years of schooling	6.43	5.63	8.04	6.60	7.03	5.96
Female	Primary school completion	42.0%	32,9%	72.0%	59.3%	52.9%	41.7%
	Mean years of schooling	5.14	4.17	7.82	6.39	6.26	4.98

#### Persons with disabilities (percentage of total population), 1998

Source: World Health Organisation.

One of the main reasons for low education outcomes is that in most countries, including Pakistan, the government strategy has been to offer education for children and adults with disabilities in separate schools. This has many drawbacks, including that these facilities are accessible to only a small proportion of persons with disabilities; they are costly from a public budget standpoint and keep children excluded from the rest of society.

Other socio-economic reasons also come into play. Families may simply be too poor to send their children to school, or there are limited transport options where schools are far away. Beyond needing the means for schooling, the social stigma leads many parents to withhold their children from mainstream schooling. In some cases, especially <sup>11</sup> http://futureofchildren. org/futureofchildren/ publications/ docs/22\_01\_05.pdf

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<sup>12</sup> http://www.who.
int/disabilities/world_
report/2011/chapter7.pdf
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<sup>13</sup> http://siteresources. worldbank.org/ SOCIALPROTECTION/ Resources/SP-Discussionpapers/Disability-DP/1109. pdf



where the disability is seen as profound, children do not leave their homes. In the case of girls, families are protective and worry about harassment, especially where girls need help moving around, according to Ms Akram from the National Forum of Women with Disabilities.

There are also opportunistic parents who capitalise on the sympathy that society affords to persons with disabilities. Atif Raza from the Lahore-based Movement for the Independence of the Disabled (MID) recounts how he found a child who was begging on the streets and asked to speak with his parents. "I told his father that I would give him Rs3,000 a month (US\$30) to enrol his seven-year-old child in school instead of begging. But what his father said to me was shocking. He said his child gets Rs5,000 a day (US\$50) by begging, and he is feeding a family of 30 people. So if I can give him Rs30,000 a month (US\$300), he will think about enrolling his son in school." There are many such stories, and what needs to happen is a shift away from a culture of sympathy for persons with disabilities. This can start with affording him or her quality education.

This chapter will explore the education options available to persons with disabilities in Pakistan, and the arguments for inclusive education.

# 1. Education for children with disabilities

In Pakistan, children with disabilities are at a two-fold disadvantage when it comes to education. First, the country's heavily strained education sector already excludes as many as 25m children who are not attending school,<sup>14</sup> and fewer than half of those who do attend school complete primary education. Children with disabilities are more likely to stay out of school even where efforts to return children to the classroom are successful, says Professor Stein of Harvard University. "In Ghana, for example, where the country managed to get 90% of out-of-school children back to school, the remaining 10% that remained left out were children with disabilities."

#### Persons with disabilities (percentage of total population), 1998

	Out-of-school children as a percentage of total primary school-age population	Number of primary school-age children out of school (in million)	Out-of-school children as a percentage of total secondary school-age population	Number of secondary school-age children out of school ( in million)
Bangladesh	16.2	2.6	30.7	3.0
India	6.4	7.8	5.7	4.0
Pakistan	34.4	6.6	30.1	2.8
Sri Lanka	1.9	0.03	3.2	0.04
Total		17		9.9

<sup>14</sup> The Alif Ailaan campaign to end Pakistan's education emergency.

<sup>15</sup> http://www.unicef.org/ education/files/SouthAsia\_ 00SCI\_Study\_Executive\_ Summary\_26Jan\_14Final. pdf

Sources: Global Initiative on Out-of-School Children, UNICEF;<sup>15</sup> Bangladesh MICS 2006 and UNPD 2010 revision; India SRI-IMRB 2009 unit level data and UNPD 2012 revision; Pakistan PSLM-HIES 2007-07 and UNPD 2010 revision; Sri Lanka DHS 2006-07 and UNPD 2010 revision.



And for those who do attend school, the quality of education is questionable. Three out of four children in Pakistan, for example, lack basic mathematical skills. Other problems, such as poor teacher attendance and low spending on education, are widespread.

The situation for children with disabilities is further complicated by inaccessible mainstream schools and the limited provision of special education schools—there are problems related to geographical remoteness, a high drop-out rate, scarcity of teachers, insufficient resources, poor infrastructure and difficulties in transitioning to higher levels of education. Like the rest of the education sector, private schools are generally favoured as a source of better-quality education for children with disabilities. But private schooling can be prohibitively expensive for many parents, or poor families may feel that their limited resources are better spent on educating their children without disabilities.

#### The early years were good

The provision of special education came about with the promulgation of the Rehabilitation and Employment Ordinance of 1981. At the time there was a sizeable investment made in the establishment of special education schools across the country. "There were only a few schools, but good infrastructure. The curriculum was designed with the consultation of experts from the UK," says Shahida Sajjad, the dean of the faculty of education at the University of Karachi. In the three decades since then there has been a steady expansion of special education schools, but without the commensurate investment in infrastructure.

# Special education: Taking stock by province

There are approximately 50,000 children enrolled in special education schools, according to Jawwad Afzal, deputy director of Pakistan's Directorate General of Special Education,

but approximately 100,000 children with disabilities need education. The greatest number of special education schools are currently located in Punjab, Pakistan's wealthiest and most populous province. The Punjab government's Special Education Department has established 239 special education schools at the level of every sub-district in the province. It is the only province making serious strides in the area of special education, having set aside Rs1.14bn (US\$11.4m) for the promotion of special education during the current fiscal year (2013-14); this is a significant

#### Education expenditure in Punjab

	Budget 2013-14
School education	Rs15.5bn (US\$155m)
Higher education	Rs6.67bn (US\$66.7m)
Special education	Rs1.14bn (US\$11.4m)
Literacy and non-formal basic education	Rs1.61bn (US\$16.1m)

Source: Punjab government.<sup>16</sup>

#### Government-run special education schools

Province	No. of government special education school	No. of students enrolled in special education schools
Islamabad	5	1,371
Punjab	239	27,606
Sindh	48	NA
Khyber Pakhtunkhwa	38	2,400

Source: Various interviews with government officials.

show-nominal-increases/



increase from the 2012-13 budget of Rs700m. Punjab's special education schools cover the largest area in the country, but it still remains the case that these schools are based in areas of population concentration – the main town of the sub-district – and are therefore inaccessible to the majority of students with disabilities who live in rural areas.

At present there are 27,606 students enrolled at the 239 special education schools in Punjab, according to an interview with Syed Haroon Ahmed Sultan Bokhari, minister for social welfare in the government of Punjab. The figure represents a fraction of the total number of children with disabilities in Pakistan's most populous province, home to over half of the country's population. There are several privately run special education schools, operated by NGOs and charities that school thousands more children. The Punjab government supports some of these schools, providing three-quarters of their financing in partnership with established NGOs.

In the southern Sindh province, Pakistan's second-most populous province, there are 48 special education schools. Rubina Qaimkhani, minister for special education, social welfare and women's development, admits that resources are limited, but the government is trying to support persons with disabilities in the form of rehabilitation, special education and vocational training: "If I had a magic wand, first of all I would like for people to accept people with disabilities. If we have resources, we'll use them. I want society to accept them, not squander the talent." Where the government falls short, private schools and services have come to fill the gaps. In Karachi, Pakistan's largest city, there are 17 special education schools run by the government, and 50 special education schools run by private organisations. But the expanse of the city and a population of 20m mean that many of its neighbourhoods, as well as an overwhelming majority of its children with disabilities, are without any access to schools at all. In Karachi there are a handful of excellent mainstream schools that include children with disabilities, but because of their high fees (at least US\$100 per month) they are out of reach for all but the wealthiest residents.

In the north-west province of Khyber Pakhtunkhwa there are separate schools for children who are visually, intellectually or physically impaired. However, there are only 38 such special schools with a total of 2,400 students, according to Motasim Billah, director of the province's Social Welfare Department. "The lack of trained teachers is one of the biggest problems we have. We have asked the University of Peshawar to introduce special education programmes, and Khyber Medical University has been asked to introduce courses on physiotherapy and other health-related courses to meet the needs of persons with disabilities."

The poor security situation in the south-western province of Baluchistan has similarly disrupted the education of most children. The province has the unusual status of being geographically the largest province, but with a small and diffuse population. This



means that there are many far-flung rural areas without regular schools for children with disabilities. The volatile security situation in the province—scarred by a flickering nationalist insurgency, sectarian violence and Islamist militancy—has meant that private alternatives have not been pursued by charitable institutions or NGOs as they have in other provinces. At the time of writing this report, there was also no full-time education minister in the cabinet.

