

# Pakistan Disability Report 2021

By:  
Social Protection  
Resource Centre  
(SPRC)

**SOCIAL PROTECTION  
RESOURCE CENTRE**

A Think Tank Dedicated To Promote Universalization Of  
Social Protection In Pakistan.

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# Table of Contents

Foreword.....	4
Acknowledgements.....	6
List of Figures .....	7
List of Tables .....	8
Abbreviations .....	9
Glossary.....	10
Introduction.....	11
1.1.Evolution of Rights for Persons with Disabilities .....	12
1.2. Pakistan’s situation on ratification of international conventions and history of local organisational efforts for PWDs and legal framework .....	13
<b>State of Disability in Pakistan.....</b>	<b>15</b>
Global Scenario.....	14
Disability Scenario in Pakistan .....	14
2.1. Older Persons with Disabilities.....	23
2.2. Children with Disabilities.....	23
<b>Mental Health Problems in Pakistan: Challenges, Current Responses and the Way Forward</b>	<b>25</b>
3.1. Mental Health and Disabilities .....	25
3.2. Youth Mental Health Problems Today .....	29
3.2.1. Demographic data of Pakistan .....	29
3.2.2. Strengths of Mental health system in Pakistan .....	31
3.2.3. Weaknesses of mental health system in Pakistan .....	32
3.2.4. Social protection .....	32
<b>Institutional Arrangements for PWDs.....</b>	<b>34</b>
4.1. Introduction .....	34
4.2. Eligibility to Avail Benefits .....	34
4.3. Laws and Policies for PWDs in Pakistan .....	36
4.3.1. Policies for Health Sector.....	36
4.3.2. Policies for Education Sector .....	36
4.3.3. Policies for Employment sector .....	37
4.3.4. Policies for Banking Sector.....	37
4.3.5 Policies for Housing sector .....	37

Taking Care of the Physically Disabled.....	43
5.2. Bazeecha Trust: A Case Study .....	45
5.2.1. Common Challenges faced by PWDs .....	49
Institutional Challenges of PWDs during Covid-19 .....	50
General effect of pandemic on PWDs, Families and Institutions thematic findings .....	52
Results and insights .....	55
<b>Conclusion &amp; Policy Recommendations</b> .....	57
<b>References</b> .....	59

## Foreword

Estimated statistics of World Health Organization shows that more than one billion people live with a disability worldwide, out of which approximately 200 million are facing the significant functioning disability. In the coming time, disability will become the topic of major concern as the prevalence of disability is increasing day by day. This is because of the rise in the chronic health diseases like diabetes, cardiovascular diseases, cancer, mental health disorders globally and ageing population's increased risk of incapacity as well. In addition, mental health has a specific link with disabilities and persons with disabilities. There is a strong evidence that mental illness is contributing at least 25% to 30% of disease burden, globally.

Persons with disabilities throughout the world have inadequate health services, lower level of education, less economic as well as social participation and higher poverty rates than that of people without disabilities. The major reason behind this is the lack of affordability and accessibility of basic services and social protection like health, education, employment, and transport as well as information. Moreover, the situation is worse in the developing countries like Pakistan where social protection system is already weak.

In Pakistan, there is little attention given on mainstreaming PWDs, the consequence of which they have to face in multiple aspects of life. They are unaware of their rights, suffer from low self-esteem, feel themselves as unfit and end up being poorly treated by the people around them. The challenges that come in addition to the physical difficulty include mental health issues, social stigmas and economic challenges. Differently abled persons require additional financial support to fulfill their additional medical needs and for improved physical mobility. Often people are not aware of sensitivity of differently abled persons due to which in addition to the physical challenge they face social alienation too.

In the context of mental impairment or disorder, Pakistan lacks a reliable data that can give us a detailed account of the extent of the mental illnesses and related disabilities. The topic of mental health has not given much attention by the state. There are only around 400 qualified psychiatrists working in Pakistan and most of the psychiatrists are working in urban cities.

Disability or impairment should not be the barriers to successful and happy life. In fact, it is the moral duty of the state and society to remove the participation barriers like education, employment facilities and to provide the adequate social protection to the differently abled persons so that it could be helpful for them in realizing their full potential.

Social Protection Resource Centre (SPRC), being a premier think tank dedicated to the universalization of social protection, decided to work on a comprehensive Report on "The Pakistan Disability Report 2021" in order to mainstream the challenges faced by the persons with disabilities in Pakistan. This report provides the detailed view of the situation of the differently abled person in Pakistan and provides recommendations for action at national level.



I believe it will be a significant resource for policymakers, academics, practitioners, activists, and volunteers who work or deal with persons with disabilities and it will be helpful for inclusion of the differently abled person in social protection schemes and society as well.

Dr. Razia Safdar  
Executive Director, SPRC

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## List of Figures

- Figure 2.1: Current Scenario of the disability globally
- Figure 2.2: Type of Disabilities in Pakistan (1998)
- Figure 2.3: Available data on Persons with Disability
- Figure 2.4: Comparison of the statistics of PWDS
- Figure 2.5: Number of registered PWDs with NADRA
- Figure 2.6: Percentage of Disability and Functional Limitations
- Figure 2.7: Disability & Functional Limitation among different age groups
- Figure 2.8: Educational attainment among PWDs
- Figure 2.9: Gender Comparison of Differently Abled Population (Punjab)
- Figure 2.10: Wealth Quintiles and Functional Difficulty
- Figure 2.11: Region (Rural/Urban) Comparison of Functional Difficulties
- Figure 2.12: Gender Comparison of Functional Difficulties
- Figure 2.13: Age Comparison of Functional Difficulties
- Figure 2.14: Determinants of Healthy Ageing
- Figure 2.15: Disease Breakup of Patients at Department of Developmental & Behavioural Paediatrics (DBP)
- Figure 3.1: Facts about Mental Health in Pakistan
- Figure 3.2: Public Mental Health Interventions
- Figure 3.3: Percentage of Suicide Ideation
- Figure 4.1: Timeline of the Laws and policies for the rights of Person with disability (PWDs)
- Figure 5.1: Facilities for PWDs at Bazeecha Trust's project Sunshine home

## List of Tables

Table 2.1: Socio-economic Profiling of Households in Punjab with PWD(s)

Table 3.1 Institutional Profiles

Table 3.2. Demographic profile of the institutions

Table 4.1. Policy reform by the Government for PWDs

Table 4.2 Acts and provisions adopt by provinces for PWDs

## Abbreviations

<b>ADA</b>	Americans with Disabilities Act
<b>AJK</b>	Azad Jammu and Kashmir
<b>CP</b>	Cerebral Palsy
<b>DBP</b>	Department of Developmental & Behavioral Pediatrics
<b>ICESCR</b>	International Covenant on Economic, Social and Cultural Rights
<b>ICF</b>	International Classification of Functioning Disability and Health
<b>ICF-CY</b>	International Classification of Functioning, Disability and Health for Children and Youth
<b>CH-ICH</b>	Children's Hospital and Institute of Child Health
<b>KP</b>	Khyber Pakhtunkhwa
<b>MICS</b>	Multiple Indicator Cluster Survey
<b>NADRA</b>	National Database & Registration Authority
<b>NARC</b>	National Association for Retarded Children
<b>PBS</b>	Pakistan Bureau of statistics
<b>PMH</b>	Public mental health
<b>PSLM</b>	Pakistan Social and Living Standards Measurement
<b>PSPA</b>	Punjab Social Protection Authority
<b>PWDs</b>	Person with disabilities
<b>SDGs</b>	Sustainable Development Goals
<b>SPRC</b>	Social Protection Resource Centre
<b>SSP</b>	Sehat Sahulat Program
<b>UDHR</b>	Universal Declaration of Human Rights
<b>UN ESCWA</b>	The United Nations Economic and Social Commission for West Asia
<b>UNCRDP</b>	United Nations Conventions on the Rights of the Persons with Disabilities
<b>UN-ESCAP</b>	The United Nations Economic and Social Commission for Asia and the Pacific
<b>WHO</b>	World Health Organization
<b>YLD</b>	Years Lived with Disability

## Glossary

Term	Definitions
Disability	<p>WHO defines disability, having the three dimensions:</p> <ul style="list-style-type: none"> <li>● Impairment in the body or mental function and structures, for example visual loss, memory loss etc.</li> <li>● Limitations in the activity such as difficulty seeing, hearing, walking, or problem solving.</li> <li>● Restriction in participating daily activities like working. Getting health care and preventive treatments, as well as participating in social and recreational activities.</li> </ul>
Physical disabilities	<p>A physical disability is an impairment to a person's mobility, physical capability, stamina, or dexterity. This can include physical trauma, brain or spinal cord injury, multiple sclerosis, cerebral palsy.</p>
Intellectual disabilities	<p>Intellectual disability is described as a set of problems with reduction in general mental abilities that affect two key areas of functioning:</p> <p>Intellectual functioning (like learning or problem-solving).</p> <p>Adaptive functioning (Daily life activities like communication and independent living).</p>



## Chapter 1

### Introduction

The term “Disability” describes inability/decreased capacity of certain structure or function. Human structural or physical disability is not a new phenomenon that has been highlighted due to increased incidence /identification in the number of the affected people but it dates to history of humankind. Such people were considered unhealthy or sick individuals. In addition they were regarded as unable to perform any activity even with mild forms. Further, due to misconception people with disability especially visible disability had to face abusive behaviour of the society, resulting in poor quality of life of persons with disabilities as compared to the person without any disability<sup>1</sup>. Disability can be defined as **“A substantial restriction in the capacity of the person to carry on a profession, business or occupation or to participate in social or cultural life due to the reason of an enduring physical, sensory, or intellectual impairment”**. For the sake of this report, we are including the following disabilities in our list.

- Physical disabilities
- Intellectual disabilities

It is estimated that more than one billion people live with a disability, worldwide. Although “people with disabilities” sometimes refers to a single population, this is a diverse group of people with a wide range of needs. Two people with the same type of disability can be affected in quite different ways. Some disabilities may be hidden or not easy to recognise. Households with Persons with disabilities are more likely to live in poverty and have lower standards of living than persons without disabilities. Management of persons with disabilities increases cost of living even up to 60%. Similarly, the challenges faced by persons with disabilities vary across the life cycle as well as between cultures, societies, genders, and economic classes. Access to social protection can equally play a key role in enhancing the wellbeing of persons with disabilities.

Disability is highly diversified concept. Although all people having disability need access to same general mainstream healthcare services, but because of the diversification element that is present in disability, some need more extensive health care services as compare to others. In accordance with the UN Convention on the Rights of Persons with Disabilities (Article, 25), **It is the right of every person with disability to receive quality healthcare services without any discrimination**<sup>2</sup>. However, the evidence across the world shows that persons with disabilities face poor health services, low education attainment, less economic participations, and poverty especially in low-income countries. Poverty has a bidirectional impact on disability. On one hand through malnutrition, inadequate health services, poverty fuels the risk of disability and on the other hand, resulting disability increases the risk of poverty through unemployment, low educational attainment, and rising cost of living. CRPD also emphasizes the social model of disability that considers the society as a significant trigger of worsening disability. As mostly in developing countries, society is of view that persons with disability are incapable of becoming useful members of the society consider them mere dependents. In short, disability is not an individual's biological issue, but it lies inside social failure.

### 1.1. Evolution of Rights for Persons with Disabilities

During the 1800s, it was realized that the disability is a medical problem that had consequences for individual and public. Beside this, it also had certain social implications. At that time disability was considered as a medical problem that led to the medical model of disability. The medical model of disability considered disability as an issue of the person with disability only and the objective of the physicians was just to cure the disabling factors or to modify the behaviour and attitude of the person with disability. In addition, according to medical model of disability physicians knows better than the persons with disability about the required health care services. After 1800s, persons with disability, their families and certain activist groups rejected this medical model of disability in the favour of social and bio psychosocial models of disability. These models consider certain other factors like environmental and societal factors that create hurdles in obtaining required health care and the ability of the persons with disabilities to participate fully in their communities. Taking this in account, the policies and laws that were designed during 1857, promoted the inclusion of People with disability in the society. Earlier, most of these policies focused on the employment or income support instead of health services<sup>3</sup>.

Although the issue of disability had been considered during 1800's but it gained more popularity during 1900s. During 1930s, a league was organized for the physically handicapped group that fought for the employment at the time of the Great Depression. Moreover, in 1940, psychiatric patients came together to form a group named "We are not Alone". Following this, several other groups came together and formed an association named "National Association for Retarded Children" (NARC) with the objective to find out some alternative solution to educate and to provide proper health care services for the children facing any disabilities during 1950s<sup>4</sup>.

