



POLICY BRIEF

Empowerment of Persons Living with Disabilities: Democratic, Rights-Based and Inclusive Legislation





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Purpose

The rights of persons living with disabilities are the issue that requires immediate attention and action in Pakistan, given the evident gaps in the recently proposed bill. The lack of participation of people living with disabilities in the population reflects the stigmatization and taboos associated with the nature of disabilities, rendering people that are experiencing it as invisible. These conceptualizations create attitudinal barriers which limit access to private and public spaces, social and cultural inclusion.

There is a need to change the narrative of the discourse around persons living with disabilities from a charity-based model to a rights-based model. It is important that without passing an inclusive, rights-based legislation, the implementation will fail and continue to deny fundamental rights to the most vulnerable segment of the population, which comprises of 15.4% (Report PMHA 2018). This legislation is necessary to safeguard the civil and fundamental rights of persons living with disabilities.

International Legislation

For several decades, persons living with disabilities around the world have been organizing to advocate for their dignity and human rights and condemn violations of it. The global slogan of disability rights movement, **“nothing about us without us”**, demands the inclusion, participation, and representation of persons living with disabilities in all spheres of society. Conceptualisations of disability have evolved overtime from individualistic models, such as the charity and medical model, in which the disability is regarded as a person’s main attribute, to interactional models, such as the social, human rights and interactional model, in which it is seen as being caused by the interaction between the impairment and the attitudinal, environmental and institutional barriers present in the greater environment (Rohwerder 2015).

In the late 1990s and early 2000s, the UN, Member States, organizations of persons living with disabilities, academic institutions, civil society, and stakeholders in the field of disability held a series of technical meetings and global conferences to review existing international frameworks and instruments on disability (UNDESA 2018). In 2001, The General Assembly established the Ad Hoc Committee to draft an international convention to promote, safeguard and mainstream rights of persons with disabilities at an international, national and regional level (ibid). In 2006, the General Assembly adopted the Convention of Rights of Persons with Disabilities (CRPD) and its Optional Protocol, an instrument which defines disability and its categories, a development framework for national policy-making and legislation, and specific measures that need to be adapted and implemented ensuring the reinstatement of human rights and inclusion of persons living with disabilities. In 2007, CRPD and its Optional Protocol were open for signature and ratification and went into effect on the 3rd of May 2008.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) defines disability as the following:

‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (UNCRPD, 2006, p. 4).

National and Provincial Legislation

Although Pakistan signed the CRPD on the 25th of September 2008 and ratified it on the 5th of July 2011, the state has yet to submit initial and periodic reports specifying actions undertaken to meet the requirements of the convention for its citizens living with disabilities. A comprehensive law for the protection of persons living with disabilities is still awaited. Chief Executive of PMHA, Zulqurnain Asghar states, ***“Other than the 1981 Ordinance, we don’t have any legislation or act at the national level. If this gets passed, then the rights of approximately 33 million populations of persons living with disabilities will be reinstated.”***

The outdated legislation of Pakistan employs the charity and medical model in its definition. This definition is still reflective in the attitudes, mindsets and behaviour of society. In the Disabled Persons (Employment & Rehabilitation) Ordinance, 1981, the term ‘disability’ is not defined but rather a ‘disabled person’ is as the following:

“... a person who, on account of injury, disease or congenital deformity, is handicapped for undertaking any gainful profession or employment in order to earn his livelihood, and includes a person who is blind, deaf, physically handicapped or mentally retarded” (p. 1).

Previously, two provincial governments have passed legislations for the rights of persons living with disabilities: Sindh and Balochistan. The Government of Sindh passed the ‘Sindh Empowerment of ‘Persons with Disabilities’ Act, 2018’ in which the definitions of disability are aligned with the UNCRPD, rights and freedoms of persons living with disabilities are far more inclusive and comprehensive, and special measures to be taken to ensure them are mentioned. The Government of Balochistan passed the ‘The Balochistan Persons with Disabilities Act, No II of 2017’ in which the definition of ‘disability’ is the exact same as the one employed in the proposed ‘The Act Rights of Persons with Disability Bill, 2018’.

The definition of disability in proposed bill, The Act Right of Persons with Disability Bill, 2018’, defines ‘disability’ as:

“...a long term physical or mental condition that limits a person's movements, senses or activities and shall include physical, mental, intellectual and developmental disorders or sensory impairments which in interaction with various barriers hinder performance of persons suffering from such conditions to participate fully and effectively day to day performance and interaction with others on an equal basis”.

This definition above is a combination of the medical and social model of disability. However, both cannot be used in the same definition as the social model was a critique of the medical model. In the definition, there is an emphasis and repetition regarding the impairments and conditions of disability. As seen above, in the UNCRPD definition, the human rights model is utilised when it mentions “equal basis with others” (2016, p.4). The provincial governments of Punjab and Khyber Pakhtunkhwa have yet to make legislations. It is of utmost importance that the definitions and clauses in the legislation be aligned with UNCRPD.