### Bad grades for all schools

Across the board, Pakistan's schools suffer from problems such as poor infrastructure, outdated curriculums, low teacher attendance and inadequate teacher training. These problems are even more acute in special education schools. There is widespread criticism among interviewees that the training of specialist teachers is based on outdated curriculums, which results in poor standards of education. Special education schools are also costly to run, admits one government official, and it is difficult to ensure that they are made available to the majority of the population who live outside city centres.

In Pakistan, private schools – often low-cost – have generally performed better than government schools.<sup>17</sup> According to the 2013 Annual Status of Education Report, at grade 5 level 51% of students at private schools could read Urdu, compared with only 35% at government schools. When it came to reading English, 56% of children at private schools could do so at grade 5, but only 34% of children at government schools.<sup>18</sup> This is despite the fact that teachers at private schools tend to be paid less and are not as well educated or trained as their colleagues at government schools.

Some education experts attribute the differences in performance to the fact that government schools are especially vulnerable to corruption, with the widespread existence of "ghost schools," especially in rural areas of the smaller provinces, and an epidemic of teacher absenteeism. Das, Pandey and Zajonc (2006) found that public-school teachers are absent 3.2 days per month, compared with an already high 1.8 days per month for private-school teachers. They argue that the plausible explanation for this difference is that whereas private schools can fire teachers for poor effort, public schools cannot.<sup>19</sup> Teacher jobs, which are prized for their stable salaries and other benefits, can be used as a tool of political patronage. These same problems plague the special education sector, which is generally seen by policymakers as being marginal to their existing concerns for the education sector.

Special education schools suffer from the additional problem of poor teacher training, given that there are few sources of specialist training for dealing with students with disabilities. In Punjab, where there has arguably been more investment than in any other province, there were 202 vacant teaching posts at 34 government special education schools in Gujranwala Division in 2013.<sup>20</sup> And where teachers are available, they are found to be poorly trained. In Islamabad's special education school for the hearing-impaired,

<sup>17</sup> http://www. periglobal.org/sites/ periglobal.org/files/2. Student\_Attainment\_ Pakistan(Amjad&Macleod). pdf

<sup>18</sup> Annual Status of Education Report (ASER)—Pakistan, available at http:// www.aserpakistan.org/ document/aser/2013/ reports/national/ASER\_ National\_Report\_2013.pdf

<sup>19</sup> Jishnu Das, Priyanka Pandey and Tristan Zajonc, "Learning Levels and Gaps in Pakistan", World Bank Policy Research Working Paper 4067, 2006.

<sup>20</sup> http://www.nation.com. pk/national/23-May-2013/ special-students-deniedproper-education



Mushataq Butt, president of the Sir Syed Association for the Deaf, says that teachers do not even know sign language. "If you are in a special education school for ten years and still not able to read and write, what kind of education is this? Even when they use a text message, their English is so bad. Instead of saying 'I am going', for example, they will say, 'Go I am'." Aaron Awasen of the Family Educational Services Foundation, a non-profit educational organisation in Pakistan, estimates that less than 5% of children who are hearing-impaired attend school, and that the share of hearing-impaired girls is much lower.

The successes in the area of special education cited by education experts are almost entirely in the private sector. The Al-Makhtoum, Sir Syed Academy and Shah Faisal schools in Islamabad, for example, are noted for their ability to hire teachers who are trained in how to teach students with disabilities (the ability, for example, to use sign language to communicate with hearing-impaired children), and the fact that they have appropriate equipment for various disabilities (braille books for the visually impaired, computers for hearing-impaired students and physically accessible premises for physically impaired students).

### 2. Education for adults with disabilities

#### University education only for the few

The CRPD mandates lifelong learning, but higher education—the path to employment and further success—is often inaccessible to persons with disabilities. For example, Mr Memon of the Pakistan Disabled Foundation estimates that only 0.01% of persons with visual impairments complete primary and secondary education, and that only one-third of those later go on to university. The numbers are low, but the visually impaired and persons with physical impairments have a better chance of attending university: persons with visual impairments can use assistive devices to follow lessons in classrooms with non-disabled children, and where ramps and other accessible infrastructure are available, persons with physical disabilities can attend mainstream schools.

All public universities have an established quota of reserving 2% of places for students with disabilities. But quotas are often not enforced, or universities say that they do not receive the requisite number of applications from students with disabilities with a proven academic track record that makes them eligible. Pakistan's largest universities, including Government College University in Lahore, Quaid-i-Azam University in Islamabad and Karachi University, have seen students with disabilities graduate, but in small numbers. Sabah Khan, communications manager at STEP, uses a wheelchair, and the public university she attended, International Islamic University, installed ramps to support her mobility needs. Other individuals have not been as fortunate. Mr Raza of the Movement for the Independence of the Disabled says that he was admitted into a prestigious university



on the quota system. He met the required grades, but the university did not agree to make any infrastructure changes. Like many other persons with disabilities he opted for a degree from an open university, where he could complete his education from home. In doing so, Mr Raza had to forgo his preferred course of studies.

#### A tough road to education

Students with disabilities have often had to adapt to the teaching environment in universities with little or no assistance, a circumstance that puts them at an academic disadvantage. Zulqarnain Asghar, a 37-year-old trained clinical psychologist who is visually impaired, earned a Bachelor's degree from Gordon College in Rawalpindi, followed by a Master's degree from Islamabad's Quaid-i-Azam University. "When you are taking notes, it becomes difficult because you cannot write braille with the same speed as someone is talking," says Mr Asghar. "When the computer came, it helped me a lot. I used to scan books or read the lectures on MP3 players. Then I used to hear those lectures and memorise them."

During his early exams Mr Asghar was designated a writer, who would read out questions to him and then hear his answers before transcribing them. Because of his disability he would be allotted extra time to complete the exam. But the circumstances were less than ideal. "Usually I face a lot of difficulty in communicating my ideas and thoughts to my writer because when you are speaking, it is difficult for the other person to keep pace with you." This often interrupted his train of thought and the structure of his exam answers. It was only when he was sitting his final exam at Quaid-i-Azam University that he was given a computer to complete the exam. "I think that my academic record would have been much better if there had been computer-based exams from the beginning."

#### Other forms of further education: Vocational education

Across Pakistan, there are approximately 60 registered centres for vocational training for persons with disabilities.<sup>21</sup> The Punjab government is currently expanding its facilities for vocational training for persons with disabilities. "This is of paramount importance to us for the self-employment of these persons," says Mr Bokhari, the Punjab minister for social welfare. The vocational training facilities are free of charge and are located in the main cities in each of the nine sub-divisions of Punjab. Among these vocational training projects is a recently established Home for the Blind. Under this scheme 400 visually impaired persons receive a stipend of Rs3,000 per month (US\$30) and are given training in the use of computers, motor winding, cane-making and mobile-phone repairs.

In the private sector, charitable institutions have also initiated programmes that provide vocational training with a similar view to equipping trainees with the skills and resources that will allow them to earn a living. The Karachi Vocational Training Centre

<sup>21</sup> http://www.spdapsh. com/images/LIST\_OF\_ FEDERAL\_SPECIAL\_ EDUCATION\_CENTRES.pdf



#### The Rickshaw project

The Karachi-based Rickshaw Project is run by the Network of Organisations Working for People with Disabilities, Pakistan (NOWPDP). It draws on donations to purchase new or second-hand motorised rickshaws, which are then retrofitted so that persons with physical disabilities can operate them. The plan is for the rickshaws to operate like a cab service, where customers in the nearby area can book a rickshaw that arrives at an appointed location and drives them to wherever they wish to go in the city.

The Rickshaw Project, however, has encountered difficulties after authorities at the traffic police department in Karachi refused to issue commercial licences for the rickshaws. "They said there's no provision in the law, and they said they don't need to abide by the UN Convention on the Rights of Persons with Disabilities," says Omair Ahmad, the CEO of NOWPDP. "So we can't get commercial licensing. They say we put the life of another person at risk." In each case the drivers had passed medical tests, the driving test, the written test, and had secured the approval of the surgeon general of Sindh province to say that the drivers were fit to operate the vehicles. "Still, they said there's no provision in the law," says Mr Ahmad. "They cite different examples from around the world. We came back to them with 12 examples where it does happen. So it's a perpetual conversation."