Due to increasing focus on the issue of disability, leadership also paid some attention toward this. Formation of National Institute of Mental Health in 1948 and organization of certain planning committees during 1960 and 1963 to treat and to conduct research on disability were few steps taking by the leadership of that time. Further, beside all these efforts, UN congress passed certain laws and policies in the favour of the rights of differently abled persons<sup>5</sup>. The United States of America was the first to pass extensive laws or policies for the people with disabilities. Americans with Disabilities Act (ADA) signed on July 26, 1990, was the first civil law designed to prevent the discrimination faced by the people with disability in term of employment and accessibility to the public and private services. This act was amended in 2008 and expanded the coverage of the persons with disability. The four main goals of ADA were to encourage the full participation of the person with disability in the society, provide equal employment opportunities, improve their living standard, and ensure economic self-sufficiency. Besides this, Healthy people initiative 2010 had established for the first time with the intention to improve the well-being of persons with disabilities . However, slow progress had observed in meeting these objectives<sup>6</sup>.

Apart from these, the effort which is considered as the heart of all the disability rights movements is the UN Convention on the Rights of Persons with Disabilities (CRPD). It is the most popular global treaty, which provides protection to differently abled people<sup>7</sup>. UN Convention on the Rights of Persons and its Optional Protocols (A/RES/61/106) with disabilities was adopted on 13<sup>th</sup> December 2006 at United Nations Headquarters New York and was opened for signatures on March 30, 2007. Including US, 158 countries signed the treaty out of which 138 countries had ratified it. The goal of CRPD is to protect the rights of all human beings including the people with disabilities by considering the element of self-respect into account<sup>8</sup>. United Nations Convention on the Rights of Persons with Disabilities (CRPD) defines disability as:

*“Person with disabilities include those with long- term physical, mental, intellectual or sensory impairments which in interaction with different barriers can hinder their effective and full involvement in society on an equal basis with others.”<sup>9</sup>*

Besides this International Classification of Functioning, Disability and Health (ICF) is developed by the WHO, which is approved by the general assembly in the year 2001. It provides an overview of circumstances involving human functioning and its limitations. In addition, it also acts as a mechanism for structuring this information in a meaningful as well as accessible way. The WHO's ICF, defines disability as:

*“An umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).”*

## 1.2. Pakistan's situation on ratification of international conventions and history of local organisational efforts for PWDs and legal framework

Pakistan became the signatory of the United Nations conventions on the right of the person with disabilities (UNCRPD) on September 25, 2008 while it was ratified on July 5, 2011. Despite of the fact that Pakistan is the signatory of the UNCRPD which is ratified in 2011 but the country has been taking a variety of constitutional, policy, legal, and institutional measures to ensure the rights of PWDs in accordance with constitutional provisions since the 1980s. UN announced the year 1981 as an International Year of Disabled Persons and that brought the systematic care and protection of PWDs into sharp focus in Pakistan.

The systematic care and protection of PWDs was brought into focus in Pakistan with the observance of the International Year of Disabled Persons in 1981 proclaimed by the United Nations. After that, Government of Pakistan and some private sectors started working on mainstreaming the rights of the PWDs. An ordinance was passed in 1981 titled “Disabled Persons (Employment & Rehabilitation) Ordinance, 1981” that shed light on the responsibility of the state in facilitating and providing the PWDs rights, protection, education, health services and employment also. Besides this, certain other acts or policies were passed for the protection of the rights of the persons with disabilities. All these acts and policies are discussed in detail in section 4 of this report.

The constitution of Pakistan (1973) provides a shield to the rights of PWDs. According to the constitution, it is the state's responsibility to provide the necessities of life to all its citizens without any discrimination in terms of gender, cast, race, creed, or any other basis<sup>10</sup>.

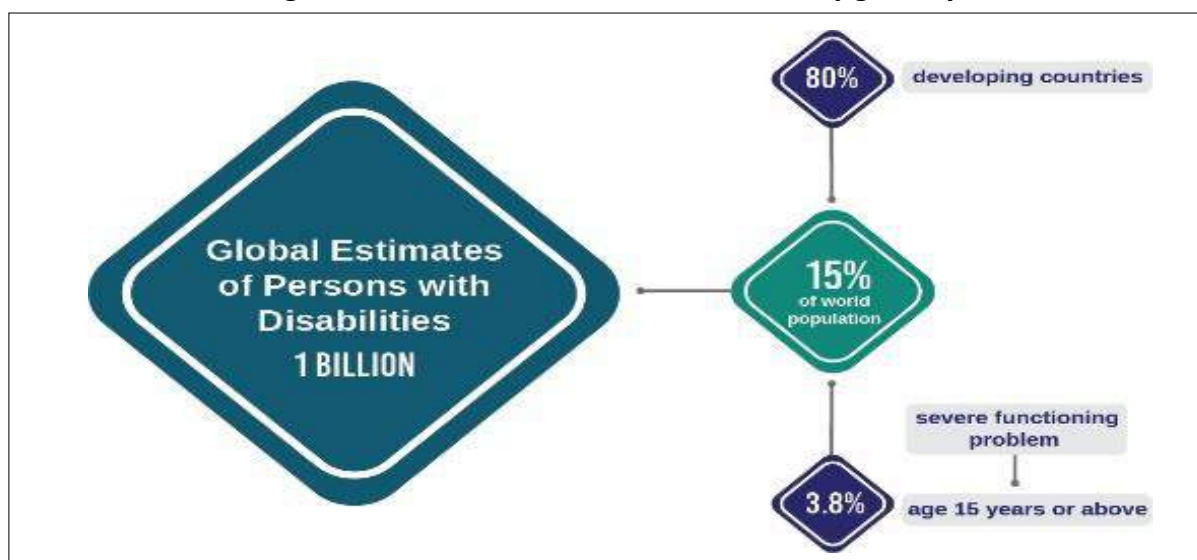
## Chapter 2

### STATE OF DISABILITY IN PAKISTAN

#### Global Scenario

It is estimated that nearly 15% (1 billion) of the world population are having some type of disability. Out of this 15 % most of population belongs to the developing countries (i.e. 80%). In term of age out of 15% of the population with some disability, 3.8% having the age 15 or above are facing the severe functioning problem (see figure 2.1).

**Figure 2.1: Current Scenario of the disability globally**



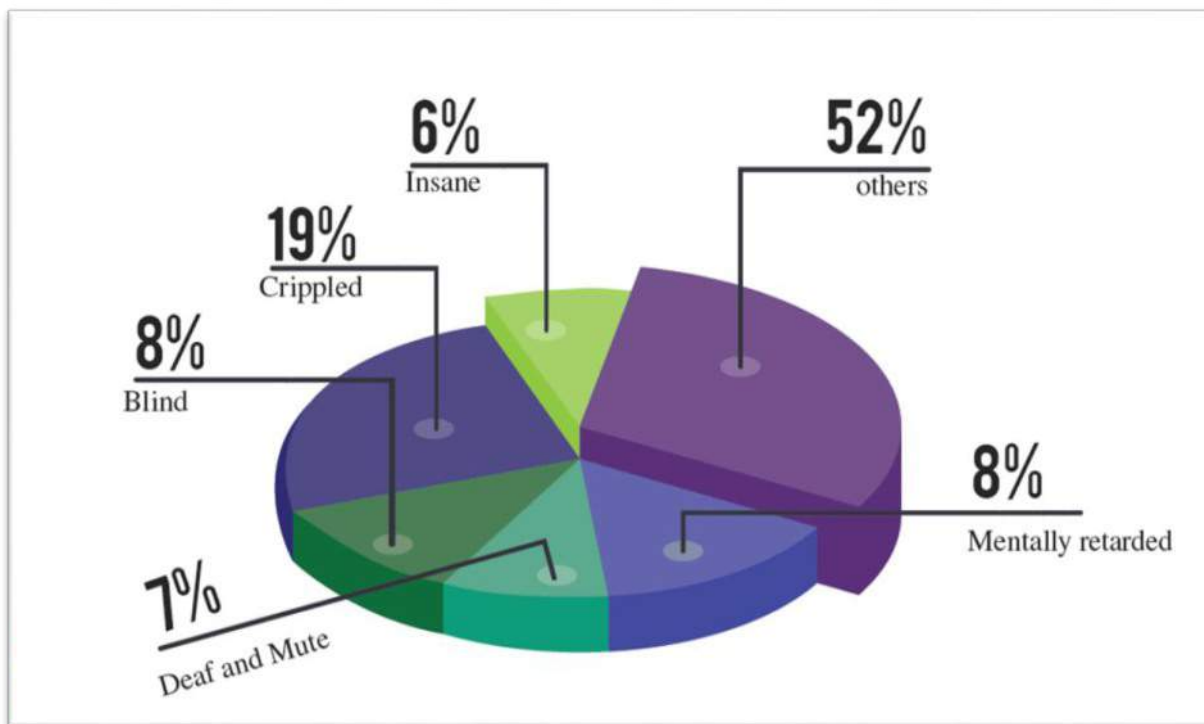
Source: [www.who.int/news-room/fact-sheets/detail/disability-and-health](http://www.who.int/news-room/fact-sheets/detail/disability-and-health)

#### Disability Scenario in Pakistan

In developing countries like Pakistan, provision of health care services is not the best, especially to persons with disabilities. The topic of disability in Pakistan has remained ignored at all levels, including administrative, financial and legal aspect. Pakistan is also facing the problem of scarcity of data on disability. Disability has been acknowledged and included in Population & Housing Census 1998 in Pakistan, but this data faces the problem of its adequacy being questioned due to multiple reasons such as lack of a standardized definition of disability. The census data shows that the percentage of the population facing any type of disability is around 2.49% and this figure is lower than the estimates of WHO i.e. 15%. In addition, Population & Housing Census 1998 also shows that out of this percentage (2.49%), the share of rural areas in terms of persons with disabilities is 66%, percentage of literate and employed PWDs is 28 and 14, respectively. Further, it was also observed that the 70% of PWDs are dependent on their families for any financial support.<sup>11,12</sup>

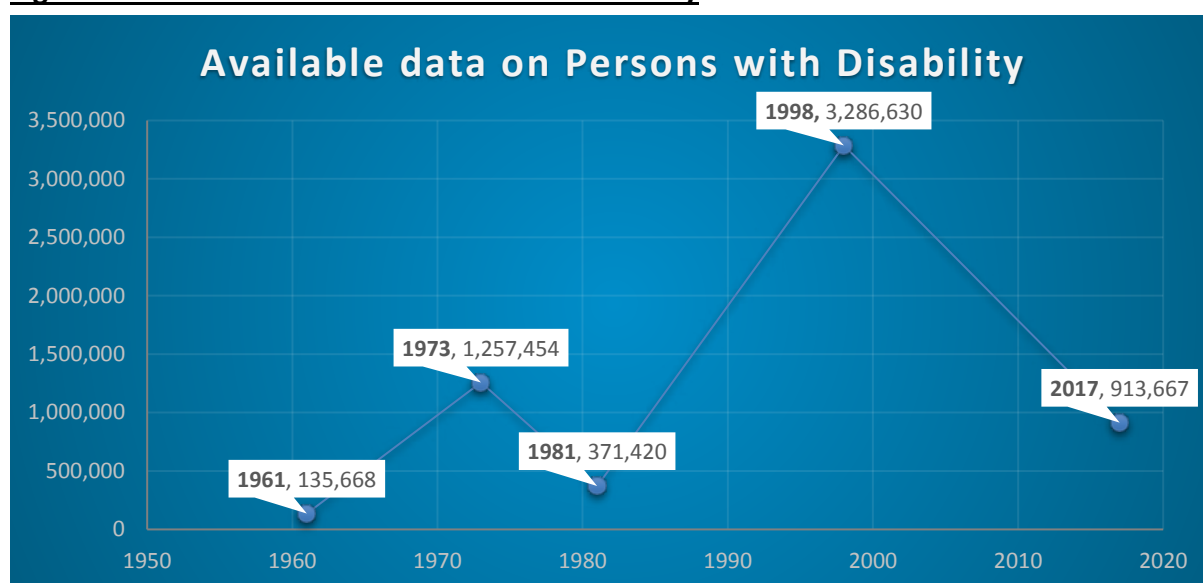
Similarly, given the estimates of 15 percent prevalence of global disability by the World Health Organization (WHO) out of 207 million population (census 2017), some 31 million are estimated to be living with some type of disability in Pakistan. No comprehensive national survey has been undertaken yet that highlight the actual burden of disability in Pakistan. The incidence of persons with disabilities in accordance to census 1998 was 2.49% (3,286,630) of the total population in Pakistan, out of which 58% were male and 42% female. Of which, 8.06 (2,647,62) percent were blind, 7.43 percent deaf/mute, 18.93 percent crippled, 6.39 percent insane, 7.60 percent mentally retarded<sup>13</sup>.