Process of Consultative Dialogues

A series of consultations were held in which key representatives and stakeholders engaged in dialogues regarding the ‘The Act Right of Persons with Disability Bill, 2018’. The contents of the bill were contested

due to its significant implications on the 15.4% or 33 million populations of persons living with disabilities in Pakistan. There is a need to review the definition, language, and clauses of this bill as it is not inclusive of the voices for whom it's being made. The conceptualization and definition of disability is outdated and needs to be aligned with definition of disability employed in UNCRPD. The language of the bill is gender-blind and excludes the voices of women and girls living with disabilities. The clauses of the bill are generic and are in dire need of further specifications to ensure effective and smooth implementation.

Below are key messages made by human rights experts, civil society activists, heads and representatives of organizations of persons with disabilities, academics, researchers, lawyers, and political leaders regarding the evident gaps in the bill.

Farhatullah Babar
Secretary General
Pakistan People's Party (PPP)

“If from here any message goes to address this issue, then I think that this message should be given that disability is such a thing that can affect anybody, anytime in their course of life. If society takes this issue seriously, I think the perspective will change and that is the most important thing”.

The society and government in which persons living with disabilities live is a jeopardy from which they suffer. The other jeopardy is that some persons living with disabilities hide their own disabilities. They do this because they know that social attitudes are not okay.

The bill has been presented in the National Assembly. The National Assembly needed to send this to related committees. However, there was a delay in the formation of the committee, as we know. Now that the committee has been formed, the bill has landed in that committee. However, that committee has not met. This has gone to the human rights committee because the pilot of this bill was the Minister of Human Rights, Dr Shireen M. Mazari. This bill hasn't been put up for discussion in front of the committee yet.

“The thing that caught my attention in this bill is that, for example, the definitions chapter in which various things are defined, it is important to praise disability. Through this bill, what do you think of disability? I think the available definition is not complete”. The definition of disability needs to be expanded and aligned with the definition of UNCRPD. When the Government of Pakistan presented their case in Universal Periodic Review, they also made some promises. Those Universal Periodic Review (UPR) need to be taken out and the promises that the Government of Pakistan have made, in this regard, need to be implemented so that they are incorporated in this definition.

In all provinces, local bodies are going to be devolved this year. In the light of the past 5 years of experiences, new laws are being made. Now that new local government laws are being made, it is necessary that in all of these provincial laws and local government, a quota be reserved for persons living with disabilities. For this, there is no need to revise laws but to implement them, which is happening at this time. The first credible step is that you make representation of persons living with disability a reality, political parties should also raise



their voices. In the Senate, the representative of the federation, you should bring a resolution requesting all provincial governments to focus on the revisions that are happening in the laws of the local bodies in order to increase the representation of persons living with disabilities.

Another thing that I found lacking was under section number 7 in this bill. It was that in the bill it says the right to political participation. It is correct that right to political participation is necessary, but the right of political participation is limited to facilitate the voting process for person living with a disability; that's all. This is not political participation; political participation is that they shouldn't just be able to give votes but also participate in the political process and they can become a member of assembly. The right to political participation, it isn't complete. It needs to be completed to give these people a genuine right to political participation. Not merely that they should have their own booth to vote and should be facilitated to cast it. This is correct but not adequate. You need real representation.

“Currently, the members of the council in this, except for one person living with a disability, all the other people are government officials. The deputy chairman, who is a member of the national council, a serious limitation is that the government is responsible for the selection of the deputy chairman. It is essential that the formation of the council be done through a selection or election process of the council and include far greater representation of persons living with disabilities to ensure their voices are heard and valued. Also, there is no mention of the jurisdiction of the deputy chairman. Just one person, what the deputy chairman will do? He is a representative of persons living with disabilities, but he has no control”.

**Khawar Mumtaz, Chairperson / Minister of State
National Commission on the Status of Women (NCSW)
Government of Pakistan**

It is very important that the voices of persons living with disabilities are included in a complete manner. If their voices aren't included in a substantive manner, then right legislation cannot be made. What is the purpose of this bill? The people that are living with disabilities do they want to see themselves as excluded, considered sick or side lined from mainstream society! There is a dire need to think, research and document what the barriers are, what is the adequate enabling environment and how it can be enabled. If the environment is not facilitating and conducive, then persons living with disabilities will never be mainstreamed. For example, general elections 2018 took place and the election commission did make a lot of efforts as compared to before, but it wasn't successful because the people that were responsible for managing it weren't sensitized nor were they answerable for such failure.

There are issues of access and mind-sets, when we look at things that have come forth when people living with disabilities are given opportunities, their performance compared to other people is far greater. We have seen in our society, that if people are given opportunities they can go far. This means that the opportunities that society facilitates for them are based on their needs. There are a few things that we need to sit down and think about. How can we mainstream this vulnerable segment of the society? How can we facilitate persons living with disabilities based on their needs not ill informed societal misgivings and misplaced pity!

In this bill, there is no segregation of disabilities. There are some people that need more facilitation while others need less. There are some people that need technical facilitation, for example, wheelchairs make a

huge difference in case of people with limited mobility. Hence we need to ensure doors or transports that are wheelchair accessible. The whole approach needs to be changed.