(KVTC), for example, provides vocational training programmes specifically designed for persons with learning disabilities. It takes students from the age of 12, and this helps to ease the burden on families. Rubina Inam, the centre's principal, says that the teenage years are difficult because young people become irritable and aggressive if they are forced to stay at home all the time. Approximately 85% of the centre's 140 students are from lowto lower-middle-income households, and costs per students are approximately Rs22,000 per month (US\$220). "But we can't charge our students this amount. Some students pay Rs3,000, others pay Rs6,000 or Rs7,000, depending on what they can afford." The centre, which depends on some government grants and private donations, offers a variety of skills, including printing, machine embroidery, tailoring, ICT and gardening, and most of its students end up later working on a variety of programmes conducted by KVTC: "Everything we do is geared towards employment. Many of the jobs are created in-house, and our trainees are paid. For example, we make woodwork to order for Buyer Pakistan and have had two successful orders from them. There are some trainees who are working outside KVTC, and they are mostly clerks," says Farhan Khan, project manager at KVTC. The centre strives to find employment for at least 30 individuals and managed to secure employment for 53 graduates last year. And while most of KVTC's trainees are male, it offers transport services to increase its reach to include females. It currently has 36 female students.

#### 3. The case for inclusive education

The medical model of disability, as has been discussed in earlier chapters, sees the person with disability as the problem: needing to be adapted to fit into the world, and where that



is not possible, "shut away in some specialised institution or isolated at home, where only ... basic needs are met," says Richard Rieser, managing director of the consultancy World of Inclusion. Special education schools, where individuals with disabilities are taught in classrooms with students of similar disabilities, perpetuate this idea of dependence and an exclusionary society. However, what is really needed is inclusive education, where the environment in mainstream schools is adapted to create a barrier-free environment for students with disabilities, gender and other advantages, and learning can happen with students of all backgrounds.

There are many arguments for inclusive education. First, special schools are generally more costly than inclusive schools, which should make it a more attractive option in a resource-constrained environment like Pakistan's. A UNESCO report estimates the cost of educating a child in a special education school in Pakistan at Rs30,000 (US\$300), as opposed to Rs2,000 (US\$20) for children in mainstream schools.<sup>22</sup> There are many studies which prove that inclusive education is more cost-effective: a study conducted on the costs of pre-school education in the US found that it was 11% cheaper in inclusive schools than in traditional schools with services for specific impairments,<sup>23</sup> and another study reviewed over 100 research papers to conclude that while start-up costs may increase with inclusive services, costs over time are likely to be lower than in segregated services.<sup>24</sup>

There are also social benefits to be derived from including children with disabilities in mainstream education, experts argue. Parents and educators sometimes feel that segregated classrooms will support the learning of persons with disabilities better, but research, such as that conducted by John Rynders (2005) finds that inclusive classrooms are beneficial for persons both with and without disabilities: a study found that children without disabilities gain awareness and realise their self-worth, while children with disabilities gain immensely from socialising with children from all backgrounds.<sup>25</sup> Mr Lashari of the Nawabshah Disability Forum in Sindh province, who has a physical disability, echoes this sentiment: "I was educated in a mainstream school in my village. If I didn't get educated from there, I would not have been able to stand on my own feet. I was able to get mainstream education, get social inclusion. The children in the school accepted me [despite my physical disability]." Over time, he adds, his fellow students abandoned their initial prejudices and embraced him as a peer. "They stopped calling me lame. They accepted me as a friend." Mr Lashari likens special education schools to gilded cages. "We want inclusion, not segregation."

Another myth of inclusive education is that educators will be focused on children with disabilities in classrooms, which may lead to less attention being paid to children without disabilities. There is yet no proof of this, explains Professor Stein of Harvard University, and empirical studies show how children, both with and without disabilities, do better in inclusive classrooms than in those without children with disabilities. With well-designed

<sup>22</sup> http://unesco.org.pk/ education/documents/ situationanalysis/Policy\_ Analysis\_Sindh.pdf

<sup>23</sup> http://csef.air.org/ publications/related/jsel/ odom\_hik.PDF

<sup>24</sup> G McGregor and RT Vogelsberg, Inclusive schooling practices: Pedagogical and research foundations. A synthesis of the literature that informs best practices about inclusive schooling. Baltimore: Paul H. Brookes Publishing Co, 1998.

<sup>25</sup> John Rynders, "Down Syndrome: Literacy and Socialization in School. Focus on Exceptional Children", 38(1), 2005. Retrieved from Academic Search Complete database.



curriculums, quality teacher training and assessment of learning needs, children with and without disabilities can thrive in the same learning environment—and benefit.

#### Early focus on inclusive education in Pakistan

In 1986 Pakistan developed a National Policy for the Rehabilitation of the Disabled, which focused on integrated education, stating that "integration will enable normal children to be aware of human diversity" and "children will accept differences more speedily than adults".<sup>26</sup> Mainstream schools located near established special education schools were identified and asked to admit children with disabilities, and the policy underlined the need for specialised teacher training. The policy was revised in 1988 as the National Policy for Education and Rehabilitation of the Disabled. The policy questioned the idea of integration, and while it was a desirable goal, it needed trained professional support for each child. Considering resources and needs, special education schools were deemed a realistic option.

Inclusive education is on the agenda again for the government of Pakistan, according to Humaira Naseer, joint programme support officer (Education) at UNESCO Pakistan and Mr Afzal of the Directorate General of Special Education. The government of Pakistan recognises that over 60% of the population lives in rural areas, and the only way to ensure access to education is to make mainstream schools accessible.

#### **Challenges in implementation**

The first challenge with inclusive education is that there is no universally accepted definition of the term. In one sense, it means ensuring that all education comes under one ministry and that all educational materials and curriculums are the same in mainstream and special schools. In the stricter sense of the term, inclusion means that persons with disabilities are taught in regular classrooms as best as possible. In some situations, where disabilities are severe, special classrooms or institutes will support their learning.

The stricter form of inclusion, which is closer to the social model of disability, requires big changes in Pakistan. It would first require identifying disabilities, training teachers and changing the physical environment of schools. Khurram Badar Alam, an educationist, shared a story about research he was doing around child labour in Pakistan. "We found a large percentage of child labourers had left school at an early age and started working. And why did they leave school? They dropped out because they could not cope with the pace of studies. They had learning disabilities, but these were not identified. If they had good teachers, they stayed in school. But in most cases the teachers were harsh and handled them negatively, beating them," he explains.

<sup>26</sup> In the late 1980s the focus was on "integration". From the 1990s "inclusion" replaced the word "integration".

So one of the first things that needs to happen, he suggests, is teacher training. His work in training teachers who were already teaching was not successful: "This has to be



a little longer-term, with academic training on how these things can be addressed. That means pre-service training: teacher training programmes."

And the other change that needs to happen, which is arguably easier, is a change in the physical environment, such as developing ramps and lifts for persons who are wheelchair users and installing tactile markers for the visually impaired. Sabah Khan of STEP, for example, who is a wheelchair user, never went to special education schools and completed her education to postgraduate level studying with her peers. However, these were private schools, not mainstream government schools (until university), which had made infrastructure changes to support her attendance.

Change is happening, but it is slow. The government of Punjab, for example, is thinking about more inclusive education: "The education department has issued directions to admit persons with minor disabilities in regular schools to promote inclusive education," says Mr Bokhari. Meanwhile, various private schools, such as CAS School, Bay View Academy and AMI School, have inclusive classrooms. Access to these, unfortunately, is still mostly reserved for children from wealthier households.

"The discrimination that persons with disabilities face is severe and widespread, but it's largely based on ignorance; it's not based on hatred. It's not like racial discrimination. People don't hate disabled people, they just don't know how to relate to them."

Philippa Thomas, independent expert on disability



# **Chapter 4: Employment**

Of the world's population of persons with disabilities (about 1bn, or 15% of the total population), the International Labour Organisation (ILO) estimates that between 785m and 975m are of working age, but many are not engaged in work. There are no credible statistics in Pakistan, but many would agree that the proportion of persons with disabilities who are employed is significantly lower.

Persons with disabilities face many barriers to entering employment. First, there are negative attitudes towards hiring persons with disabilities, with employers failing to see their talent and value in the workplace. In Pakistan, the stigma is compounded by the fact that for many the only image of a person with disability is that of a destitute street beggar. And if and when that stigma is overcome, for persons with visual, hearing or physical impairments there are infrastructure barriers to accessing work: getting to work (quality of roads and transport networks), moving around the workplace (ramps, accessible restrooms etc.) and carrying out the work (with the help of technology). For persons with speech and hearing impairments, communication is a challenge, as sign language is not widely used. And for persons with intellectual disabilities, rehabilitation and educational services specific to their needs are limited, which makes them less employable.

There are also issues when an economy is largely agrarian, as is the case in Pakistan, and many jobs are still in the primary sector: being a productive worker in a rural economy is difficult for anyone with mobility issues, for example. The country also has a large pool of workers, which means that employers are less likely to select candidates for whom they have to expend resources to make the workplace suitable.