**Figure 2.2: Type of Disabilities in Pakistan (1998)**



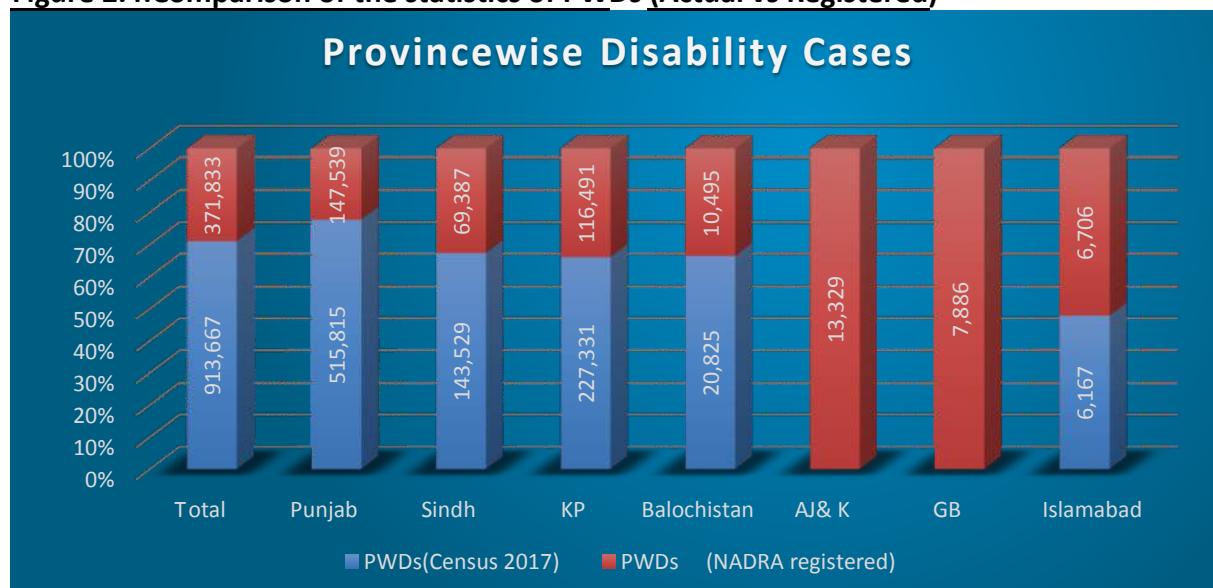
Source: 6<sup>th</sup> Population & Housing Census (1998)



**Figure 2.3. Available data on Persons with Disability**

Source: [www.pbs.gov.pk/content/disability-statistics](http://www.pbs.gov.pk/content/disability-statistics)

Recently in the year 2020, Pakistan Bureau of statistic (PBS) received the cumulative data from NADRA registered PWDs shows that there are total 371,833 PWDs in all over Pakistan. Out of these the province with registered disability cases are Punjab having 147,539 cases, KP with 116,491 cases, and Sindh with 69,387 cases. In AJK 13,329, Baluchistan 10,495, GB 7,886 and in Islamabad there are 6,706, respectively. Moreover, the data also shows that the cases of the person with physical disability are more i.e., 295,093 than the mentally retarded ones i.e., 31,914 respectively.

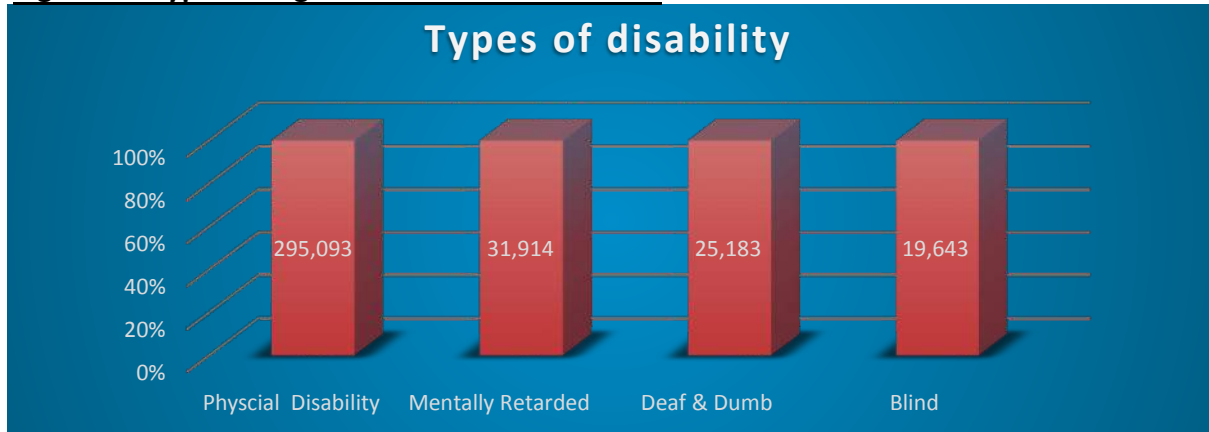
**Figure 2.4: Comparison of the statistics of PWDs (Actual vs Registered)**

Source: Population Census 2017, by Population Census Organization, Government of Pakistan and Pakistan Bureau of Statistics (PBS)



When we make the comparison of the statistics of the person with the disability of the census 2017 which shows that there are 913,667 PWDs in Pakistan with that of PBS cumulative data from NADRA registered i.e., 371,833 PWDs. This shows that the registered PWDs cases are very less than the cumulative numbers of PWDs shown by the 2017 census.

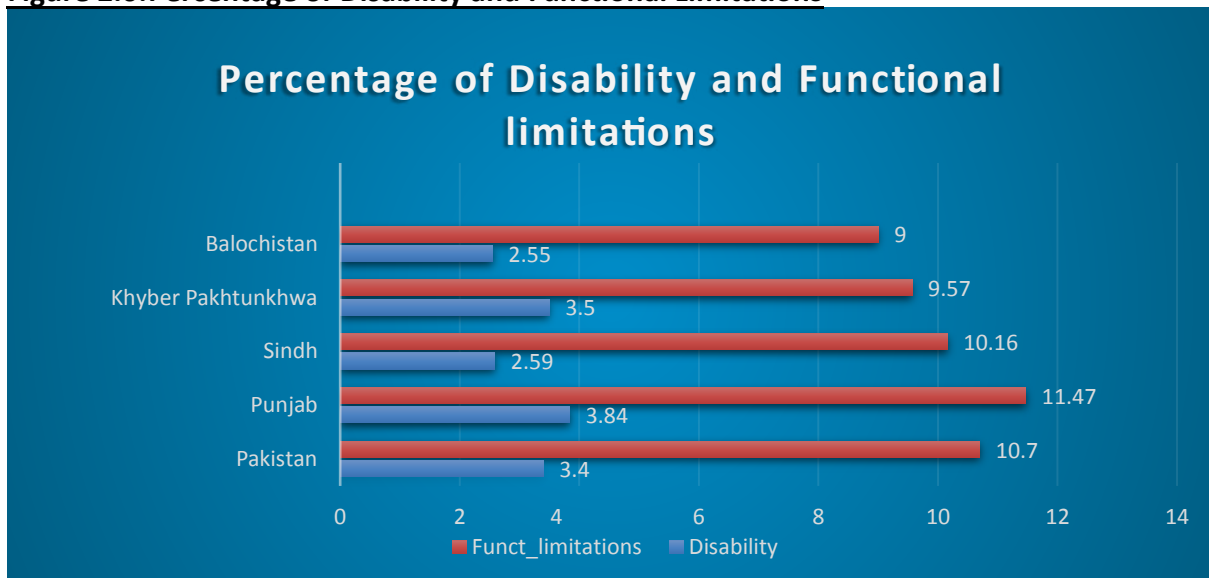
**Figure 2.5: Types of registered PWDs with NADRA**



Source: Pakistan Bureau of Statistics (PBS)

District level PSLM survey has shown 10.7% of population is with functional limitation and it includes 3.4% disability (which is more than 1998 survey 2.48%) and 7.3% with some difficulty. It is based on six questions related to vision, hearing, walking /climbing, memory, self-care and communication.

**Figure 2.6: Percentage of Disability and Functional Limitations**



Source: PSLM 2019-20

**\*NOTE:** Functional Limitation 10.7 include Disability i.e. 3.4. Some difficulty is 7.3.

Persons with disabilities are facing many challenges in Pakistan, as they are uncouneted group as shown by disparity between actual counted PWDs in 1998/2017 census and registered PWDs with NADRA 2020(PBS). Although Government of Pakistan through different policies made efforts to include the people with disabilities in the society but still there is an issue of proper implementation of such policies. Beside all these efforts, still government is not able to introduce a comprehensive welfare system for the persons with disabilities and at the end persons with disabilities remain dependent on their families for financial and emotional support, which leads to decrease in their productive efficiency. Lack of counted/exact data is a big hurdle in policy making, allocations and implementation of action plans to improve provisions to the PWDs.

There is a need to collect the comprehensive data on the persons with disabilities (PWDs) in order to evaluate the problems faced so that an efficient policy can be made to tackle the problems faced by this vulnerable group. Many reports on disability in Pakistan highlighted this issue of scarcity and unavailability of comprehensive data. In this report we are going to analyse that by the given data set or available data what steps can be taken in terms of policy making and its implementation regarding the social protection of differently abled persons to improve their living standards and to improve their positive contribution towards society & participation in the economic activity and vice versa.

This chapter compiles data from existing sources to get an overview of the disability situation in Pakistan. The latest figure of the prevalence of major categories of disabilities is 3.3 million people, in accordance to the Population Census Pakistan of 1998<sup>14</sup>. Changes in the economy's socio-economic dynamics during the last two decades must have necessitated the revision of this data. The accuracy of statistic determines the adequacy of laws/rights and the state's ability to provide support. There are certain important questions that need to be addressed before suggesting solutions to the problems that PWDs face. These questions are what type of disability is most prevalent? Which type of persons with disabilities needs most assistance? What are the avoidable disabilities? What is the contribution of man-made disabilities in the total sum? And what is status of existing social protection and how much is required for universalization of social protection.

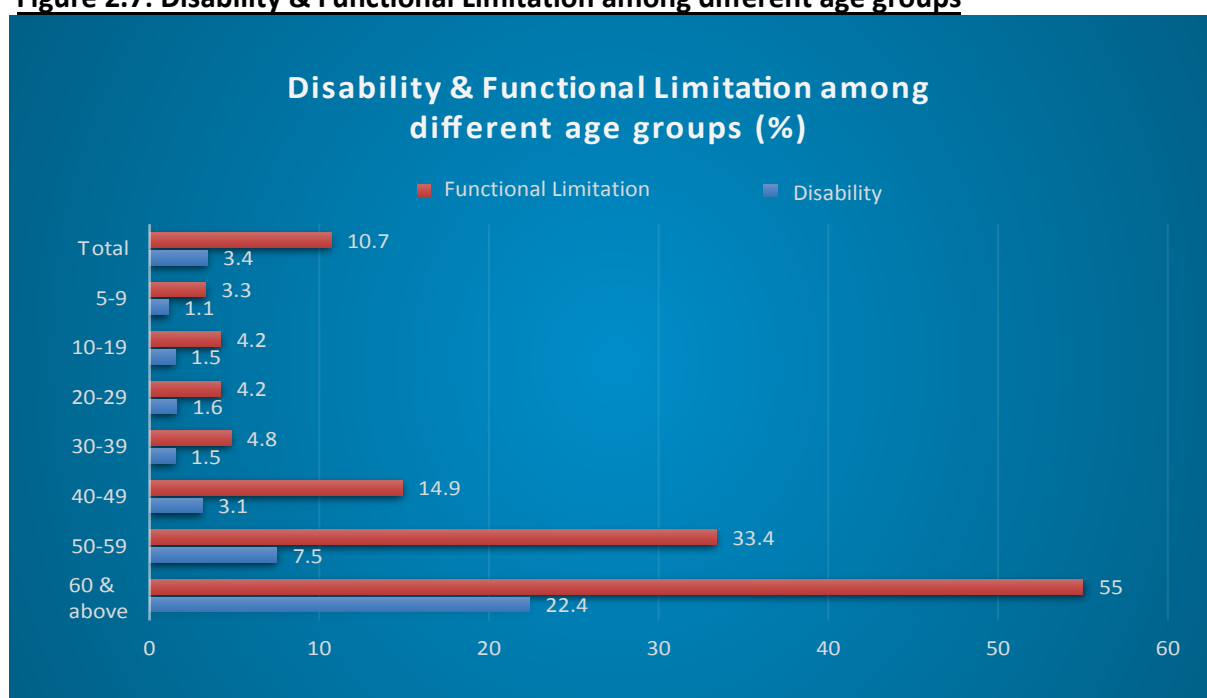
The report used Multiple Indicator Cluster Survey Punjab (2017- 2018) data to comment on the overall dynamics of disability in Punjab. Punjab is the province with Pakistan's largest proportion of population. In Punjab, out of the total households, 13% have one or more persons with partial disability and 1% have one or more persons with complete disability. Table 2.1 below shows the comparison of the socio-economic profile of households in Punjab with PWDs and households without PWDs. Note, for the former, the percentage lying the poorest quintiles is higher than the latter. This indicates there is higher prevalence of disability among poor households. Among households with PWDs, more are located in rural regions as compared to households without PWDs.