All government and other authorities, such as NADRA, create difficulty for persons living with disabilities. Many people don't even report disabilities; hence there is an underreporting of it in the census 2017. There are also some reservations regarding the structure of proposed council in the bill. Because making a council and making it subject to the availability of a Minister, whether its human rights or law, ensures that practically the councils won't meet. In Pakistan, there are a lot of institutions that are created like this in which the chair is the person with the highest accord, who has other commitments and responsibilities that the council won't ever be able to convene and do its work. The council should be independent and autonomous in which the board should have the representation of persons living with disabilities and also people who are involved in funding and financing.

“There should be broad-based stakeholders with expertise and the council should be independent. When the discussion regarding this is held, the autonomous institutions should also be called and advice should also be sought from those who cause hindrances. I am speaking from my experience. The bill should ensure that problems don't occur after it is passed and that its institutional framework is made in time; that is all”.

Zulqurnain Asghar
Chief Executive
Potohar Mental Health Association (PMHA)

“A comprehensive and well-designed legislation leads to the smooth and effective implementation. If the legislation is not thorough then its implementation will not fulfil the purpose, nor solve the issues, neither reinstates the rights of persons living with disabilities”.

Due to lack of consultative process with persons living with disabilities, this bill has technical limitations. If we look at the different components of the bill, for instance definition of disability, it could be better aligned with UNCRPD's. The definition in the 1982 Ordinance is incomplete and outdated, disability segregation is missing. In order to mainstream persons living with disabilities, it is absolutely necessary that every type of disability and degree of disability should be categorized and represented in a comprehensive manner.

When we talk about inclusive education and disability-discrimination. It starts before going into education and is visible in our attitudes, behaviour and thinking. When a child is born with a disability or if parents find out from their doctor that their unborn child might possibly be born with a disability, then discrimination starts right from there. In our society, it is common that when a child is born with a disability, the thinking pattern is that the parents are being punished for a sin that they have committed. They keep it a secret and keep the child hidden. Some people also say that it is a curse from God. This is how we think as a society, and these are common practices. Persons and especially women living with disabilities are made to disappear. Institutional attitudes exist, and infrastructural spaces don't exist.

Justice (R) Ali Nawaz Chauhan
Chairman, National Commission for Human Rights, Pakistan (NCHR)

Persons living with disabilities face multiple challenges in the Pakistani society which include the public's negative attitude towards disability, inaccessible infrastructure and transport, inaccessible information and communication, limited access to education and employment/self-employment, limited access to social services and health care and limited access to sport and recreational activities. Furthermore, inadequate legislation deprives a proportion of our citizens of economic, social and political participation.

There is a huge bulge of untapped human resource in the form of persons living with disabilities, Pakistan is facing losses of millions of dollars every day by not including persons living with disabilities in the mainstream economy. It is pertinent to mention that Pakistan signed the Convention on the Rights of Persons with Disabilities (CRPD) in 2008 but has not submitted a single report about the status of persons living with disabilities that the convention obligates to submit every year. Until the early 2000s, the only legislation in effect which provided for the rights of persons living with disabilities was the "Disabled Persons (Employment and Rehabilitation) Ordinance, 1981" which laid down a quota for them in the job market and their rehabilitation but remained silent on their wider rights.

"Today, the whimpering was that for this bill, consultations did not take place. There are a lot of deficits in the bill that need to be corrected through curative measures. Unless we discuss the legislation we are not able to take it forward, which is the apprehension expressed today, that it may take another 15 years for the bill to get through".

The recently tabled Bill for the Rights of Persons with Disabilities falls seriously short of effectively responding to the grave situation. The care of persons living with disabilities was thought to have been devolved to the provincial governments with the devolution of the federal ministry of Social Welfare. This has resulted in a very grave violation of different Articles on Fundamental Human Rights enshrined in the constitution of Pakistan. Social protection schemes although have recently been introduced for persons living with disabilities (Punjab govt. pays meager Rs.1500 to persons living with disabilities), the overall situation overwhelmingly highlights the lack of national social security system.

Zahid Abdullah
Information Commissioner, Government of Pakistan

There is an entire paradigm that needs to be changed. Even today, our society perceives disability or persons living with disabilities as deserving of charity. Discourse on their rights does not happen. If anything is given to them, it is under the pretext of giving something to people that are helpless. This entire mindset is very problematic.



“PMHA Chief Executive Zulqurnain was kind enough to send me a PDF format of the bill but the version of PDF reader software that I have, the lines were breaking, and words were not readable with my software. If it was in Microsoft word, then I would have been able to read it very well. This was the government's responsibility to make the bill available in all formats so people with different needs can read it.”

In the bill, the chairperson of the council will be the Minister of Human Rights. If there is going to be government representation in this council, this will be just like the same council that previously existed under the ordinance, from which I never benefitted as a visually impaired person my entire life nor did I know about any benefit from it.

Professor Javid Rehman
UN Special Rapporteur on Human Rights
Professor of International Law
Brunel University, London

Although the convention has been signed and ratified, but the enabling legislation hasn't been made. It is very important that state shall do something now.