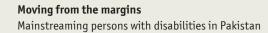
In cases where companies have an inclusive and diverse workforce, there are yet other problems. Employers and employees interviewed for this study say that there are enduring issues in terms of prospects for promotion within jobs. And where there are employers who want to build an inclusive workforce, they say that finding candidates with the right skills is difficult.

This chapter will outline the role of government, DPOs and business in facilitating a working environment conducive for persons with disabilities. It will also highlight the experiences of companies based in Pakistan which have successfully built inclusive workforces.

# 1. The role of business, government and persons with disabilities

#### A tripartite collaboration is critical

To protect the right to employment for persons with disabilities, the government first





needs to enact an overarching and effective law. This is fundamental to a rights-based approach to mainstreaming disability. Anti-discrimination laws "assume that disabled people are capable of competing for jobs in the labour market, as long as they are not discriminated against and reasonable accommodations made".<sup>27</sup> Such laws send a strong signal about changing negative attitudes when it comes to hiring persons with disabilities, explains Dianah Worman, public policy adviser, diversity, at the Chartered Institute of Personnel and Development (CIPD), a UK-based professional association for human resource management. A well-defined and strongly implemented law is missing in Pakistan.

#### Poverty and disability

There is an undisputed bidirectional link between poverty and disability. The onset of disability can lead to an adverse impact on access to quality education and employment, and therefore lower earnings. It may also require additional costs related to medical support and rehabilitation, which leads to lower socio-economic wellbeing. And for a person who is already poor, malnutrition and lack of quality healthcare services can cause disabilities, leading to further exclusion from work and fewer opportunities to break the poverty cycle. A 2010 OECD study of high-income countries, *Sickness, Disability and Work: Breaking the Barriers*, found that in 24 out of 27 countries persons with disabilities are more likely to live under the poverty threshold. In developing countries, the situation is similar. A 2011 World Bank study, *Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey*, found that in Pakistan the prevalence of disability was 6.41% among the poor and 5.06% among the non-poor (the study estimated a total disability prevalence of 5.99%, more than double the official estimate of 2.54%).

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	Multidimensional poverty measure	
	Among the poor (%)	Among the non-poor (%)
Sub-Saharan Africa		
Burkina Faso	8.20	4.50
Ghana	9.38	6.94
Kenya	6.71	3.71
Malawi	13.54	9.29
Mauritius	29.54	10.30
Zambia	6.39	4.10
Asia		
Bangladesh	18.49	8.47
Lao PDR	3.53	2.33
Pakistan	6.41	5.06
Philippines	11.67	6.99
Latin America and the Caribbean		
Brazil	23.75	11.20
Dominican Republic	11.87	7.49
Mexico	8.30	4.81
Paraguay	9.06	5.93
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Disability prevalence among working-age individuals

<sup>27</sup> Jody Heymann, Michael Ashley Stein and Gonzalo Moreno, eds, *Disability and Equity at Work*, Oxford University Press, 2014.

Source: Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey, World Bank, April 2011.



On an individual level, persons with disabilities need to communicate their needs to employers so that changes can be made to support their productivity. However, if the individual has never been in the world of work, such articulation is difficult. There is little support from the government, and voluntary organisations have stepped in to fill this need. The Leonard Cheshire Disability and Development Programme (LCDDP) is one such voluntary organisation, which helps to equip persons with disabilities with the skills to get a job or build a business.

And at the business level, companies need to see the value of a diverse workforce. "Companies can operate in their own space and do what they like. They can be creative and innovative in the way they attract and keep talent," according to Ms Worman. But she says that companies need to recognise there is a business case to build an inclusive and diverse workforce. A diverse labour force, according to the ILO, "provides significant advantages in improving a company's efficiency, productivity, competitiveness and overall success".<sup>28</sup> Facilitating employment for persons with disabilities sometimes requires extra investment on the part of the employer, which makes employing persons with disabilities less attractive from a cost perspective for a company, even where they are evidently talented and well suited for the role. This is where the government can help to reduce such perceived burdens through tax incentives, providing training programmes and offering other types of subsidies to businesses.

When designing such incentives and mechanisms, says Professor Stein of Harvard University, there are several things that need to be taken into account. First, positive discrimination policies should not be used in a way that precludes other opportunities for persons with disabilities. "So in a country like China or South Korea, where many blind persons are pushed into being a masseuse, does this mean that a blind person who is a brilliant programming analyst or musician would be precluded from opportunities?" Second, any employment-related policy should tap closely into a person's talent and allow this to develop. In other words, it should not be just any job, but one that is commensurate with ability.

#### A quota system, if well-implemented, is a start

Quotas, where the government passes a law which mandates that companies should hire persons with disability or else pay a penalty, are a common form of encouraging employment when first trying to change attitudes. Pakistan has such a system in place. The 1981 Employment and Rehabilitation Ordinance mandated that 1% of jobs in all organisations employing more than 100 people should go to persons with disability. After power was devolved to Pakistan's provinces, the quota was doubled to 2%. However, this has not been well implemented. A recent newspaper report found that many companies in Karachi, including Avari Towers, Habib Oil Mills, State Bank of Pakistan and the Election Commission of Pakistan, had not implemented the quota.<sup>29</sup> <sup>28</sup> http://www. businessanddisability.org/ index.php?option=com\_co ntent&view=article&id =114%3Athe-businessand-human-rightscase-for-hiring-peoplewith-disabilities-&catid=51%3Aboxes

<sup>29</sup> http://pakistan. onepakistan.com.pk/news/ city/karachi/274535-govtreluctant-to-implementdisabled-persons-jobquota.html



There are lengthy debates around quota systems and their impact on employment. The CRPD makes no mention of quotas, but they are nevertheless seen as a way of increasing employment. In assessing its impact, we first need to see if they are enforced. In France, for example, where the quota for employing persons with disabilities is governed by criminal law, employers neglect adhering to quotas because they know there are no penalties, according to Professor Stein. In Germany, quotas are somewhat better enforced, but employers often choose to pay the fine instead, which still means that persons with disabilities are not employed.

The question then is how the funds from these penalties are used. In Japan, the money is channelled into an agency which works on the basis of public-private partnerships (PPP) to create employment opportunities for persons with disabilities. For example, such funds were used to support Swan Bakery, a privately run firm. Swan's employees consist almost entirely of persons with intellectual and other disabilities, and they are paid regular salaries. "It works really well, and in downtown Tokyo you can see working professionals going to the bakery to buy their biscuits and cakes at Swan. So if these funds and penalties get ploughed back into really creative sorts of job-creation structures, they can be enormously useful," adds Professor Stein. In Pakistan, however, there is no effective collection of funds, and neither is there any monitoring of the use of such funds. The National Council for the Rehabilitation of Disabled Persons is responsible for monitoring the quota system, but many interviewees describe it as a dead agency. There is also no transparency of funds and how these are used, and according to one interviewee, as much as Rs7m (US\$70,000) are available in the Fund. However, since the devolution of power to the provinces in 2010 the funds are no longer available because of a procedural hiccup: "Each provincial government is asking for their share, but they can't get it. The money can be used for so many things, but it is just sitting there," says an interviewee who regularly has dialogues with the government.

#### Quota system and penalty, selected countries

Country	Requirement	Levy
Austria	4% of public- and private-sector employees	At least €238 (US\$320) per month
France	At least 6% of companies must be persons with disabilities	600-1,500 times the hourly wage
Germany	At least 5% of jobs must be held by severely disabled employees	€105-180 (US\$140-245) per month
Japan	1.8% of workforce	¥50,000 (US\$490) per month

Source: iGlobal Law.

Another question is whether quotas are applied to public-sector jobs. In Pakistan, government jobs are attractive to persons with disabilities looking for employment because they are generally viewed as stable jobs with decent salaries. However, getting a job with the government is difficult. An unemployed Peshawar resident with a physical disability explains that he has been trying to get a job for the last five years despite having



a Bachelor's and a Master's degree. "I want a government job, but that's not possible, because everywhere I have approached, my disability has been an issue. Three years ago I completed two teaching courses and applied for a teaching post under the government quota. The merit list puts me on top priority, but I never got a call back." Part of the problem is that the government of Pakistan does not have a proper definition of a person with a disability: "They don't have clear guidelines on who is eligible and who is not. If someone is missing a finger, he is considered a disabled person and can apply under the quota system, which puts him at an advantage," explains the head of a DPO in Lahore.

The quota system can be a good start in encouraging a change in attitudes and increasing the employment of persons with disabilities. But even when well implemented, it should not be a long-term solution. "If I say that the quota system is bad, bringing full inclusion of persons with disabilities at its own pace is impossible. Asking society to change on its own and be all-inclusive, it will never happen. The quota system is good if considered as a step towards inclusive society. But it should be a temporary policy," says Mr Waheed of HelpAge International.