**Table 2.1: Socio-economic Profiling of Households in Punjab with PWD(s)**

VARIABLE	CATEGORY	WITH PWD(S)		WITHOUT PWD(S)	
		n	%	n	%
Wealth Quintile	Poorest	687	25.1	69,246	21.2
	Second	669	24.4	69,246	21.5
	Middle	597	21.8	69,885	21.4
	Fourth	462	16.9	63,112	19.3
	Richest	322	11.8	63,112	16.7
Age Group	<15	0	0.0	122,374	37.3
	15 - 55	1242	45.4	175,068	53.5
	>55	1495	54.6	29,848	9.1
Area	Rural	2079	76.0	234,719	71.7
	All Urban	658	24.0	92,571	28.2
Education of Household Head	None/Preschool	1236	45.2	128,099	39.1
	Primary	489	17.9	58,667	17.9
	Middle	320	11.7	44,766	13.6
	Secondary	440	16.1	60,619	18.5
	Higher	252	9.2	35,139	10.7
Receiving Benefit	Zakat	10	0.4	35	0.02
	BISP	17	0.6	439	0.2
	Khidmat card	12	0.4	21	0.01
	Pension	22	0.8	253	0.1
	Watan card	3	0.1	56	0.03
	Other	7	0.3	203	0.1
	No Assistance	2652	96.9	184,156	99.2

Source: Multiple Indicator Cluster Survey (MICS) Punjab, 2017-18

**Figure 2.7: Disability & Functional Limitation among different age groups**

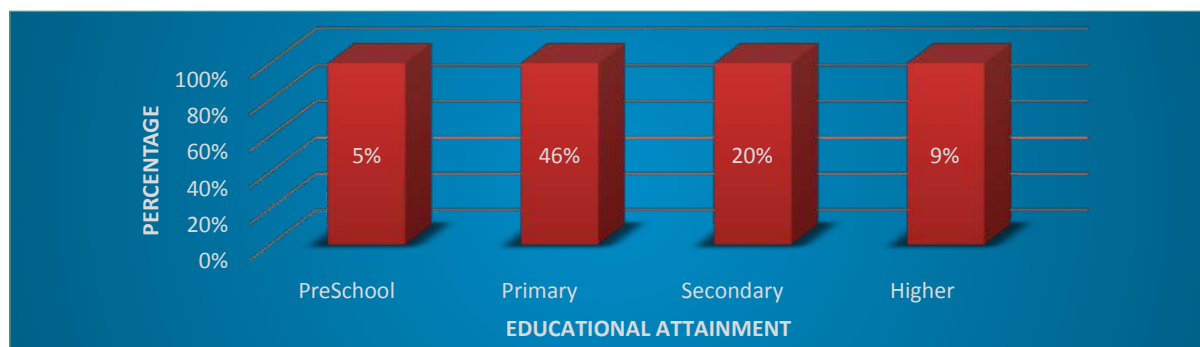


Source: [www.pbs.gov.pk](http://www.pbs.gov.pk) (PSLM district level 2019-2020)

**\*NOTE:** Functional Limitation 10.7 include Disability i.e. 3.4. Some difficulty is 7.3.

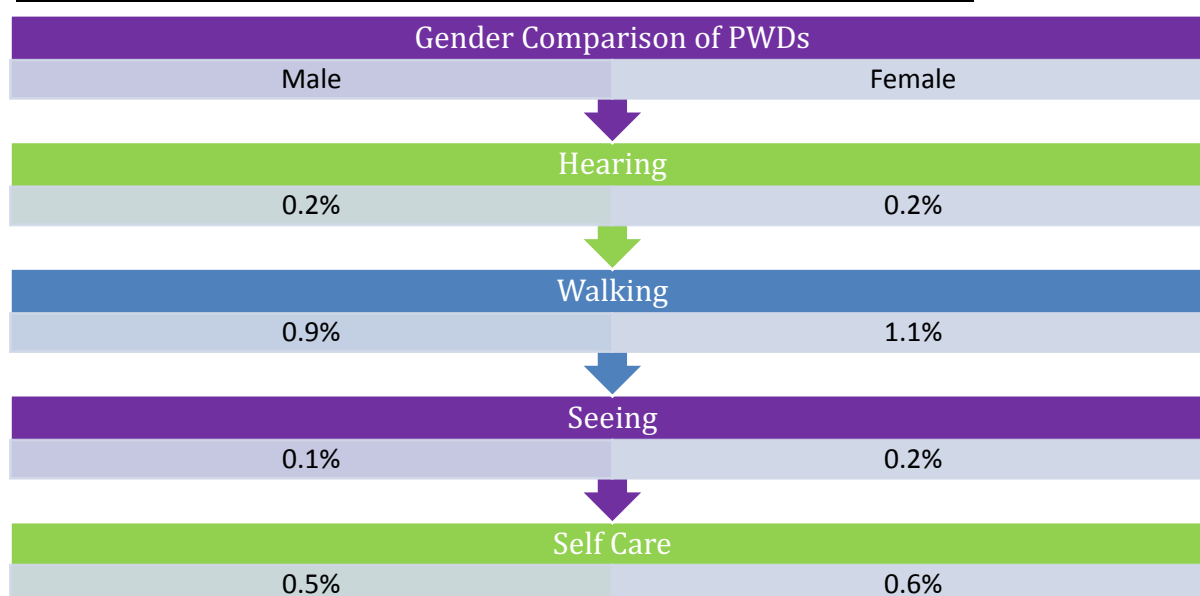
Furthermore, comparing education of head of households, among households with PWDs there are 45% households where the head of household has attained either no education or has attended only pre-school education, this percentage is 39% for households without PWDs. Similarly, as we move from no education to higher education, percentages for households start reducing and get lower than households without PWDs. This brief socio-economic profile indicates that the already marginalized households with one or more Person(s) with Disability are likely to have a head of household with no education, are poor and inhabitants of rural region. Out of these, 97% do not receive any assistance from the state. Broadly categorizing disability into major types, hearing is 4%, communicating 9%, concentrating 11%, seeing 9% and walking with the highest percentage is 67% of total disability in Punjab. Overall, the difference in prevalence of disability among gender is not a lot, out of total PWDs 46% are male and 54% females. Among PWDs, 5% have attained education only till preschool, 46% till primary school, 20% till lower and upper education each, and the remaining 9% till higher education.

**Figure 2.8: Educational Attainment among PWD's**



Overall, total women population has a higher percentage of PWDs. For both male and female, the most common disability is of walking and the least common is hearing.

**Figure 2.9: Gender Comparison of Differently Abled Population(Punjab)**



Source: Multiple Indicator Cluster Survey (MICS) Punjab, 2017-18

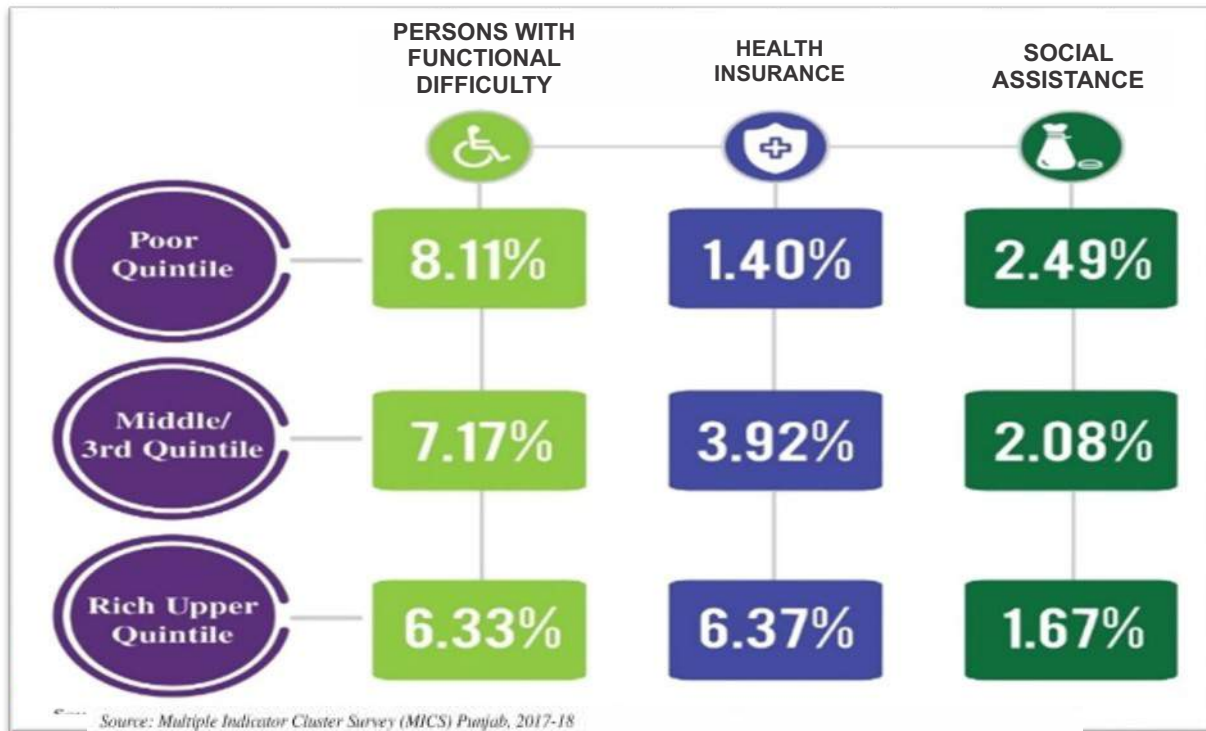
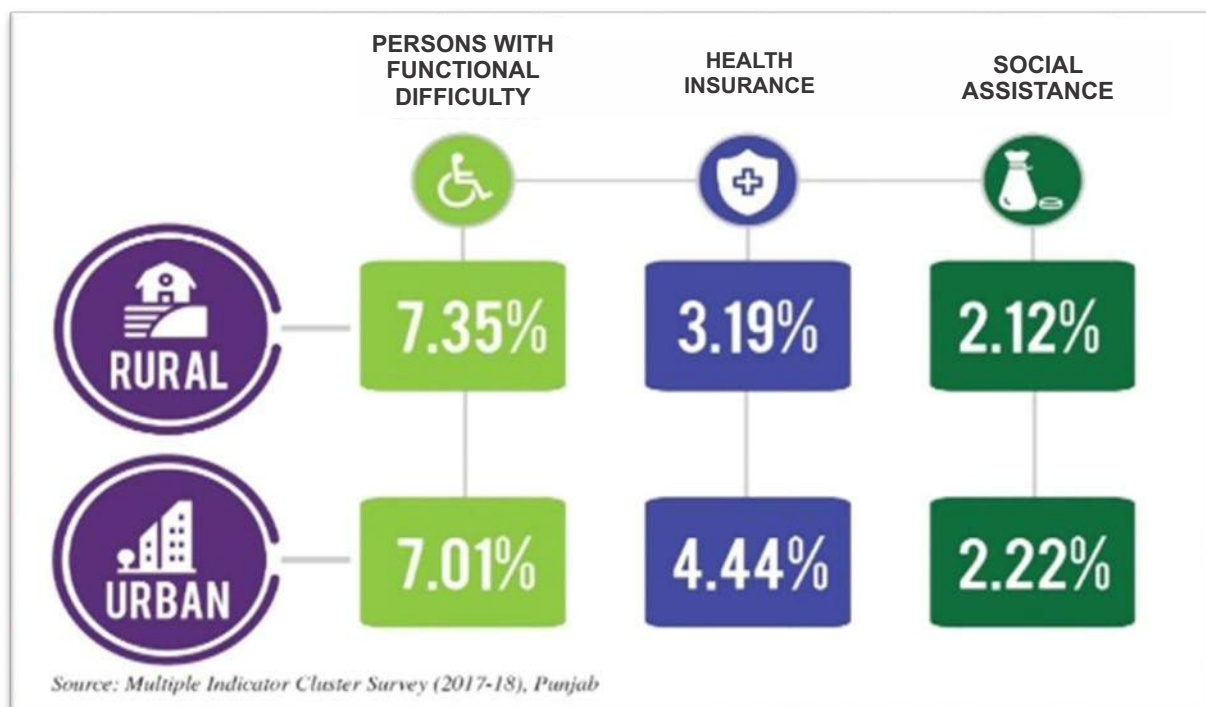
**Figure 2.10: Wealth Quintiles and Functional Difficulty (Punjab)**

Figure 2.10. shows persons with functional difficulty in each wealth quintiles; note that this percentage is highest in the poorest two wealth quintiles and lowest in the richest two wealth quintiles. Moving from poorest to richest it can also be observed that percentage of PWDs receiving health insurance increases while their social assistance reduces. Overall, out of

**Figure 2.11: Regional Comparison of Functional Difficulties**



persons with functional difficulties in the poorest wealth quintiles only 2.5% are receiving social assistance and 1.4% health insurance. In urban and rural comparison, the incidence of persons with functional difficulties out of total region population is almost the same at 7%, however for the later the percentage exceeds by 0.34%. Out of persons with functional difficulties for each region, those receiving health insurance and/or social assistance are higher in urban region than in rural region.