There's something we don't consider often because our system is such that accidents happen quite a bit, for example, work-related or road, from which people become disabled. What happens to them? What is the procedure for them to get into this fold of being recognised and valued as persons living with disabilities? Another challenge that we have is that there is a lot of violence in our society. Disability is also generated from violence and terrorism-related issues. We also need to gather data on that and have a clear understanding. A lot of disabilities occur during childbirth. Unfortunately, we don't have any accountability mechanism for those who create negligence and accidental disability.

“I mean, it's very mind-boggling, it's so unacceptable that 2017 census is showing that 0.48% of the population is disabled. When the 1998 census says it was 2.4%. How is it possible? You see, you need to question it. There must be some kind of discrepancy”.

To get special CNIC issued you have to visit many offices and the burden of proof is on you as an individual. The state has no responsibility. You have to prove that you come under the criterion. It is very important that it becomes simplified. Also, there is a lack of awareness and sensitivity. In our districts, they don't know what the system of registration and rights of persons living with disabilities are, this is very important. The other thing that troubled me is that the forms are not in indigenous languages. That form is available in English. How can you justify that where there's a low literacy rate and high poverty rates, people will be able to fill them properly? There are also other issues that come under this. There was a discussion on gender. There are other issues as well, such as minorities, refugees, children, IDPs. They have double the issues, like gender, of course, gender is a very serious issue, when an individual is a refugee, displaced person, transgender, or a minority, they are facing societal discrimination and it becomes even more difficult to survive as a person

living with a disability and to secure the registration and rights attached to it. *“What I note regarding persons with disabilities in our society. They are treated as invisible. There is no acceptance in our society. From sympathy to outright shame to have someone who is disabled. We try to hide disability. This is an unfortunate situation. In Pakistan, I don’t see public role models among persons living with disabilities”.*

Hadia Nusrat
Program Manager, Gender Justice
OXFAM Pakistan

After viewing the contents of this bill, it is evident that it has been drafted without the consultation of persons living with disabilities.

“The drafting of this bill is a commendable effort, however, in the very first paragraph of this bill, ‘his’ rights and ‘his’ access has been used to refer to a person living with a disability. There is gender-blindness in the language. If the language of the bill won’t be inclusive, then its implementation will similarly suffer”

We also know that only about 203,000 persons living with disabilities have special CNICs (Report PMHA 2018). Can we say that is society applying an inclusive lens when working on persons living with disabilities? Absolutely not. If we would like to, it is necessary to understand the difficulties a person living with a disability faces when acquiring a special CNIC, and for women living with disabilities, these difficulties and their degrees are far greater.

Globally there are 1 billion persons living with disabilities (WHO & WB, 2011). If we look at the global poverty ratio, 1 in 5 of those persons living in poverty is a person living with a disability, and if we were to do a gender disaggregated analysis of that, 80% of them will be women (ibid). To eradicate poverty, property needs to be accessible. There is an article in UNCRPD addressing and ensuring that persons living with disabilities are protected and have access to property.

In this entire bill, except for reproductive health, that women living with disabilities should have access to inclusive reproductive health facilities, there is no mention of any other rights such as to political participation, leadership rights, right to education, and employment quota. This bill needs a lot of work. If we acknowledge this as the first draft of the bill, then that is fine. From this point on, there is a lot of hard work that needs to be done.

We also know that women and men living with disabilities face different barriers. The patriarchal barriers women face also affects those that are living with disabilities. There exists a great deal of discrimination from their families which claim to be protecting them, but they are actually limiting them and discriminating against them from being able to enjoy equal human rights. Of the many segments of the society who are excluded, persons living with disabilities are also not included in many of the legislation for protection, access, honouring constitutional liberties, civil liberties, citizenship rights, etc. In this, like women are excluded or neglected, so are persons living with disabilities.

It is not sufficient to make an endowment fund for persons living with disabilities because 15% of the population is disabled, majority of whom are women living with disabilities. They face a triple burden as they are already living in a patriarchal society, with a disability, threat of facing violence. If there is a triple burden, how will they be represented and fight for their rights? Monetization, capacity enhancement, and accountability are absolutely necessary.

Pakistan makes a large number of bills and legislation. However, the deficiency is always in its implementation, contextualisation, revisions and monetisation. These issues can also be predicted with this bill. If the bill is passed as is, it won't be able to ensure rights and protections. In the Act Rights of Persons with Disability Bill 2018, it is absolutely necessary to bring rationale changes.

**Amjad Nazeer, Executive Director
Institute of Development Research and Corresponding Capabilities (IDRAK)**

The main thing to understand and acknowledge is that there is no disagreement regarding the fundamental principles of human and political rights, and the issues of basic societal acceptance and intellectual and participatory rights of the persons with disability. The difference is really in our attitudes. It is especially necessary to say that for a long time, a particular mindset has continued to prevail in political, electoral, legal and government organisations categorising persons living with disabilities as *'different'*.

“Current or past political parties have failed to give party tickets to PWDs to contest elections let alone to be backed by the entire party and be elected as a representative. The bill only briefly mentions the right to vote but is quiet on the right to be represented at national forums including the parliament”.