#### Going beyond quotas: The perspective of low-income countries

Daniel Mont, who has worked extensively on disability issues in developing countries for the World Bank, argues that anti-discrimination laws and quotas in low-income countries may not be as effective, considering the structure of society: "First, many jobs are in the informal sector, in which quotas are irrelevant. Second, in many countries the legal structures that can allow people to sue for damages are not in place. Third, self-employment is a bigger share of the economy." As such, he suggests other "counterbalances" and "substitutions" to support employment for persons with disabilities. Counterbalances include vocational rehabilitation programmes, microfinance options and supported employment structures such as job coaching. And where persons with disabilities cannot compete successfully in the labour market, he recommends approaches such as "sheltered employment, enclave employment (basically a segregated environment within a regular company) and specialised work crews of disabled people". Such segregated options are admitted for persons with more severe disabilities, he adds, "but sometimes with the 'aim' of graduating to regular employment."<sup>30</sup>

#### LCDDP training and employment (no. of persons), June 2009–April 2014

	Male	Female	Total
Total registered	7,123	3,514	10,637
Skill training programme	2,287	1,376	3,663
Self-employment	1,290	598	1,888
Salaried employment	658	242	900
Total employment	1,948	840	2,788

 $Source: Leonard\ Cheshire\ Disability\ and\ Development\ Programme\ (LCDDP)-Pakistan.$ 



In Pakistan, there are limited options of government-led initiatives on such counterbalances and substitutions. However, DPOs and NGOs have stepped in to fill this gap. Since 2011 the Leonard Cheshire Disability and Development Programme, for example, has been running Jobability.org, a disability portal specifically for persons with disabilities and employers who wish to hire persons with disabilities. But beyond simply uploading their résumés, the organisation provides training programmes in personal development to grooming and employability skills. Imran Nazir, country director in Pakistan, says of the 10,637 persons with disabilities registered on the portal, 3,663 have been given training and 2,788 have successfully gained employment since 2011.

#### Women and the world of work

Pakistan has one of the lowest female labour force participation rates in South Asia, and women with disabilities face even greater barriers when it comes to the world of work. Ms Aslam of the Saaya Association says that mobility is a big concern: "They cannot use public transport. And travelling by taxi or an auto rickshaw is also difficult. They are heavily dependent on their family to move around, which makes opportunities for work difficult."

# Female labour force participation (percentage of total labour force), 2012

Afghanistan	15.7
Bangladesh	57.3
India	28.8
Nepal	79.9
Pakistan	24.4
Sri Lanka	35.0
Courses World Deals	

Source: World Bank.

MCR, a family-owned group of US fast-food franchises, admits that almost all the persons with disabilities they have hired are men.

There are limited work and training opportunities for women with disabilities, according to Ms Akram of the National Forum of Women with Disabilities. Her organisation runs between three and four training programmes a year that focus on leadership, independent living, communication and job-search skills. There are at least 25 women at each training session, but she adds that the employment rate for women is low: "I can count on one hand

#### **Road hazards**

Interviews with a range of persons with disability reveal that public transport is often inhospitable and even hazardous. In Karachi, Pakistan's largest city, the buses are neither well regulated nor do they provide easy access for persons with disability. Not only are there no ramps, bells or braille buttons, but also the buses often do not stop for persons struggling with a disability. There is, in fact, an incentive for bus drivers to leave passengers with disabilities behind as they are fined if they do not complete the journey within a fixed period of time. Interviewees say that they have experienced occasions where buses have simply left them in the middle of the main road, perilously close to running traffic. According to one interviewee, cars have repeatedly run over his clearly visible white walking stick and even hit him.

Transport is better in Lahore, Pakistan's secondlargest city, whose recently opened metro bus system allows persons with disabilities to access public transport complete with ramps and space for wheelchairs. The government of the prime minister, Nawaz Sharif, has vowed to introduce a similar bus system for the Islamabad-Rawalpindi area. At the moment, Islamabad has almost no public transport serving the city.



the number of women who are employed, because we are already in touch with them." A woman's primary role in society is still that of a homemaker and mother.

## 2. Building an inclusive workforce: Examples from Pakistan

With limited government support, several companies in Pakistan have made changes in the workplace to support the working needs of persons with disabilities. Making an office wheelchair accessible, for example, requires an investment of between US\$3,000 and US\$10,000, depending on size of office and other facilities already available. Some of these initial dollar investments may be extensive, but they go a long way in broader benefits to a company. These include tapping into a wider talent pool, for example, and other social and economic benefits that come from a diverse workforce.

This section outlines two case studies: Telenor, a global telecommunications company with operations in Pakistan, which has applied the knowledge acquired at its parent office in Norway, and a local food and beverages company, MCR Pakistan, which decided to start a new culture of diversity within its organisation.

#### A three-step programme at Telenor

Telenor, one of Pakistan's largest mobile-phone companies, has been able to learn from the employment practices at its headquarters in Norway to introduce a scheme for employees with disabilities. In 2009 Telenor Pakistan inaugurated its Khuddar Pakistan programme. "It is not a charitable initiative," says Zainab Hussain Siddiqui, manager for corporate social responsibility. "It is an initiative to recognise persons with disabilities who are more than qualified to be part of an organisation. And we wanted to create a space for them to shine."

The first step the company took was to create awareness and sensitise their employees to disabilities. This included an element of volunteerism, where employees would go out of the workplace and help persons with physical disabilities. As a second step, Telenor tried to improve accessibility to its premises. As is commonly found among large companies in Pakistan, the premises are under lease, and so it becomes difficult to alter their physical dimensions. But Telenor has introduced ramps and wheelchair-accessible washrooms at each of its four main offices in Islamabad.

Third, Telenor introduced a highly competitive trainee scheme for persons with disability. The scheme was in part inspired by an Open Minds programme at Telenor Norway, but it was adapted to suit the local employment market. The company received advice from STEP, which provided guidance on developing traineeships and how to work with and support the productivity of persons with disabilities. The scheme is entirely judged on merit, making it stand out from the traditional charity approach. The call for applications started in 2013, and Telenor received over 1,000 applications from graduates for the scheme. These were reduced to a shortlist of 60 people, and a round of interviews



eventually produced 16 candidates, who received three months of training on project and financial management and the telecommunications industry. They were then assessed for two additional weeks on the job, after which a final selection of eight trainees was made. The trainees are currently undergoing their nine-month programme, during which they are working in various departments in the organisation.

The trainee scheme is key in terms of giving competitive persons with disability the sort of work experience and exposure that they are usually denied. It helps make them more attractive as candidates for jobs elsewhere in the private sector. The trainee programme is not permanent, so there is no guarantee of a job at Telenor. But if there is an opening at the end of their trainee programme, they will be considered for the job on the basis of merit. Telenor is looking to make the scheme, currently in its first year, permanent, moving it from the "corporate social responsibility" department to the "human capital division", reflecting the broader acceptance within the company of the scheme.

#### Growing from small to big: MCR's group of restaurants

At MCR, a family-owned group of US franchises such as Burger King and Pizza Hut, there have been successful attempts to include persons with disability with lower educational attainment at the minimum-wage level. Starting in 2013, MCR began recruiting persons with disabilities to make up at least 2% of its total workforce of 3,000 employees. Since the devolution of power to the provinces it is now incumbent on all employers of more than 100 people that at least 2% of their workforce consists of persons with disability. That said, no one has enforced this quota, says Saba Hassan, the director for social corporate responsibility at MCR.

MCR was able to reach its goal within a few months. The process was trying at first, says Ms Hassan, and involved adapting the software, creating access for ramps, sensitising the staff, and determining which members of staff with certain disabilities could best fit in different parts of the restaurants. "We have mostly hired persons with hearing impairment in our restaurants and visually impaired persons in our call centre," says Ms Hassan. "Intellectual disability is something that we haven't done properly yet. I'm still working on that. It's much more complicated."

For the call centre, which handles calls for deliveries from all over the country, the initial challenge was adapting the company's in-house software and making it compatible with JAWS (Job Access With Speech), a screen-reading software that allows employees who are visually impaired to use computers with ease. "It wasn't accessible at all to start with," explains Ms Hassan. "Now we have a lot of pop-ups that are compatible with JAWS." It took the staff a few months to get used to JAWS and the system. With the technology, employees with disabilities are just as productive as others: "They were taking the same number of calls, doing the same number of transactions," says Ms Hassan. "The same



results we were getting from a sighted person we were getting from a visually impaired person. I think that's a success story for them." MCR is now looking to increase the number of persons with disability from 2% of the total workforce to 10%.