**Figure 2.12: Gender Comparison of Functional Difficulties**



Figure 2.12. indicates unlike the case of persons with disabilities, males have a higher percentage of functional difficulties. Around 3-4% of both males and females with functional difficulties receive health insurance and even smaller proportion of them receive other social assistance (1-2%), for instance pensions.

**Figure 2.13: Age Comparison of Functional Difficulties**

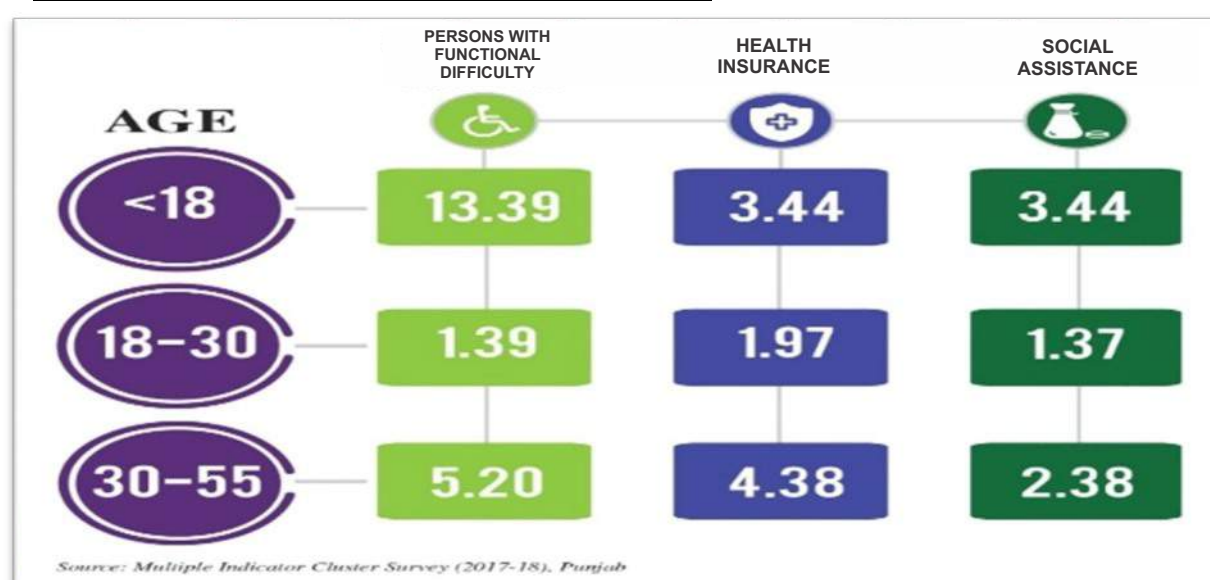


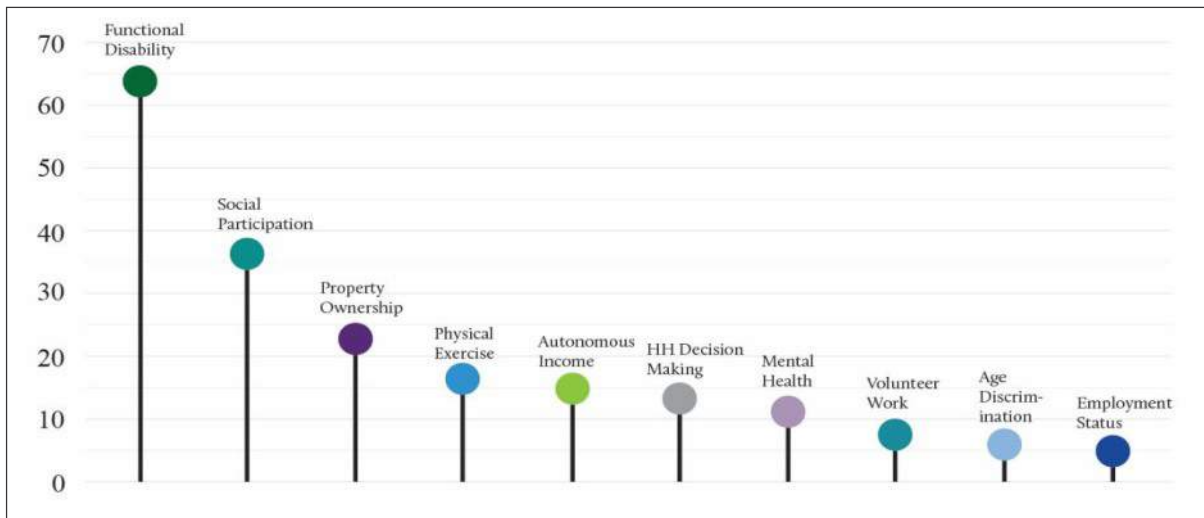
Figure 2.13 shows different age brackets and the prevalence of functional difficulty in each. Children (i. e., < 18 years) have the highest percentage of population with functional difficulty. Persons with functional difficulties in the age bracket of 18 to 30 years have the least amount of health insurance and social assistance receiving.



### Older Persons with Disabilities

Intrinsic functional disability is a serious concern among the elderly where data guides us that nearly 38% of the people have hearing problems, almost 48% elderly population faces eyesight issues, 27% of the population lacks in communicating, while 34% of elders face problems in remembering something and concentration while almost 52% of the old age population face serious problems in walking and climbing up. Overall, females have a higher percentage of any form of functional difficulties. Figure 2.14 shows the results from the SPRC Old Age Well-being Survey which indicates that functional difficulty is the most significant determinant of healthy ageing in Pakistan.

**Figure 2.14: Determinants of Healthy Ageing**



Source: SPRC Old Age Wellbeing Survey 2020

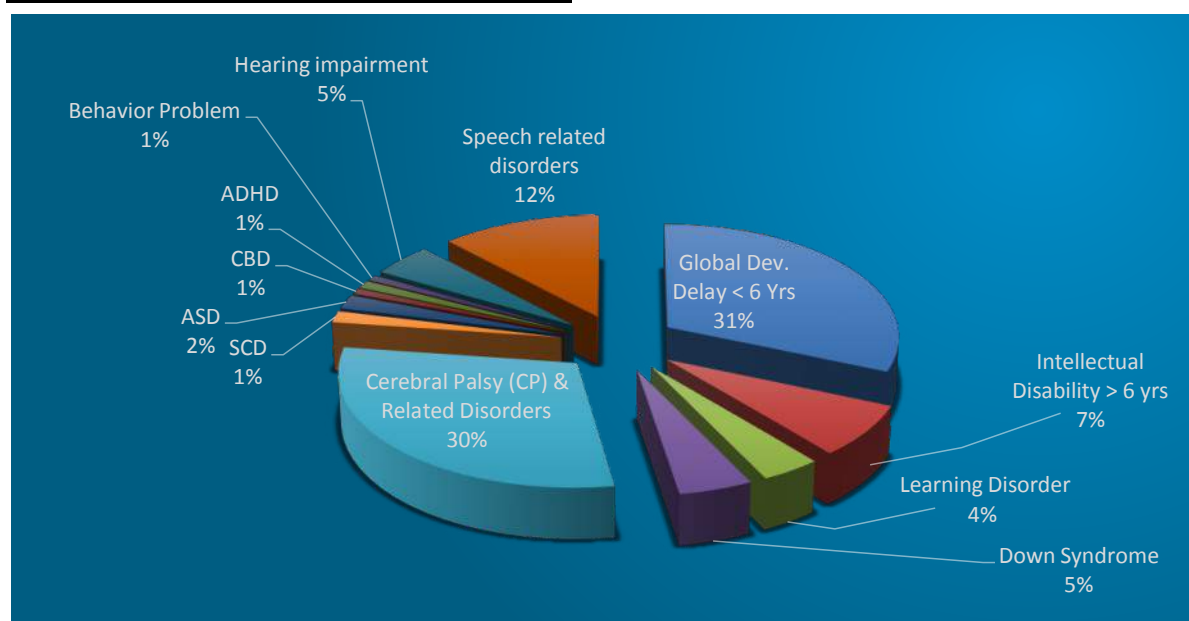
### Children with Disabilities

The factors that contribute to the disability and functioning particularly in children may be developmental disorder that may occurs due to maternal causes, malnutrition, birth trauma, any injury that has an impact on the brain and spinal cord. The children ICF Framework and the six F-words in childhood disability highlighted six F-words i.e. Function, Family, Fitness, Fun, Friends and Future in approaching the disability at childhood level. The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) approved by WHO is now vastly used framework in order to set rehabilitation goals in many health departments. It shed light on some other factors to disability like social interaction and environment.

According to Department of Developmental & Behavioural Paediatrics (DBP), Children's Hospital and Institute of Child Health (CH-ICH) Lahore, the most common types of disabilities observed during the time 2015-2019 are Global Developmental Delay (< 6 Yrs.) 31%, Cerebral Palsy (CP) & Related Disorders 30%, Speech related disorders 12%, Intellectual Disability > 6 yrs. 7%, Hearing impairment and Down syndrome 5%, while Learning Disorder is 4% respectively.

The highest prevalence of functional difficulty type found among children in Pakistan is that of seeing i.e., 8%. According to Aser's Disability Booklet 3.8% of the children, face mild functional difficulty. Similarly, in term of schooling 58% of the children having mild difficulty got admission in government school while 39% in private schools<sup>16</sup>.

**Figure 2.15: Disease Breakup of Patients at Department of Developmental & Behavioural Paediatrics (DBP) Children Hospital Lahore**



*Source: Disease Breakup of Patients at DBP Department, CH-ICH (2015-2019)*

Situation analysis from the available data sources, it is realized that still data is deficient on disability, more on intellectual disability in children which requires very specific tools to diagnose the condition and to utilize it in policy making and strategizing the interventions. There is a huge gap in number of cases with disability and registration with NADRA, which is required to disburse the social protection whatever is available in Pakistan like Sehat card. Data from children hospital has shown that 31% children are diagnosed with global developmental delay in less than six years of age and additional seven 7% in more than six years of age with intellectual disability which needs lifelong support. Cerebral Palsy is another group of children, which needs management through life course universal social protection. This also affects the institutional arrangements for Health and education for children and employment in working age group and coverage of care of older persons with functional limitations.

## Chapter 3

# Mental Health Problems in Pakistan: Challenges, Current Responses and the Way Forward

### 3.1. Mental Health and Disabilities

There is ample evidence that mental disorders are contributing towards at least 25% to 30% of global disease burden<sup>17</sup>. Due to this increasing prevalence of mental health problems, the slogan “No health without mental health” is gaining more attention from clinicians, policy makers and health planners all over the globe. Global proportion of burden of disease due to mental disorder and self-harm is exceedingly high as measured by Years Lived with Disability (YLD)<sup>18</sup>. However, despite these alarming trends, we still underestimate the true burden & actual extent of the global mental health problems. Many factors influence the impact of such problem especially sub-threshold treatment of mental disorders and effects of mental disorders on physical health are overlooked in terms of the actual impacts. Furthermore, the reports suggest that the proportion of disease burden due to mental and neurological disease has increased by 41% between 1990 and 2010<sup>19</sup> and still showing growing trends.

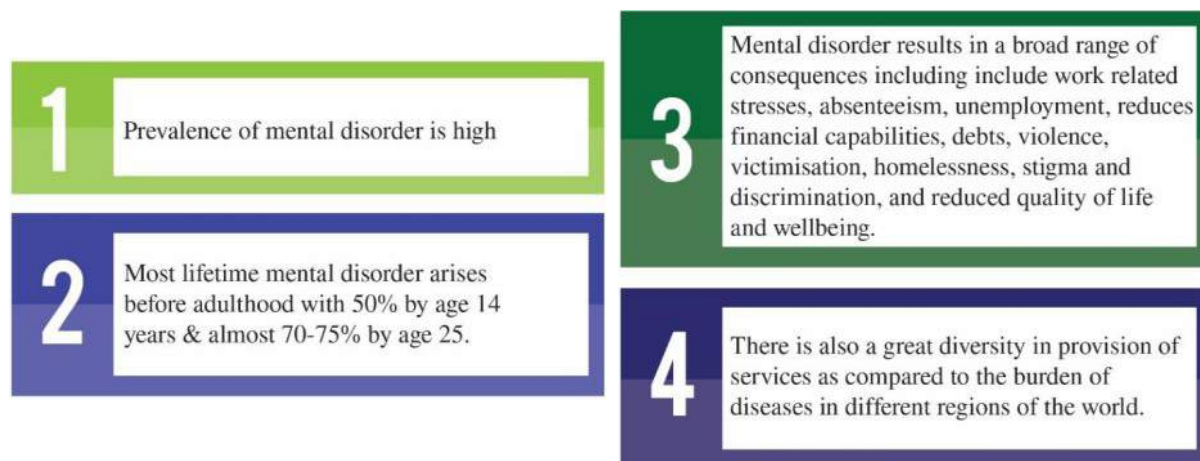
Despite this high number of mental health problems, it is a pity that the services and available resources for dealing with psychological & mental health difficulties are scarce and not getting a priority in most of the countries. This is even true for high resource countries and the problem does not just limit to low and middle-income countries alone.