In the general elections of July 2018, 95% of polling booths were not accessible for persons living with disabilities of any category. It is important to mention that for men the situation wasn't satisfactory and for women it was demeaning. Regarding ballot boxes and ballot papers, according to the point of view of persons living with disabilities, desire to attend polling booths and cast their vote to enjoy their political right and activity was not fulfilled.

In the past, the election commission had accepted the need to provide assistance to persons living with visual impairment, but practically the polling agents were overall observed to be clueless, improperly trained, inconsiderate and discouraging towards persons living with disabilities which led to the feeling of dejection and inability to vote.

**Zille Huma, Member National Assembly
Member Standing Committee on Human Rights, Pakistan**

“Our people break our spirits. They leave our qualities behind and start giving us sympathies of a weird type”.

When I was nominated for a reserved seat, people congratulated me quite a bit, but they also said, “You have a problem with your feet, how will you go to the national assembly? What will you do?” Believe me, there was not a single person that hasn't said how I became a member of the national assembly. I can't walk properly. In the beginning, having gotten irritated from their talk, I replied to one or two by saying that I am going into the National Assembly as a member, and that I have not been selected in the cricket team. If we raise an issue and speak about it, there are many people that use violence to quite those who speak out.

Malik Mohammad Nawaz, Disability Mainstreaming Advisor Federation Handicap International, Pakistan

The questions regarding disability were not added in the census in a way that could automatically capture what the disability ratio is. The thing that was more important was that data regarding persons living with disabilities was not considered. Before this, statistical bureau of Pakistan was involved and responsible for data collection but it didn't take its importance seriously.

There is a tool that is used globally by the name of The Washington Group Short Set for data collection in censuses. This tool also wasn't used when the census in Pakistan was conducted. There was no type of questionnaire used that would, at the end of the census, capture data categorically such as hearing impairment, visual impairment, physical impairment, intellectual impairment. This led to the missing information regarding persons living with disabilities. There were data collection teams consisted mostly of the army personals and teachers. They weren't properly oriented on how to collect data.

If facilities, funding and legislation is made on the basis of data gathered in census 2017, it will automatically fail in the implementation phase. In 2008, Pakistan signed the UNCRPD and ratified in 2011. If we look at this critically, the first report to UNCRPD was due in 2013 but it is still pending in 2019. Although there has been work done on that and draft was made, but it was never submitted. In UN it is only when the report is duly submitted that the work on it is started.

“Any planning in which persons living with disabilities are not included or if something is being made for them and they are not in it will eventually lead to a weaker legislation, policy and regulation. There was no focus on persons living with disabilities in the planning phase of census 2017. Government allocate funding for persons living with disabilities based on the inaccurate figures that are available. When implementing, the needs are not met as there is a mismatch and resources are wasted”.

Environmental barriers limit persons living with disabilities from leaving their home and being included in society and access further services. All of our already constructed buildings or new buildings have designs that do not ensure accessibility. The roads and footpath construction standards are also a problem for a person living with a disability. All of the public places that exist are not accessible, whether they are parks, food streets, offices, etc. Then regarding transportation, buses and railway systems don't have ramps. Even in houses, there isn't accessibility in that sense. The doors are usually narrow; their width isn't suitable for a person living with a disability, especially with a wheelchair, to access. In hotels, the washrooms next to the rooms, their doors are narrow. Addressing the needs of persons living with disabilities are not considered in design and planning. Other than this, sanitation and wash facilities are not accessible for a person living with a disability to use independently.

Even if someone is educated and applies for a job, the negative perceptions regarding persons living with disabilities render them dependent and unable to do anything. Even if that person is offered a job based on the 2% quota, the persons living with disabilities are given jobs that require sitting, such as gardening, watchmen, guard, doorman, etc. There is lack of understanding among decision makers that persons living with disabilities have the capability to have jobs and skills above a certain level and according to their skills and education

A reasonable accommodation is a big gap in institutions. Even if they are employing persons living with disabilities, they don't have an idea regarding the needs of the person they are hiring for a particular position

and how to make the environment accessible for them. Departments find it is easier to hire them for lower cadre and positions to meet and claim the total quota and adjust responsibilities. Job opportunities should be given on an equal basis and at all levels. If someone has merit and received education, then it isn't necessary that they are allocated lower-cadre jobs due to his/her disability.

If we look at institutions, websites are not accessible for persons living with sensory impairments. There is no software available on the website for people who can't see or hear. Websites are not made to make it easy for them to use. Sign language is not common. The family of persons living with hearing impairment manage but the rest of the community is not sensitised nor does the average person have awareness. Braille isn't common, people also don't have an understanding regarding what it is, why it is important, how it is used, etc. Public libraries are not accessible. Education institutions such as schools, colleges, universities, are not accessible and their inclusion is limited. Teachers aren't sensitized in this regard. This is a violation of fundamental rights. At the primary level, they are excluded from mainstream society and therefore, not a part of the education system. Because of these barriers, lack of inclusive approach and the lack of visibility of persons living with disabilities is reflected in policy makers' / legislators' understanding when they make legislations and policies for persons living with disabilities.