Having persons with disabilities staffing the customer-facing operations is also designed to help sensitise customers. "The customers look at things on the counter," says Ms Hassan, "and using rudimentary sign language, customers can communicate with the cashiers. And at the back of the restaurant, staff communicate between themselves with sign language."

But at MCR, as with other businesses, there are unanticipated challenges that emerged. A key challenge in terms of attracting employees with disabilities for lowincome jobs is transport. The jobs at call centres across Pakistan pay the minimum wage, which is approximately US\$80 per month. Many employees with physical disabilities need to take a rickshaw or taxi to work, a form of private transport that takes up a significant share of their incomes.

#### **Challenges still exist**

Positive stories of employment for persons with disabilities do exist, but they are limited. On the employers' side, some find it challenging to even attract applications from persons with disabilities. Abacus Consulting, a Pakistani professional services firm with a wellarticulated policy of a diverse and inclusive workforce, has approximately six persons with disabilities on its payroll, out of 2,500 employees. "We don't have exclusive quotas, it is all about merit. We advertise on print media and LinkedIn, but hardly ever receive applications from persons with disabilities," explains Fatima Asad-Said, executive director of human capital excellence at Abacus Consulting.

And even where businesses have successfully hired persons with disabilities, they have not always found it easy. In some cases, persons with disabilities were not accustomed to attending a place of work regularly for five days a week. Some employees had previous experience at government departments, where, along the lines of the charity model, they were given jobs with a view of fulfilling the government quota rather than providing meaningful employment. They were also used to higher salaries in the public sector than they were able to find in the private sector.

And where persons with disabilities do secure jobs, there is limited upward mobility within the organisation. In rare cases, persons with disability have been able to achieve executive-level positions in private-sector firms. In the public sector, teachers can find steady promotion with a commensurate increase in salary. But the majority are hired in low-skilled, low-paid jobs, where there is little prospect of advancement.



Indicator	2013 (or latest available)
Total population	182.5m
Size of labour force (economically active population)	62.4m
Various estimates of persons with disabilities	3.3m-27m
Estimated economic losses from excluding persons with disabilities from work	US\$11.9bn-15.4bn

Sources: The Economist Intelligence Unit; WHO; World Bank; Pakistan census 1998; EIU estimates based on World Bank calculations.

#### 3. The economic imperative

The current Pakistani government led by the prime minister, Nawaz Sharif, has made the revival of the local economy the central plank of its governing agenda. It was because of this focus on the economy that Mr Sharif's Pakistan Muslim League-Nawaz party was voted into power at the 2013 general election. But those hopes of rousing the country's economy from its torpor could be at risk if as many as 27m persons with disabilities are not active in the economy. This is on top of the already low percentage of the female population being a part of the workforce.

Where persons with disabilities do not have access to quality education, there are limited opportunities for employment. There is no standard calculation of the economic cost of excluding persons with disabilities; statistics are often dated or inconsistent where countries have different definitions for disabilities. In 2000 the World Bank developed a bottom-up approach that estimated the global losses incurred as a result of disability at between US\$1.37trn and US\$1.94trn every year.<sup>31</sup> Using the World Bank's estimates and the Economist Intelligence Unit's macroeconomic data for 2014, annual losses to Pakistan as a result of excluding persons with disabilities from employment range between US\$11.9bn and US\$15.4bn annually, or between 4.9% and 6.3% of the country's GDP. By 2018 losses could be as high as US\$21.4bn.

Reducing the number of persons with disabilities who are economically inactive also reduces the burden on other resources. OECD countries as a whole, for example, spend as much as 10% of their social expenditure on disability benefits. Admittedly, these countries have stronger welfare benefits than Pakistan. But in Pakistan the family is an important welfare system. And where persons with disabilities do not partake in work, they rely on financial and emotional support from their families, which results in further productivity losses. There are, thus, immense benefits to the individual, the family and wider society if persons with disabilities are included in the world of work.

<sup>31</sup> RL Metts, Disability issues, trends and recommendations for the World Bank. Washington: World Bank, 2000. "Having a disabled daughter is a huge burden the family. Culturally, women are to get married and get out of the homes. Even their siblings are not getting good proposals because people think that if a family member has a disability, they will later

give birth to children with disabilities."

Abia Akram, National Forum of Women with Disabilities



# **Chapter 5: Moving from the margins**

Almost 50% of Pakistan's population of approximately 186m is living in poverty.<sup>32, 33</sup> The number of children not attending school amounts to 5.1m, (the second-highest number globally),<sup>34</sup> and over 50% of the country's economy is in the informal sector.<sup>35</sup> Keeping persons with disabilities at society's margins impedes the country's development in several ways: (a) the two-way link between disability and poverty is undeniable, which means poverty rates are harder to reduce without mainstreaming disability; (b) a large number of children are likely to drop out of school because mild disabilities are not detected or access to education is limited (both with regards to fewer school options and stereotypes that force their exclusion, such as parents who feel their limited resources are better spent on their children without disabilities); and (c) excluding as many as 15% of a country's population from the world of work has critical implications for productivity and economic progress. Mainstreaming disability is thus critical—not just as a human rights issue, but also for the country to progress economically. There is a need to explicitly include the protection of the rights of persons with disabilities in the laws, policies and strategies governing health, education, labour, housing and the information and communications sector.

To do this successfully, three critical elements need to work, explains Philippa Thomas, an expert with experience in mainstreaming disability in developed and developing countries: (a) the state, which deals with legislation and policy development, (b) services, which can be provided by the state or civil society, and (c) DPOs, which need to lobby effectively on behalf of persons with disabilities. If any of these elements are weak, effective mainstreaming from a rights-based approach is difficult: "You can have the most wonderful legislation, it can be rigorously enforced, but if they do not have access to assistive devices, the law cannot be enforced. You can have top-notch disability services with cutting-edge medical provision, but you will then only be approaching disability from a medical perspective and not addressing it as a human rights issue. Or you can have very vibrant DPOs which are fighting for the rights of persons with disabilities, but if there are no specialist services, they won't have access to those rights."

<sup>32</sup> Pakistan Bureau of Statistics.

<sup>33</sup> Human Development Index, 2013.

<sup>34</sup> UNESCO, 2010.

<sup>35</sup> http://pide.org.pk/ psde/pdf/AGM28/M%20 Ali%20Kemal%20and%20 Ahmed%20Waqar%20 Qasim.pdf Using this framework, this chapter will review the role of the state, the availability of services and the effectiveness of DPOs in mainstreaming disability in Pakistan. It will also review examples from other countries and offer potential solutions for Pakistan.

### 1. The role of the state

#### Comprehensive legislation is a priority

First and foremost, the state is responsible for enacting the laws that protect the rights of persons with disabilities. It is also responsible for developing policies, setting standards



and budgets, and monitoring implementation. There are several examples of developing countries that have enacted laws, but these are often poorly implemented. Bangladesh, for example, has enacted the Rights and Protection of Persons with Disabilities Act 2013, which covers 11 impairments. It also mandates the issuance of national identity cards, enrolment in mainstream schools, reserved seats on public transport, changes to ensure accessibility in public places, equal opportunities in employment, and protection of inherited property rights. But as Professor Stein of Harvard University explains, implementation has been ignored by the government. "This has been the case in many countries, including the United States, which has been a disaster for the employment of persons with disabilities under the Americans with Disabilities Act."

In Pakistan, such a law is being drafted and, when passed, it will need to be strongly enforced and monitored. There is a draft law in place, says Dr Mallick of the WHO, whose team has consulted with various stakeholders, persons with disabilities, lawyers and provincial governments in drafting the law. She is hopeful that change is near: "I can see the law coming into place at the end of this year, and the WHO and its partners are working with the provinces on implementation strategies. This will help in creating better awareness and mainstreaming of disability in the development agenda, and there will be a sense of responsibility and ownership by the government."

Recommendation: Comprehensive set of laws to protect the rights and dignity of persons with disabilities in all aspects of living and accessing public spaces.

#### Lead department or ministry for disability affairs

Second, there need to be stronger governing agencies with a clear mandate to oversee issues related to disability. In Pakistan, the Department of Special Education within the provinces provides services for children with disabilities and vocational training for adults, but no other department works with other ministries on other issues related to persons with disabilities.

Disability is a cross-cutting theme, and to ensure proper mainstreaming, a disability affairs department must co-ordinate with the health, education, labour, housing and information and communications ministries. This has taken root in several developing countries. In India, for example, the Department of Disability Affairs is one of two departments under the Ministry of Social Justice and Empowerment. It was created in 2012 to focus on policy issues around mainstreaming persons with disability and is responsible for liaising with various stakeholders, state governments, central ministries and national and international NGOs on policy and strategy development. Article 33.2 of the CRPD requires states to appoint an independent mechanism to promote, protect and monitor progress on the implementation of the Convention. In Pakistan, since the



devolution of power to the provinces in 2010, there is no federal-level government agency overseeing disability affairs, and therefore no monitoring of the performance of the provinces with regard to mainstreaming disability.