Mental health has a specific link with disabilities and persons with disabilities. While looking at mental wellbeing, it becomes significantly important about the broader population impacts of mental health problems across populations. Current century has seen a big shift towards effective mental health interventions to treat mental disorder, prevent mental disorder from arising, promote mental wellbeing & limit associated impacts. Although implementation for such interventions is poor and vary from country to country, at least, this gives a promising move from the earlier concepts and practices in mental health. Two aspects of mental health, concepts about positive mental health & disabilities linked to mental health problems, therefore, need further recognised.

Mental wellbeing can be defined as ‘a state in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community’. Mental wellbeing comprises several constituents including satisfaction, pleasure, engagement, relationships, meaning and achievement<sup>20</sup>. Disability refers to a condition having a long-term effect on the normal day-to-day activities. Experiencing mental ill health may be considered a ‘disability’ if the mental illness (considered as if with or without treatment) has a substantial, negative long-term effect on the ability to undertake normal day-to-day activities. However, there is no requirement for the disability to

to be consequent of a medical diagnosis, although some conditions may be specifically excluded from the list. As per Disability laws, with any other disabled person, someone with mental health disability is equally entitled to consideration of reasonable adjustments to their work or study including changes to working hours or allowing time off for treatment, assessment or rehabilitation.

**Figure 3.1: Facts About Mental Health in Pakistan**

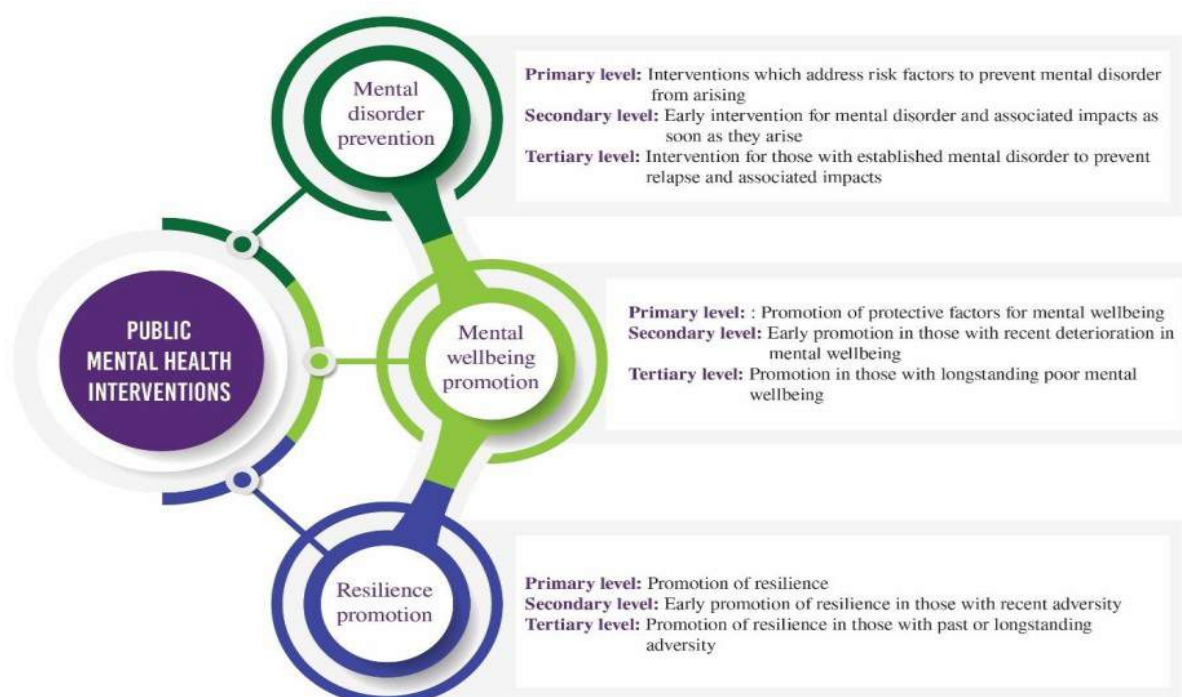


The link of mental disorders to disability is well established & highlighted by many reports. A recent American study<sup>21</sup> found that adults with disabilities report experiencing more mental distress than those without disabilities. In 2018, an estimated 17.4 million (32.9%) adults with disabilities experienced frequent mental distress, defined as 14 or more reported mentally unhealthy days in the past 30 days. Frequent mental distress is significantly associated with poor health behaviours, increased use of health services, mental disorders, chronic disease, and limitations in daily life. The world's institutions have increasingly become dumping grounds for people with disabilities, including psychosocial disabilities. Many people with mental disabilities are assumed to have no capacity to make decisions for themselves and therefore being detained and treated in psychiatric institutions unjustifiably and against their will, where they are being treated appallingly and inhumanely. An abundance of evidence shows that these settings cause extensive physical and psychological harm in particular to young & vulnerable individuals. Low numbers of staff, lack of training, and poor quality of care, harmful treatment practices, violence, abuse and overall neglect preclude any positive outcomes and as a result, many remain in institutional care for the rest of their lives, and many others die prematurely. The reports underscore the urgent need for countries to move from institution-based care to community-based care. A firm commitment to redirecting investments towards community alternatives is critical, if we are to end these institutional abuses, and provide children with the best possible start at life.

In 2008, the UN Convention on the Rights of Persons with Disabilities (CRPD) came into force. The Convention sets out a wide range of rights including, among others, civil and political rights, the right to live in the community, participation and inclusion, education, health, employment, and social protection. It is coming into force marks a major milestone in efforts to promote, protect and ensure the full and equal enjoyment of all human rights of persons with disabilities.

Public Mental Health (PMH) interventions show a promising hope across many mental disorders & associated disabilities<sup>22</sup>. Public mental health takes a whole population approach to sustainability reduce mental disorder and improve mental well-being through the provision of PMH. PMH can be considered at primary, secondary, and tertiary levels. The importance of primary level intervention is, furthermore highlighted by treatment being unable to avert 60% of disease burden<sup>23</sup>.

**Figure 3.2: Public Mental Health Interventions**



**Public Mental Health interventions** can be delivered by different organizations from various sectors including primary care, secondary mental health care, public health, social care, education, employers, housing, criminal justice, voluntary sector and others. Current literature shows that evidence based, cost-effective PMH interventions exist to treat mental disorder, prevent associated impacts, prevent mental disorder from arising, and promote mental wellbeing and resilience, which result in broad impacts and associated economic savings even in the short term. Public mental health practice is therefore also a key part of sustainable economic development. However, implementation failure of PMH interventions results in large-scale human suffering, a range of associated impacts for individuals, families and communities, and economic costs. It also represents a breach of the right to health.

**Social protection** plays a key role in realizing the rights of persons with disabilities of all ages: providing them with an adequate standard of living, a basic level of income security; reducing levels of poverty and vulnerability. Moreover,



such social protection schemes concerning persons with disabilities can have a major role in promoting their independence and inclusion by meeting their specific needs and supporting their social participation in a non-discriminatory manner. These social protection measures may include poverty reduction schemes; cash transfer programmes, social and health insurance, public work programmes, housing programmes, disability and mobility grants.

There is increasing evidence confirming that persons with disabilities are more exposed to risk of poverty due to barriers in accessing employment, education, and health care as well as disability related costs and lack of access to support services. It is also widely acknowledged that social protection is critical to support the inclusion of persons with disabilities as reflected at global level within the SDGs and the Addis Ababa Agenda for Action and at regional level in initiatives such as the UN-ESCAP incheon strategy implementation and the recent UN-ESCWA report<sup>24</sup>.

### Evolution of Institutional care for mental health

Like many developing countries, Pakistan is still struggling in several health and social spheres, which have substantial impact on the health system of the country. It is worth reviewing the history of mental health services in Indian subcontinent before looking at the current developments in our country. It is interesting to note that most of the formal services for mentally ill individuals were started by the British during their colonial period of subcontinent. Dating back to 1795, there has been demonstrable developments for health care provisions for mentally ill.<sup>25,26</sup>

Year	Incidence
1787	Establishment of first facility for mentally ill lunatic asylum Calcutta
1794	Mental hospital in Kalipauk (Madras)
1840	Lahore mental asylum/ hospital
1858	Lunacy Act
1865	Mental asylum/hospital Hyderabad (Pakistan)
1888	Modification of Lunacy Act
1912	Modification of Lunacy Act
1920	Term asylum was change to Hospital
1947	Total number of mental hospital were 40

British Raj focused their service provisions mainly in the coastal cities, Calcutta, Madras and Bombay to begin with. After control of most of the subcontinent in 1857, new asylums were established.<sup>27</sup> The number of asylums continued increasing, after which the focus shifted to expansion of existing facilities and quality of treatment. In 1920, the ongoing efforts of a British Army Psychiatrist, Lt. Colonel Owen Berkeley - Hill, the term 'asylum' was changed to 'hospital'.<sup>28,29</sup> Muslim religious scholars also recognized the misery suffered by those with mental health problems and established necessary facilities at many places in the community.

There are only around 400 qualified psychiatrists working in Pakistan & most of the psychiatrists are working in urban areas. WHO's Mental Health Atlas 2017, reported that there were only four big psychiatric (mental) hospitals in the country, with 344 residential care facilities and 654 psychiatric units in general hospitals<sup>30,31</sup>.



Mental Health Care unfortunately did not get a priority by the state and remained as a patchwork of care in almost all provinces<sup>32</sup>. However, the last few decades, influenced by the World Health Organization (WHO) and other regional & international developments in the field, primary care and community-based models have been tested & being practiced in many parts of the country<sup>33,34</sup>.

Pakistan lacks a reliable data that can give us a detailed account of the extent of the mental illnesses & related disabilities. We are still arguing about the physical disabilities as the main source of our statistics. The concept of mental health disabilities is still not been spotlighted in our country. It is the need of the time that attention should be given to data collection and gathering of reliable information about such disabilities. We have never looked at a national disability survey or a database & are still using statistics where disabilities are not well documented. It may be true that many bills have been introduced in many provinces to emphasize the issue of persons with disabilities, but these legislative exercises have not so far resulted in major improvements in the current situation. These intermittent efforts have failed to produce an effective & integrated policy framework to address this multifaceted challenge.

### 3.2. Youth Mental Health Problems Today

Adolescent health is now emerging as one of the areas for major healthcare concern. Adolescence is considered as a transitional stage of physical and mental human development between childhood and adulthood. This stage in life is regarded important because it brings about pubertal, social, and psychological changes. The World Health Organization defines adolescent as an individual between 10-19 years of age.

#### 3.2.1. Demographic data of Pakistan

Pakistan is ranked as world's sixth most populous country with 2017 estimated population of around 220 million.<sup>1</sup> From 1950 to 2012, Pakistan's urban population stretched over sevenfold, whereas total population amplified by over fourfold.<sup>2</sup>

The 2019 report of United Nations Development Programme's Human Development concludes human development index (HDI) value for 2018 in Pakistan as 0.560, which ranks the country in medium human development category. Being at 152 out of 189 countries<sup>3</sup>, Pakistan's literacy rate is reported as 60% for total populations.

According to UNDP report, 64 percent of nation is younger than 29 of which nearly 30 percent are between 15 and 29. Pakistan now has more young people than ever before and this has been predicted to continue to increase until at least 2050.<sup>4</sup> Out of the 32.6% of adolescents' share of the population of Pakistan; 65% live in rural areas.

<sup>1</sup> Pakistan Bureau of Statistics at: [www.pbs.gov.pk](http://www.pbs.gov.pk)

<sup>2</sup> [www.indexmundi.com/pakistan/#Introduction](http://www.indexmundi.com/pakistan/#Introduction)

## Structure of challenge in Pakistan

Mental health issues in Pakistanis occur in various forms, and symptoms can overlap with physical complaints and mask each other, especially when seen in primary care.