**Furkhanda Aurangzeb, Senior Consultant
National Commission for Human Rights, Pakistan (NCHR)**

The reason we think people are disabled is because society doesn't have the arrangements in place that provide opportunities for persons living with disabilities.

When UNCRPD was ratified, a lot of promises were made by the government. *“In 2014, the regional commission on disability held a regional conference in Pakistan. When I heard from people during the three days of the conference, the extent of how passionately and diligently work is being done and the facilitations being made available in regional countries, only at that time I realised how behind we were in Pakistan”.*

Living with disability is an experience. In front of us, there are examples of persons living with visual impairment who have completed PhDs from top universities. If we don't take an interest in mainstreaming such people, then society will stay behind.

Another important thing is that until we continue to see special education institutions in marginalised forms, until then, our society will be disabled; not persons living with disabilities but society itself because we marginalised them through exclusive education system. Persons living with disabilities have different needs; we have imposed a disability on them by not creating support systems and not making a conducive environment. We don't even understand that in order to deal with a person living with a disability, a sensitivity of heart and mind is necessary.

There are no standardized instruments for data collection in Pakistan on disability that provides comprehensive data; a prime reason, why the figures presented in the 2017 census received a backlash from civil society, especially from the organisations working for the rights of persons living with disabilities. It is important to mention that the last census held in 1998 showed the population of persons living with

disabilities as 2.49% of the total population. According to **the World Bank's website**, almost 15% of the world population experiences some form of disability. The number of persons living with disabilities in India is 15% of its population, 17% in Afghanistan and 18% in Nepal. World Health Organisation (WHO) estimates that approximately 15% of Pakistan's population is disabled as per the definition provided in the UNCRPD.

Dr. Bashir Hussain Shah
Psychologist & Human Rights Activist

Primary school is the most neglected segment and giving attention to it is most important. If there is only one special education institution in one tehsil and the population of a tehsil is in hundreds of thousands, then how is it possible for a small tehsil to enrol children living with disabilities all over the tehsil?

“We implement things without consulting those that are affected the most and we fail every time. We must do it right this time with proper research and input from all concerned”.

Noreen Khan
Assistant Director Legal
Pakistan Bait-ul-Mal

When we talk about women, in our society they are mostly dependent on males. Women living with disabilities are even more dependent. Women and girls with disabilities experience double discrimination, which places them at higher risk of gender-based violence, sexual abuse, neglect, maltreatment and exploitation.

In section 6 of this bill, it mentions that special measures will be taken. There are no specifications regarding what those special measures will be. According to the drafting of this legislation, the rules that will be under it will have these details added. However, until the rules aren't made, no government special measures, whatever rights have been given to persons living with disabilities, mention any special measures. In section 14 of the bill, regarding the reproductive rights of women living with disabilities, the government should provide services because they face a lot of difficulties. From the beginning, parents get disheartened when thinking of matrimonial and future related setups. These are very difficult as being a woman with a disability, and often, parents take punitive action regarding reproductive rights which is why it is a non-compoundable offence. The fundamental and civil rights that the constitution gives us, we still don't have access today.

“I have a certificate and a job. I have obtained a stage, few women living with disabilities attain this stage in their span of life but even after reaching this stage, people's attitudes haven't changed”.

The right to education is everyone's right, but until it is made inclusive, our education system won't see changes until every person is facilitated on the basis of their needs as without facilitation, it is difficult for them to receive a quality education. Until we don't problematize the attitudes in society and tell them that persons living with disabilities have rights and they should be given them, others in society will accept us.

Recommendations

Participants of the consultative dialogues organized by PMHA under the leadership of Zulqurnain Asghar and the generous support of Federation Handicap International discussed all aspects of the bill with a positive attitude and provided informed and practical feedback. Following key issues along with mitigation measures and recommendations are synthesized here for making the bill more impactful and more applicable by the persons living with disabilities themselves.

- The definition of ‘Disability’ needs to be updated and in-lined with UNCRPD. In the definition, it should be marked that no one has the right to make or pass judgement on a person's disability or its extent and on that basis, exclude them from resources and services.
- It is important to create a monitoring, observation and complaining process as part of the Act itself. If the disability is evident and the person living with it is saying that he/she is disabled, then it should be regarded as that. Purpose of the Act should be enabling rather than discouraging persons living with disabilities and their families in getting their fundamental, constitutional and civil rights as per law.
- The civil society, persons living with disabilities and their representative organisations must be involved and enabled to participate fully in the evaluation and monitoring process under this Act.
- Whatever is made the part of the final Act, it must be binding with associated accountability and penalties for non-compliance.
- To mainstream persons living with disabilities, the objectives of the bill should be clear and loud. The language of the bill should be specific and clear without being left at the mercy of bureaucratic interpretation. Rules drafted based on the Act need to be clearly constrained by the Act itself in so far as these rules must not curtail any of the measures passed by the parliament as part of the Act.
- Act must be thorough in so far as recognizing and including all globally defined and accepted categories of persons living with disabilities.
- It is important to modify the bill from a charity-based discourse to rights-based discourse. Persons living with disabilities need to claim their rights on the basis of rights and not charity.
- The Act must create a disability rights commission comprising three people instead of current council described in the bill. The commission that is made under this bill needs to be an autonomous and independent body and the government should not be the part of the commission.
- Qualification criteria and search process for the commission members need to be specified.
- Members should bring diverse and complimentary skill set to make the commission effective. Following criteria may be used as a basis for forming the commission:



- ✓ A retired 22-grade bureaucrat
- ✓ A judge of the high court bringing knowledge of legal matters, and
- ✓ A commissioner from the field of disability activism or funding

- Review of building codes as well as the implementation of the same should be within the preview of the commission

- The tenure of five years should be written and protected in the law. Commission should have powers to evoke contempt of court charges as well as call state institutions to enforce its decisions

- There is a need to revisit the section 9 to specifically mention the jurisdiction of the commission.

- There is a need to form a separate ministry along with the disability rights commission. Such ministry for persons living with disabilities should be tasked with the framing of rules under the Act and across the board implementation of the law protecting the rights of the persons living with disabilities

- It is necessary for the language in the bill to be gender sensitive to ensure that its implementation is inclusive and effective

- There should be segregation of disabilities because disability is not one thing. Disability comprises a diverse range of different types and degrees of disabilities that need to be acknowledged, respected, given dignity and provided access to all rights as enshrined in the constitution.

- Act must ensure the rights, awareness, capacity building and access to participatory democratic process for persons living with disabilities are fully protected and are not curtailed in any way at the implementation stage

- Reserved seats need to be created in the national, provincial and local elected and appointed bodies all over the country for persons living with disabilities.

- The bill needs to include the voices, opinions, experiences and observations of all stakeholders. Bill should ensure that global best practices are adopted and reviewed periodically with regional and global participative consultations.

- There is an organisation by the name of International Foundation of Electoral Systems (IFES) which provides extensive support, information and training regarding the electoral experiences of every category of persons living with disabilities. The bill should create such a body within the election commission of Pakistan to learn from such institutions and include the suggestions made from their experiences in our own electoral process and trainings

- There are statutory five-year strategic guidelines for ensuring accountability. Current Bill, in a section involving marginalized groups including persons living with disabilities, says that there needs to be

accountability regarding achieving target goals over specified time frame. However, a section should be added regarding any unethical medical procedures performed on persons living with disabilities along with punitive and disciplinary measures for non-compliance.

- Act must be an overarching and comprehensive legislation to mainstream women living with disabilities with special protections regarding women's rights, liberties, access and protection from being isolated and denial of freedom in the name of protection.
- Where child labour is concerned, we see children living with disabilities in labour, so they should also be protected in the bill.
- Persons living with disabilities should be given positions based on their skills and capacities, not necessarily on the basis of social welfare or as a minister of organisations that work with persons living with disabilities. Positions should be available in any sector, for any qualified or aspiring a person living with a disability to pursue such fields as health, education, financial, communication, IT etc. The government also needs to equally involve them in policy-making processes and decision making.
- The administrative affairs need to be carried out in a proper manner and budgetary resources need to be allocated accordingly. It is not that persons living with disabilities are a burden on resources or that resources are a requirement for them; they can also be resourceful. Their intellectual, human, personal and political agency should be utilized as a human resource as until persons living with disabilities are not empowered financially, one cannot ensure their social and cultural mobility and inclusion in the society.
- Where funding for rehabilitation is concerned, it is necessary that the government establish an endowment fund and allocate adequate funds for it. There must be sufficient seed money for the fund. The clause in existing bill regarding such funding should be revisited
- To ensure right to vote, ballot boxes / ballot papers should be as defined as possible for various types and degrees of persons living with disabilities. It is absolutely necessary to provide the most optimum option and without compromising their political participation and inclusion at any level. Depending on the types of impairment, the introduction of braille ballot papers or boxes, changes in text size or colour, or assistive environmental, infrastructural or other mechanisms should be considered and implemented
- Regarding schools, it may be beneficial to have some specialized schools for children living with disabilities but independent of that all schools must cater to the educational and social interaction needs of children's living with diverse types of disability.



- It is extremely necessary to simplify the procedures of civil registration in the recently presented bill. This responsibility is of the state to include the verification of the disability in that one-window operation from which the disability certificate is obtained.
- For implementation of poverty alleviation programs including the Benazir Income Support Program, persons living with disabilities should be automatically linked using NADRA records. The moment the name of a person, particularly woman, appears on any of the poverty alleviation programs, it must immediately be reflected as a beneficiary and recipient of the poverty alleviation funds and services within the NADRA database
- Along with a man and woman, it is critical that there shall be a representation of a transgender / minorities living with disabilities. The Government of Pakistan acknowledges three genders: male, female, and transgender, which includes other non-conforming gender identities. Like other gender, sexual, ethnic and religious minorities, transgender face extreme levels of discrimination and violence due to their gender and sexual orientation. In case of disability, the vulnerability is increased to extreme levels. It is important to extend outreach to them and understand the particular issues they face as a person living with disability and being transgender. This issue, similar to other issues, needs to be handled with dignity, sensitivity and understanding in the bill.