Recommendation: Lead government department to develop and monitor the implementation of policies that protect the rights of persons with disabilities.

### 2. Services for persons with disabilities

#### Better government-led rehabilitation services

Rehabilitation, assistive devices and support services are crucial to reduce the impact of impairments and enable persons with disabilities to access their rights. Generally speaking, government-led rehabilitation and welfare programmes for persons with disabilities in Pakistan are limited and lacking in quality. In fact, many are not even aware about the availability of these services: according to a survey conducted by the ILO in Islamabad, of the 441 persons with disabilities interviewed in a 2013 study, only 4% of male respondents (and no female respondents) were using some form of government support to secure medicine and treatment.<sup>36</sup> Fully 87% of respondents did not even know about the existence of organisations or government agencies working for the rehabilitation of persons with disabilities. Given these findings, awareness of such services is likely to be even lower in rural areas and large cities outside Islamabad.

Developing countries are stretched on resources. Professor Stein, who has worked with several developing countries in formulating laws and policies, suggests making sure that what limited resources countries do have are used efficiently and effectively. "More funding can help, but well-spent funding is better. South Africa spent a small fortune on written textbooks for blind students that they could not use. Part of the goal is to make sure countries understand that the disability sector overlaps with the poverty sector and that more efficient use of funds can be made."

Recommendation: Effective use of government and other stakeholder resources and funds for rehabilitation, health, education and employment services.

#### Starting with the community

Early detection of disability is extremely weak in Pakistan, and there is a focus on physical disabilities. Intellectual and learning disabilities are almost never identified at an early age, according to Dr Siham Sikander, director of research at the Human Development Research Foundation in Pakistan. According to a 2009 WHO report, there are 820 trained psychologists and psychiatrists for a population of 186m, or 0.49 for every 100,000

<sup>36</sup> Quantitative Survey People with Disabilities and Their Needs for Vocational Rehabilitation in Islamabad Capital Territory, International Labour Office (ILO) Pakistan, 2013.



persons in Pakistan. There are creative solutions to such human resourcing issues, Dr Siham says, and we can learn from community-based mechanisms in Pakistan, most notably the Lady Health Worker Programme. With the majority of the country's population living in rural areas, community health workers have long been delivering basic health services—mostly antenatal care, but also postnatal services that ensure the health of both mother and baby. There are about 125,000 women delivering this service, and with the outbreak of polio they have also been mobilised to deliver polio vaccinations. Dr Sikander suggests that in a similar vein Pakistan could develop a group of community-based peer volunteers who could help identify certain learning or other disabilities, educate families and provide support. "We have all these young energetic girls who graduate from universities and go back to their villages. We can train them to be community workers, and that can make a huge difference," adds Dr Farah Qadir, assistant professor at the Fatimah Jinnah Women University.

There are other, similar community-based mechanisms which link health and education services to build more inclusive communities. CHEF International, an NGO based in Islamabad, has a number of community-based rehabilitation (CBR) programmes in Charsadda district in Khyber Pakhtunkhwa. They first worked with the local hospital to ensure it was providing physical rehabilitation and mental health and eye services, and later set up community centres to identify persons with disabilities and put them in touch with medical services and assistive devices. They then worked with several government schools in training teachers and making infrastructure accessible. In total, nine government schools were equipped with ramps and facilities for children with limited vision. Most of the funding came from private donors, which makes it difficult to expand such projects. But the success of other larger-scale community-based programmes, such as the Lady Health Worker Programme, show that small steps can go a long way towards raising the awareness of communities and demonstrating that positive strides are possible despite the constraints they face in Pakistan.

Recommendation: Where resources are limited, innovative community-based mechanisms can alleviate the burden on the government.

#### Education for all: Inclusive education

Education is generally provided by the state in Pakistan, and special education schools are available, but they are of low quality and their number is limited. Private schools for children with disabilities sometimes offer better-quality education, but they can be expensive. Inclusive education is found only in small pilot programmes, such as the ones run by CHEF International. Realistically, a broader implementation of inclusive education in public schools will be difficult in light of the current state of education in Pakistan:



Pakistan ranks 162nd out of 187 countries in the UN Education Index (part of the Human Development Index), while neighbouring India ranks 146th, Bangladesh 157th and Sri Lanka 74th.<sup>37</sup> Education budgets from primary to tertiary level account for approximately 2.5% of Pakistan's GNP,<sup>38</sup> which is far too low for quality education. Bigger education budgets and an overhaul of the education sector are sorely needed.

Globally, inclusive education is only slowly gaining momentum, and several developing countries, such as India, Lesotho and Uganda, have developed policies around inclusive education. India, for example, has made a commitment to universal primary education, and in 1994 the government launched the District Primary Education Programme. In 1997 children with disabilities were explicitly mentioned, and the focus was on children with mild or moderate learning difficulties. "Recently this has been extended to the full range and severity of impairments. In the first six years 877,000 disabled children were identified across India, and 621,760 were enrolled. Through a combination of state, regional and district resource centres and widespread in-service teacher training, practice has begun to change significantly. By 2003 over 1m teachers had received one day's training, 171,000 had attended three- to five-day orientation courses and over 4,000 had attended a 45-day orientation course to become master trainers," writes Richard Rieser of the consultancy World of Inclusion.<sup>39</sup> In 2010 the government also promised additional funding for its Sarva Shiksha Abhiyan (SSA—Education for All) programme, such as the provision of an additional Rs1,200 (US\$12) per child to meet their additional learning needs, which includes learning aids, mobility assistance and other support.

Conditions in India (or indeed in any other developed or developing country) are by no means perfect. But at least here the wheels have been set in motion, whereas a wellarticulated policy is sorely missing in Pakistan. The good news is that the government in Pakistan recognises that inclusive education should be implemented, and it has made progress on this. According to Mr Afzal at the Directorate General of Special Education, the government is working on a three-A approach: "The first is accessibility. We made 20 schools in Islamabad accessible for persons with disabilities. The second is awareness of parents and communities. The third is proper assessment of disabilities." He adds that teacher training is also important, and the government is working on better training and financial incentives to build capacity and improve the quality of teachers.

<sup>37</sup> Human Development Index.

<sup>38</sup> The Economist Intelligence Unit.

<sup>39</sup> "Implementing Inclusive Education: A Commonwealth Guide to Implementing Article 24 of the UN Convention on the Rights of People with Disabilities". Recommendation: Inclusive education is critical in ensuring that education is within reach of persons with disabilities. This requires changes in school infrastructure and investment in better teacher training.

#### Increasing employment of persons with disabilities

There are a variety of constraints that impact the employability of persons with disability, and both the government and civil society can offer services to increase the employability



of persons with disabilities. First, limited access to education and skills training could prevent a person from acquiring the requisite skills for certain jobs. There are also infrastructure and environmental barriers to accessing work, such as inaccessible public transport, for example. From within the labour market, individuals may not have access to job application processes, face discrimination from employers or find workplaces inaccessible. In Pakistan, the government does not offer extensive employment support from within the labour market, but some low-interest loans are available for the self-employment of persons with disabilities.

The first step towards employment policies for persons with disabilities is a situational assessment of disability and employment, writes Sophie Mitra in *Disability and Equity at Work*.<sup>40</sup> With an understanding of these barriers, policymakers can design policies that are based on the needs of persons with disabilities and take the administrative capacity of the country into account. She provides some examples of labour market interventions and success stories in low-resource countries.

• For skills training, the government or civil society members can offer varying degrees of basic to vocational skills programmes. In Chile, the Chilecalifa post-schooling programme provides both basic education and technical training and has been successful in increasing wages especially for women. In India, the government runs vocational rehabilitation centres, where persons with locomotor disabilities account for approximately 80% of individuals taking part in these programmes. Of the 29,124 trainees in the programme in 2004, 10,490 found a job, became self-employed or went on to further training programmes.

• As far as job creation is concerned, Ms Mitra suggests creating more opportunities in mainstream public works programme, although admittedly this may not be accessible to persons with more severe impairments. In India's Andhra Pradesh state, the government has made special provision to specify 150 days of employment for persons with disabilities. Working with an NGO, the Ashagram Trust, the government has identified the types of work persons with disabilities can do. These include helping on plantations, levelling roads and hedging and fencing.