What should be done in a culture where drug addiction is seen as a simple getaway for individuals enduring stress or depression? Issues identified with emotional and mental well-being escalate the cases of suicide, particularly among the adolescents aged 25 years and younger. The unprecedented rise in psychological disturbances among young population is an alarming situation. Sadly enough, it is the adolescents in the society who receive much less sympathy from our social segments. This is also expressed in the limited research conducted at a national level in the field of mental disorders among young people.<sup>5</sup>

The period of adolescence is pivotal in growth and development of an individual because youth during this time undergo rapid physical, psychological and social changes. These changes make them vulnerable to health threatening behaviours as compared to other age groups. Following is some of the issues identified in adolescents, which pose a threat to their physical and emotional well-being:

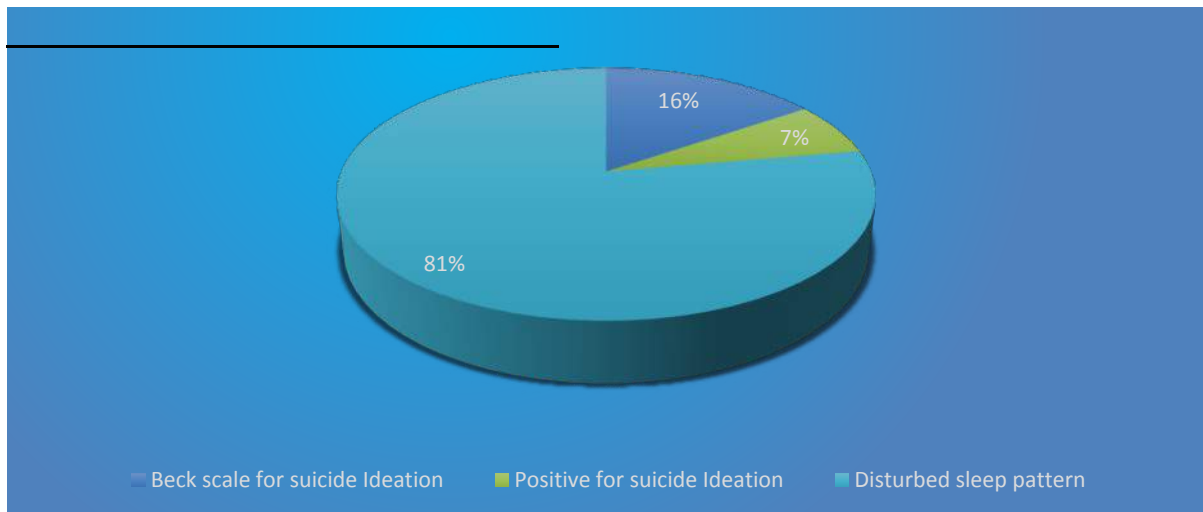
- **Increasing prevalence of obesity.** Several factors responsible for worsening obesity problem among youth include increased consumption of fast food, soft drinks and increased sedentary lifestyle. Increased obesity leads to physiological ailments, low self-esteem and psychological issues.
- **Anxiety and depression in younger age groups** is increased due to increased expectations from elders, extra burden from teachers and unnecessary competitions in studies by the peers and bullying. Overambitious and unrealistic plans of teenagers are also contributory in this context.
- **Reproductive health and its related issues are of special concern for the youth.** They lack access to reliable and correct information sources related to reproductive and sexual health. It is reported that our youth is less aware about reproductive and sexual health issues as compared to their counterparts in the rest of the world.<sup>6</sup>
- A grave concern is their **inability to protect themselves from sexual, physical, and emotional abuse** and their being ill-equipped to handle the reproductive health burden.
- Recent explosion in electronic media and unchecked **easy accessibility of internet facilities have played a profound negative impact on the youngsters.**
- **Stress of leaving home** and starting university.
- **Stress caused by the struggle for a better life.**
- **Poverty related issues** such as malnutrition, infections and illiteracy
- **Readily available prescription and illicit drugs of all kinds.**

According to the WHO half of all mental illness begins by the age of 14 but most cases go undetected and untreated.<sup>7</sup>

Study was conducted in 2019 at Pakistan Institute of Medical sciences Psychiatry department, revealed a considerably high prevalence of co-morbid anxiety and depression among medical students.

Demography	Anxiety	Depression
Total	71.5%	42%
Male	61%	
Female	82%	
Age Group		20-24 years Associated
Professional Year	3 <sup>rd</sup> & 4 <sup>th</sup> year	

71.5% students had Anxiety while 42% had depression. A significant association was observed between depression and age group 22-24 years. Only 16% respondent filled Beck scale for suicide Ideation, 7% were found positive for suicide ideation. 80.5% had disturbed sleep pattern.



**Source:** Pakistan Institute of Medical sciences Psychiatry department, 2019

Anxiety, depression, substance abuse, sexual abuse and cyber bullying are being reported among the youth of Pakistan. Other common psychological disorders are eating disorders such as Bulimia are on the rise in the upper economic strata<sup>8</sup>. In terms of the burden of the disease posing challenges in Pakistan, among adolescents, suicide is the second leading cause of death among 15-29 years old caused by depression. The harmful use of illicit drugs among adolescents is a significant concern and can lead to risky behaviours such as suicide, temper outbursts, violence or dangerous driving and bad eating habits.<sup>9</sup>

In Pakistan, around 300,000 people are at risk of making suicide attempts and about over 10,000 people take their lives every year in urban areas. There are a number of barriers to taking care of the mental health needs of the youth including lack of services, lack of awareness, myths, misconceptions and stigma and low priority to mental health.<sup>10</sup> The mentally ill youth population pose a burden to the society in the form of idleness, violence and abuse.

### 3.2.2. Strengths of Mental health system in Pakistan

- A disaster/emergency preparedness plan for mental health was revised previously in 2006. The mental health legislation was enacted in 2001.<sup>13</sup>
- All provinces have mental health legislation in place.
- There are NGOs in the country involved in individual assistance such as counseling, housing, or support groups.
- 27% of training for medical doctors is devoted to mental health. In terms of refresher training, 16% of primary health care doctors have received at least two days of refresher training in mental health, while 5% of nurses and 13% of non-doctor/non nurse primary health care workers have received such training.<sup>14</sup>

### 3.2.3. Weaknesses of mental health system in Pakistan

- Mental health policy, plan and legislation do exist in the country but are not implemented.
- The health-care system is not well established and lacks sufficient resources. Community work is limited to a few tertiary care hospitals and in big cities. Only 1% of 1.926 beds per 100,000 population, in the community based psychiatric inpatient units are available for children and adolescents.
- Community based residential facilities and day treatment facilities are not available in the country.
- Training at the undergraduate level is meagre and no training is offered in psychiatry sub-specialties.
- The distribution of human resources between urban and rural areas is disproportionate.
- None of the mental disorder for any age group is covered by social insurance schemes.
- Only 0.4% of health care expenditures by the government health department are devoted to mental health.

### 3.2.4. Social protection

The right of persons with disabilities to social protection is recognized by many international conventions and declarations. The 1948 Universal Declaration of Human Rights (UDHR), the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) & more specifically the UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes the right of persons with disabilities to an adequate standard of living and to social protection, ensuring the enjoyment of both rights without discrimination based on ability. These international conventions underline the need for the States to take appropriate measures to ensure that they provide equal access to mainstream social protection programmes and services including basic services, social security systems, poverty reduction programmes and housing programmes but also specific programmes and services for disability-related needs and expenses.

It is a matter of distress that despite the recognition & such acknowledgments, majority of persons with disabilities do not enjoy social protection coverage and adequate benefits. Only 27.8% of persons with severe disabilities worldwide receive a disability benefit, while wide regional discrepancies in coverage are significant: for instance, almost universal in Eastern Europe compared to 9.4% coverage in Asia & Pacific. The development of social protection systems thus needs to support the full and effective

participation and inclusion of persons with disabilities. It is important to ensure that national social protection floors are fully inclusive of persons with disabilities and support their full participation in society and the economy. There are many challenges that need to be addressed and there is currently a growing momentum among stakeholders to invest in this critical area.

A recent report prepared by Development Pathways Limited on “Leaving No-one Behind” has examined how to make social protection systems and schemes more inclusive of persons with disabilities. The research underpinning the report comprised a review of relevant literature, an analysis of household survey datasets and consultations with key stakeholders and persons with disabilities in seven low- and middle-income countries: Brazil, India, Kenya, Mauritius, Rwanda, South Africa and Zambia.

## Chapter 4

# Institutional Arrangements for PWDs

## 4.1. Introduction

Persons with Disability (PWDs) often face difficulties and inadequate facilities that's why states are responsible for the protection of rights of the differently abled persons. Special persons gained more significance in social setup, but policies made for them by developing countries are usually not satisfactory. Laws, Acts and Policy reforms are there to avoid any kind of discrimination against PWDs in all spheres of life. People with certain disabilities must be socially protected by the respective states and they must be ensured free and easy access to necessities of life including food, clothing, housing, health, education, and employment.

In countries like Pakistan, PWDs face many cultural and socioeconomic problems and to protect them from these challenges government of Pakistan devised various plans and policies for person with disabilities (PWDs). Constitution of Pakistan 1973 ensures the wellbeing of every citizen of the country, included Persons with Disabilities (PWDs). Constitution has a proper list of fundamental rights of all citizens and can be used as a tool to protect the basic rights of every citizen including special persons. It serves as a shield against any violation of rights of the PWDs. Moreover, Pakistan ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on July 5, 2011. Ministry of Human Rights is the Focal Ministry to coordinate and facilitate implementation and reporting of the UNCRPD.

## 4.2. Eligibility to Avail Benefits

Every Special Person has the right to avail the opportunities available in their country and there are policies and laws which protect them from discrimination but there is an issue of lack of information of rights especially in developing countries like Pakistan. Due to less privileged in terms of education and health, PWDs usually do not know about their rights and a gap is created between policies and their implementation. Therefore, government tries to register them based on their disability so that they will get disability benefits. Persons with disabilities must be protected and facilitated by institutions and they must not face any difficulty. To be eligible for the benefits provided by government of Pakistan for special persons one must fulfil the following requirements:

- Person must have Employment Exchange Card (for Sindh only)
- Person must have Disability Certificate (applicable to all provinces)
- Person must have Special CNIC (Computerized National Identity Card) (applicable to all provinces)

Government of Pakistan has introduced many policy reforms for "Differently abled Persons" from time to time.

**Table 4.1. Policy reform by the Government for PWDs**

Acts for PWDs in Pakistan	Provisions
Disable Persons (Employment and Rehabilitation) Ordinance, 1981	<p>To protect the rights of PWDs.</p> <ul style="list-style-type: none"> <li>● State will provide facilities in education and health</li> <li>● To take steps for their rehabilitation.</li> <li>● To reserve employment quota for PWDs is main point of this ordinance.</li> </ul>
National Policy for PWDs, 2002	<p>To empower person with disabilities:</p> <ul style="list-style-type: none"> <li>● To provide them facilities in every sphere of life including social, political, cultural, and economic.</li> <li>● Realization of full potential of differently abled persons was also the part of policy.</li> </ul>
National Action Plan (NAP) for PWDs, 2006	<p>To operationalize the public strategy for people with disability, 2002.</p> <ul style="list-style-type: none"> <li>● To support, capacity building and networking and used an incorporated methodology</li> </ul>
Special Citizen Act, 2008	<p>To improve the accessibility of the special citizens</p> <ul style="list-style-type: none"> <li>● Provides facilities on footpaths for wheelchairs and blind persons.</li> <li>● Special seats allocation in public transport.</li> <li>● Priority while crossing the roads</li> <li>● Traffic police should be responsible for its implementation.</li> </ul>
Special Citizen (Rights to concession in movement), Act 2009	<p>To provide concessions to special citizens in public and private transport.</p> <ul style="list-style-type: none"> <li>● Air, railway, and other transport authorities are bound to charge less/half rates from PWDs.</li> </ul>
Duty Free Imports of cars	<p>Duty free import of cars with 1350cc engine capacity.</p> <ul style="list-style-type: none"> <li>● Actual user can import one used duty-free motorized wheelchair.</li> </ul>



**Sources:** *The Disabled Person (Employment and Rehabilitation) Ordinance, 1981; Government of Pakistan.*

*-National Plan of Action for the Persons with Disabilities, 2006; Directorate General of Special Education, Government of Pakistan.*

*-Special Citizens Act, 2008; Government of Pakistan.*

*-Special Citizens (Right to Concessions in Movement) Act, 2009; Government of Pakistan*

*-Trade Policy, 2009-10, Ministry for Commerce, Government of Pakistan.*

*-SRO No: 16(1)/2006-import II, dated 28<sup>th</sup> September 2009; Ministry of Commerce; Government of Pakistan.*

### 4.3. Laws and Policies for PWDs in Pakistan

Laws and policies for special citizens in Pakistan laydown regulation regarding multiple dimensions of their lives such as health, education, employment, transport and communication, housing, and rehabilitation.

#### 4.3.1. Policies for Health Sector

From “1981 Ordinance for disabled Persons”<sup>35</sup> to “ICT Rights of Persons with disability Act 2020” almost all policy reforms focused on protection of PWDs and ensures their respect and dignity in society. In “Disabled Amendment Act of 2015”<sup>36</sup> government ensures free medical treatment of differently abled persons at federal, provincial and district level and in private healthcare units they will only be charged 60% of the total expense. In “ICT Act of 2020”<sup>37</sup>, Government ensures free access in public health service for differently abled persons. For this purpose, health insurance is provided to the persons with disability (registered) so that they can avail health services free of cost. Government also provides various incentives for private health sector so that person with disabilities get treatment at affordable rates. For early identification and prevention of disability, special health services shall be implemented.