Conclusion

A series of consultations were held in which key representatives and stakeholders comprising of human rights experts, social activists, heads and representatives of Disabled Persons Organizations (DPOs), lawyers, community and political leaders participated. Comprehensive dialogue and detailed analysis regarding the proposed 'The Act Rights of Persons with Disability Bill, 2018' were conducted through open and participative forums.

The content of the bill were vociferously contested due to its significant implications on the lives of not only 15% or 33 million population of persons living with disabilities in Pakistan but also on their immediate families. It was specifically pointed out that there is a need to review the definition, language, and clauses of this bill as it is not inclusive of the voices of those for whom it is supposedly being made!

The conceptualization and definition of disability was found to be outdated and need to be aligned with UNCRPD. The language of the bill was also determined to be gender-blind with the result that it excludes the voices of women and girls living with disabilities. The clauses of the bill are generic and lack specificity and hence will be a hindrance when it comes to actual implementation. The above are just a few of the glaring gaps that are in dire need to be revised with proper input from DPOs and other relevant experts and bodies. Efforts and discussions at appropriate forums are urgently required to ensure improvements in the proposed bill for its effective and smooth implementation.

This document summarizes the key input and important points made by human rights experts and activists, heads and representatives of Disabled Persons Organizations (DPOs), lawyers, and political leaders regarding the glaring gaps in the bill and it is intended as a policy input document for the legislative bodies to improve the language and proposed measures in the bill before it is enacted as an ACT to make it more effective and forward looking.

Specific input from some of the participants that captures the sentiments as well as range of proposed amendments and measures for making the bill more inclusive and representative of the issues of persons living with disabilities is given here under for consideration in framing the policy and legislative framework.

It must be emphasized here that the discussion should always begin from the parliament, government, political parties and grass roots organizations. This is because political parties control positions and later introduce many economic policies and measures. It is essential for political party manifestos to give importance to persons living with disabilities in every respect and express the respective policy measures, promises, and political commitments. Their inclusion as an integral part of our society is only possible if and when we treat them as common citizens in political and social affairs. Hence, there should be political will behind the Act and affirmative action for mainstreaming persons living with disabilities.

This is a generalised bill and specifics are missing. It is important for the human right committee and ministry of law to review this aspect. In order to mitigate barriers, there is a need for categorisation and to identify what facilitation is important for different types of disabilities in order to ensure mobilisation.

References

- Assembly, G. (2015). Sustainable development goals. *SDGs), Transforming our world: the, 2030*.
- CRPD, U.N. (2006). Convention on the rights of persons with disabilities and optional protocol. *New York: United Nations*.
- PAIE. (2018). *Accessibility Audit of Polling Stations in Islamabad Capital Territory (ICT)*. Centre for Peace and Development Initiatives.
- PMHA. (2018a). *Inclusion of Persons Living with Disabilities in Electoral Process*.
- PMHA. (2018b). *Bringing Disability in the Constitutional Net*.
- Rohwerder, B. (2015). *Disability inclusion: Topic guide*. Birmingham, UK: GSDRC, University of Birmingham.
- Sindh Empowerment of 'Persons with Disabilities' Act (2018).
- The Balochistan Persons with Disabilities Act, No 2 of (2017).
- The Disabled Persons (Employment and Rehabilitation) Ordinance (1981).
- The ICT Rights of Persons with Disabilities Act (2018).
- The Right of Access to Information Act. (2017).
- The Washington Group on Disability Statistics. The Washington Group Short Set of Questions on Disability. Retrieved from <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/The-Washington-Group-Short-Set-of-Questions-on-Disability.pdf>
- UNDESCA. (2018). Realisation of the Sustainable Development Goals By, For and With Persons with Disability. <https://www.un.org/disabilities/documents/2019/UN-flagshipreport-disability.pdf>
- UNDP (1998). Human Development Report. Oxford University Press Inc. Retrieved from http://hdr.undp.org/sites/default/files/reports/259/hdr_1998_en_complete_nostats.pdf
- WHO & World Bank. (2011). World report on disability. Geneva: WHO. http://www.who.int/disabilities/world_report/2011/report.pdf
- World Bank. Health, Nutrition and Population: Reproductive Health and Disability. Retrieved from <http://go.worldbank.org/FRRGTUUL20>

POTOHAR MENTAL HEALTH ASSOCIATION

Potohar Mental Health Association (PMHA) is a registered non government organization, working on mental health of persons living with disabilities including children, youth, adults (men and women).

PMHA is registered under the Voluntary Social Welfare Agencies; Ordinance 1961 on September 12th 2002, registration number is VSWA328 ICT.

Our aim is to striving for a society that is well informed, educated, mentally healthy and progressive, in a way that it lives beyond differences and has acceptance for those who are differently able without any distinction of class, sex, color or creed and disability.

We endeavour to attain these goals through research projects and by playing an advisory role to motivate government to introduce better legislation for the betterment of the mental health and disability scenario in Pakistan specifically and over all society in general.