• Anti-discrimination laws and quotas are common in reducing workplace discrimination and facilitating the employment of persons with disabilities. However, implementation is notably poor in low-income countries. Pakistan's 2% quota system, for example, is almost never enforced. Thus, efforts to reduce existing prejudices need to go beyond any form of laws or quotas in place. The BBC World Service Trust, for example, has used different forms of the media to reduce the misconceptions surrounding leprosy in India. This was later found to have a significant impact on public perception and reduce the stigma individuals faced.

<sup>40</sup> Jody Heymann, Michael Ashley Stein and Gonzalo Moreno, eds, *Disability and Equity at Work*. Oxford University Press, 2014.



• To facilitate job searching for persons with disabilities, there can be specific job-finding agencies or portals that work with persons with disabilities and employers. The Leonard Cheshire Disability and Development job search portal is one such solution already in place in Pakistan. Other larger job portals, such as Careers.pk, can also make their websites accessible to persons with disabilities. In China, for example, there are as many as 3,000 employment services specifically for persons with disabilities.

• Where self-employment and small businesses dominate, especially in rural areas, loans and other incentives can help to empower persons with disabilities. In Cambodia, the ILO developed a Alleviating Poverty through Peer Training (APPT) programme aimed at providing training programmes for aspiring entrepreneurs. Of the 958 clients between 2002 and 2007, over 50% were women or women with disabilities, and 609 of the 958

Recommendation: Build a broad and effective ecosystem to support the employment of persons with disabilities. This includes anti-discrimination laws, incentives for employers, vocational training services and job-matching support.

clients successfully started their own businesses.

## 3. The role of DPOs

#### A united voice for rights-based change is missing

DPOs work to represent persons with disabilities, lobby for their rights and/or offer various forms of health, education and employment services. Pakistan has a plentiful supply of DPOs—several online directories put their number at over 100 across the country. They come under various regional and sub-regional networks and forums such as the Pakistan Disability Persons Organisation (PDPO), Sindh Disability Forum and Khyber Pakhtunkhwa Disability Forum. Most recently 18 DPOs and several national and international NGOs have come together to form the Community Based Inclusive Development (CBID) network, which connects DPOs on one platform and works with provincial and national governments to implement the CRPD.

DPOs in Pakistan are thus relatively organised, but a majority of them are still focused on providing assistive devices and related rehabilitation support instead of embracing a rights-based approach to mainstreaming. Still beholden to funding from the government, the private sector and international agencies, they may be reluctant to lobby for changes in human rights or are not aware of the human-rights approach to mainstreaming. That said, rehabilitation services provided by DPOs are nevertheless very important, especially where government services fall short. However, without fully embracing a rights-based change, DPOs tend to lobby the government for more rehabilitation or welfare support instead of calling for more inclusive and holistic change.



The strength of the disability rights movement determines the success of any form of mainstreaming, and it is critical that DPOs are included in the decision-making processes. In Sierra Leone, the government has passed legislation to ensure that service provision for socially marginalised groups is devolved to the district level. As a result of effective advocacy activities by the main DPO, Disabled Rights Movement, Sierra Leone, the co-ordinator of the DPO was given a seat on one of the sub-committees to represent persons with disabilities. This has helped to make the inclusion of disability a mainstream theme in the Moyamba District Council development plan.<sup>41</sup>

Similarly, in Peru four organisations formed a consortium to gather 130,000 signatures to urge the government to introduce an inclusive disability law. This was followed by more lobbying by DPOs, which eventually led to a progressive disability law being approved in Congress in 2012.<sup>42</sup>

Recommendation: DPOs need to work together to ensure a united front that communicates change from a rights-based approach.

#### A representative voice needed

Finally, a big change is needed to include persons with disabilities in any law, policy or strategy that involves them. One way to do this is to ensure representation in parliament. As discussed in earlier chapters, there is representation for women and various minority groups, but not one seat in Pakistan's legislature is reserved for persons with disabilities. Public representation has many benefits, including not just speaking on behalf of persons with disabilities to influence decisions at higher levels of government, but also to change any negative perceptions. For example, Florence Nayiga Sekabira, the minister of state for elderly and disability affairs in Uganda, says that her position is seen as a role model by many: "It gives them the knowledge that having a child with a disability is not a curse as it used to be thought. Instead, if their child's potential is developed, she can contribute to the family and to the nation at large."<sup>43</sup>

Recommendation: Representative seat for persons with disabilities in parliament will have an impact on policy development and changing society's image of persons with disabilities.

#### 4. From exclusion to inclusion in Pakistan

With 15% of the world's total population and 20% of the world's poor made up of persons with disabilities, mainstreaming is an important policy agenda, not only from a human rights point of view, but also from a broader economic development perspective. The CRPD has only recently been introduced, and both developed and developing countries are starting to make changes. The task is not for the government alone; it requires <sup>41</sup> Handicap International [HI] (2010). The Inclusion of a Disabled People's Organisation Representative on the Moyamba District Council Social Welfare Sub-Committee. Rights in Action-Good Practices for Inclusive Local Governance in West Africa. http://www. ak-project.com/IMG/pdf/ rapport150PDesiciph\_GB\_ PRODP104\_301110.pdf

<sup>42</sup> http://www.cbm.org/ Peruvian-Congressapproves-disabilitylaw-372083.php

<sup>43</sup> As cited in http://www. disabilityworld.org/12-02\_05/gov/pwdingov.shtml



collaboration and commitment from the government, civil society, businesses and persons with disabilities themselves. And in developing countries, where the resources are limited and the to-do lists long, efficient use of resources by each stakeholder is important.

In many ways, the wheels were set in motion early in Pakistan—the successes of the disability movement have given rise to several policies, plans and strategies since the 1980s (albeit with a charity and medical focus). Unfortunately, the lack of capacity, weak implementation and other institutional changes have turned into roadblocks that have halted growth in the last few years. Similar challenges still exist, but Pakistan can learn from the variety of examples in developed and developing countries and set a leading example as a South Asian country. From the government to the man on the street, there first needs to be a shift from a culture of pity to one focused on dignity, empowerment and rights. To make this shift, persons with disabilities need to be empowered through quality education; they must have equal access to employment and be able to live and work in a broader physical environment conducive to their mobility, learning and working needs. Disability is not inability—it is a diversity that needs to be accepted.



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Trisha Suresh was the author of the report, with contributions by Sadia Mumtaz and Omar Waraich. If tikhar Firdous and Seema Khurram contributed to the research and analysis. Gaddi Tam was responsible for the design.

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(listed alphabetically)

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Omair Ahmad, chief executive, Network of Organisations Working for People with Disabilities (NOWPDP), Pakistan

Malik Shabbir Ahmed, caregiver, Pakistan

Abia Akram, chair, National Forum of Women with Disabilities, Pakistan

Khurram Badar Alam, civic and voter education officer, IFES, Pakistan

Zulqarnain Asghar, manager, NOWPDP, Pakistan

Saima Aslam, director of project management, Saaya Association, Pakistan

Marriyum Aurangzeb, parliamentary secretary, Ministry of Interior, Pakistan

Tahira Aurangzeb, legislator, Pakistan Muslim League

Aaron Awasen, head, Deaf Reach, Family Educational Services Foundation, Pakistan

Samina Baloch, Karachi Vocational Training Centre, Pakistan

Naheed Bibi, teacher, Umeed Special Education School, Pakistan



Motasim Billah, director, Social Welfare Department, Government of Khyber Pakhtunkhwa, Pakistan

Syed Haroon Ahmed Sultan Bokhari, minister for social welfare, Government of Punjab, Pakistan

Sadia Bundgaard, senior adviser, International Committee of the Red Cross, Pakistan Mushtag Butt, president, Sir Syed Deaf Association, Pakistan

Ihsanullah Daudzai, general secretary, Special Person Development Association, Pakistan

Mohammed Ghaly, professor of Islam and biomedical ethics, Hamad Bin Khalifa University, Qatar

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Zammurad Khan, former chairman, Bait-ul-Maal, Pakistan

Muniba Khurram, artist

Abid Lashari, president, Nawabshah Disability Forum, Pakistan

Malik Mahazullah, PTCL

Muhammed Idrees Mahsud, director, National Disaster Management Authority, Pakistan

Maryam Mallick, technical adviser on disabilities and rehabilitation, World Health Organisation (WHO) Pakistan

Roohi Maroof, head, Center for Autism, Pakistan

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Shahid Ahmed Memon, chairman, Pakistan Disabled Foundation

Sadia Mumtaz, co-founder and executive director, Inclusive Society, Pakistan

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Ghulam Nabi Nizamani, president, All Sanghar Handicap Association, Pakistan

Qari Saad Noor, president, Pakistan Association of the Blind

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Shahida Sajjad, dean, Faculty of Education, University of Karachi, Pakistan

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