Government with the help of scientific community also initiate research on the causes of disabilities so that they can be identified at initial stages and steps should be taken to prevent them. For women with disabilities government shall provide services regarding reproductive health and no person with disability should be forced towards medical procedures leading to infertility. Recently government launched a project named Sehat Sahulat Program for PWDs and their families. Through this Sehat Cards program, all PWDs and their families would be provided with free medical coverage indoor health care services worth PKR 720,000 from empaneled hospitals through a very transparent and systematic mechanism.<sup>38</sup>

#### 4.3.2. Policies for Education Sector

Same as health sector government also incentivize education sector with new policy reforms under ICT Act of 2020 so that persons with disabilities have access to free education. Unlike previous laws and acts where free education to PWDs only limited to intermediate level now under ICT Act of 2020, free education shall be up to higher education. Now persons with disabilities have access to free education without any discrimination in both public and private institutions.



Government also ensures to establish special education institutions equipped with all the necessary infrastructure and provision of free textbooks, wheelchairs, white canes along with psychological needs and personality development. Under the Act of 2020 government shall provide special training to teachers who will be appointed to special education institutions so that they can easily cope up with students with disabilities. Last but not the least, government ensures full access of students with disabilities to all institutions not limited only to virtual or distance learning programs, online education, and vocational training. Another plan is also devised to add some topics in national curriculum regarding disability, its causes and difficulties related to disability so that our youth must be able to aware about the problems and challenges faced by the PWDs.

#### 4.3.3. Policies for Employment sector

Facing disability in addition to being unemployed brings its own set of challenges for an individual particularly in developing country. Similar is the case in Pakistan where such vulnerable groups receive little or no social protection. That is why under ICT Act of disabled persons of 2020, government ensures hiring of the workers with disability both at public and private sector. For public sector government have fixed 3% quota and for private sector government ensures to allocate sufficient resources and try to give incentives to encourage them to employ some fixed number of differently abled persons so that they become part of all professions.

Government has provided many facilities like special elevators, chairs, lifts and ramps for employees with disability. One of the major policies to protect the rights of PWDs in employment is that government ensures that if an enterprise is not hiring people with disabilities than they must pay a fine equal to the amount of salary and if they are hiring person with disability so that amount will go into funds of government.

#### 4.3.4. Policies for Banking Sector

Banking sector is also one of the main sectors for any economy. In this regard with the help of State Bank government allow persons with visual impairments to have their individual bank accounts in national or private bank and for this purpose, they are provided with special **Braille cheque** books so that they can easily manage their accounts because initially in policies they are not allowed to open their personal account. **Microfinancing** in the form of loans shall provide chance to include themselves in various economic activities especially they can easily start a business to become financially independent. **Special ATM cards** and machines for person having visual disability were introduced in the market to facilitate them is also a part of policy reforms for differently abled persons.

#### 4.3.5 Policies for Housing sector

**Housing** is a basic right of every citizen and PWDs should be given the right to facilitated housing catering their special needs. In this regard in ICT Act of disabled persons of 2020<sup>39</sup>. People with disabilities have the right to own, sell, purchase, and inherit property, a plan to provide affordable housing to person with disabilities in both government and private housing

schemes. Government provides free shelters with the help of civil society organizations and authorities of federal capital to the Persons with disabilities who do not have any decent place to live.

#### 4.3.6. Policies for Transport Sector

Under ICT Rights of PWDs Act 2020<sup>40</sup>, government plans to provide elevators and lifts to Metro Bus stops at every entry and exit point so that people having any disability do not face any hurdle in transport sector. Spaces for person with physical disability using wheelchairs will be provided. Special buses for students with disabilities will also be provided by the government.

#### 4.3.7. Policies for Rehabilitation of PWDs

In 2018, an act was passed by national assembly for the establishment of rehabilitation facilities for welfare of PWDs. National Commission for persons with disabilities Act, 2018<sup>42</sup> was passed for the rehabilitation of differently abled persons. It extends to the whole country. Commission was responsible to evolve a national policy for the rehabilitation of PWDs. The commission is responsible to provide instructions to federal government agencies to laydown programs, operate services, start pilot projects for rehabilitation of PWDs, and ensure implementation of these programs. Commission is also responsible to review policies for special persons from time to time and give their suggestion for more improvement in policies.

#### 4.3.8. Ehsaas Kafaalat Program for PWDs

Seven million families are currently eligible under Ehsaas Kafaalat fall under the poverty-ranking threshold of 29<sup>42</sup>. Under the new “Ehsaas Kafaalat for Special Persons Policy”, this threshold is being increased to 37 for such households with at least one special person. These households will now be eligible to get Ehsaas Kafaalat cash. It is estimated that 2 million families with at least one PWD will benefit from Ehsaas Kafaalat for Special Persons Policy. Each family with a special person registered with NADRA, will get Rs. 2000 per month. Only one benefit per family will be given. Payment will be made using the existing Kafaalat payment mechanism. Since payment is biometric based, payment to amputees will be made following the payment rules being implemented under Ehsaas Kafaalat.

Government also devises policies in some other social sectors for the ease of differently abled persons.

- Differently abled persons have the right to free access to justice and for this government plans to provide special treatment at courts all over the country.
- Differently abled persons also have freedom of expression and right to political participation.
- Differently abled persons have the right to home and have a family.
- Government will provide support for advertisements to the publications focused on PWDs.
- Government devise plans to provide facilities to PWDs in sports, cultural and recreational activities.

#### 4.4. Provincial Scenario of Institutional Arrangements

After 18<sup>th</sup> Amendment in Constitution of Pakistan, functions related to social security are devolved to provinces. Now it is the responsibility of provinces to amend and adopt related laws and ensures social security especially to PWDs. Table 4.2 shows Acts and provisions adopted by provinces for PWDs.

**Table 4.2 Acts and provisions adopted by provinces for PWDs**

Provincial Acts for PWDs	Provisions
<b>(Provincial) Employees' Social Security Ordinance, 1965.</b>	<p>Two main benefits "Injury Benefits" and "Disablement Pension and Gratuity" were provided to PWDs.</p> <ul style="list-style-type: none"> <li>● A person shall receive injury benefits fixed by government if he becomes incapable of work as a result to employment injury.</li> <li>● Persons with partial or total disablement shall receive disablement pension, upon expiration of his entitlement to injury benefit. Pension will be terminated upon the death of recipient or if disablement ceases.</li> <li>● Person with minor disabilities entitled to disablement gratuity fixed by the government.</li> </ul>

<p><b>Punjab Rights of Persons with Disabilities Act, 2019.</b> Government of Punjab.</p>	<p>District level committee on disability shall advise district authorities on rehabilitation and empowerment of PWDs.</p> <ul style="list-style-type: none"> <li>● Unconditional Cash Transfer Program through PSPA provides: <ul style="list-style-type: none"> <li>a) Rs. 2,000/month for PWDs who are incapacitated or not able to work</li> <li>b) Rs.1,500/month for the PWDs who are able to work, as per the assessment of Medical Assessment Board.</li> </ul> </li> <li>● Punjab Social Protection Authority (PSPA) has designed two graduation schemes (Rural and Urban) that serve as "exist strategy" of PWDs from unconditional cash transfer support.</li> </ul>
<p><b>Sindh Empowerment of Persons with Disabilities Act, 2018</b></p>	<p>Focuses on equality and non-discrimination of PWDs.</p> <ul style="list-style-type: none"> <li>● Policies are devised to ensure education of children who are visually impaired or deaf.</li> <li>● Punjab Social Protection Authority (PSPA) has designed two graduation schemes (Rural and Urban) that serve as "exist strategy" of PWDs from unconditional cash transfer support.</li> </ul>
<p><b>Balochistan Persons with Disability Act, 2017</b></p>	<p>No individual or organization, will be permitted to victimize a PWDs or abuse their privileges or confine benefits in any way.</p> <ul style="list-style-type: none"> <li>● Women, children and senior citizens with disabilities, the government shall take special measures to ensure that such women, children, and elderly people are given full protection under law in enjoying their rights.</li> </ul>
<p><b>Khyber Pakhtunkhwa Rights, Rehabilitation, Accessibility and Empowerment of People with Disabilities Act, 2018.</b></p>	<p>Focuses on categorization of disability,</p> <ul style="list-style-type: none"> <li>● Online system of registration of Persons with Disabilities,</li> <li>● Provisions of ICT Accessibility to special citizens.</li> <li>● Establish Rehabilitation Fund for PWDs.</li> <li>● 2% Employment quota reserved for PWDs.</li> </ul>

Sources: (Provincial) Employees Social Security Ordinance, 1965.

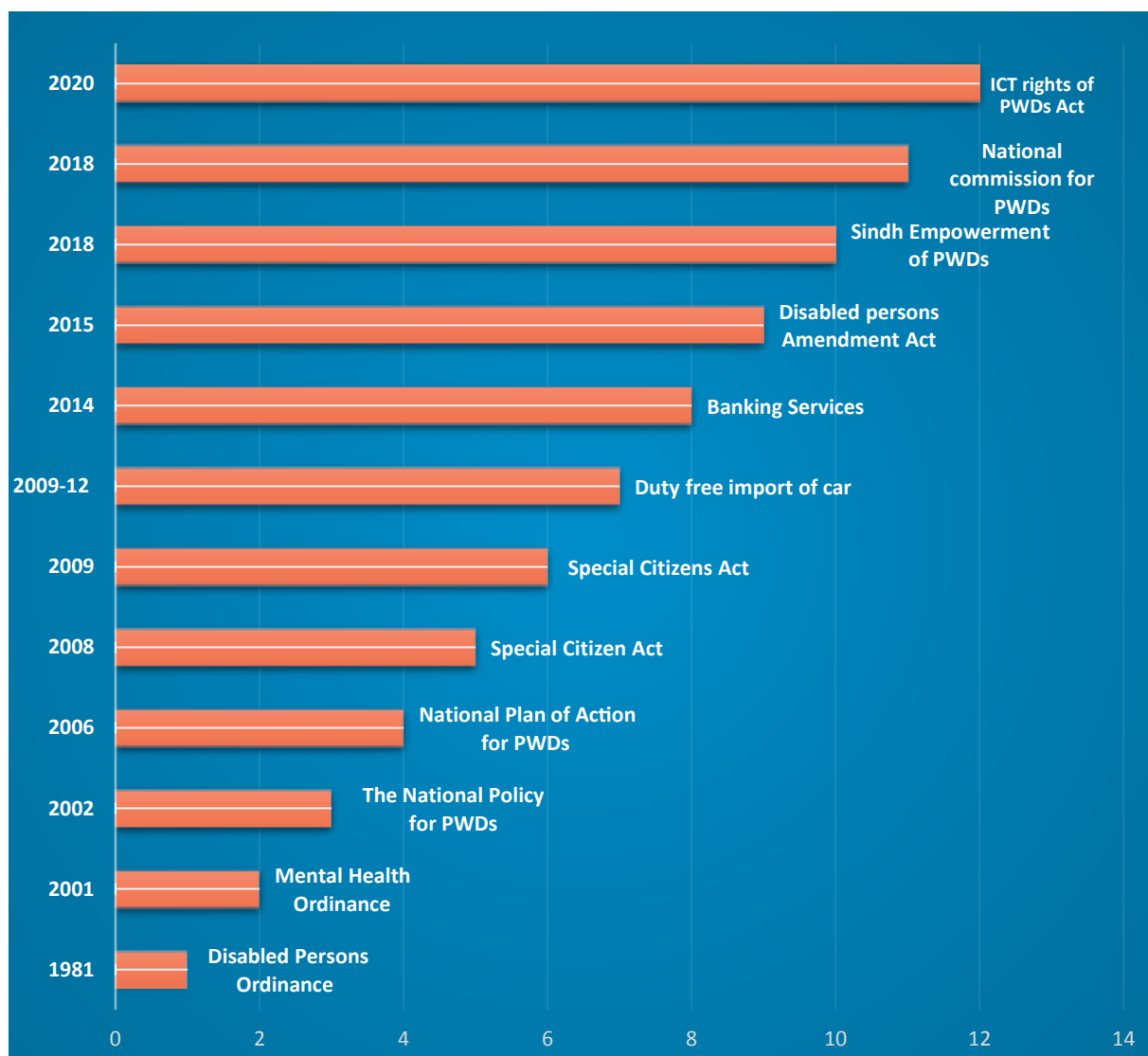
Punjab Rights of Persons with Disabilities Act, 2019. Government of Punjab.

Sindh Empowerment of Persons with Disabilities Act, 2018. Government of Sindh

Balochistan Persons of Disability Act, 2017. Government of Balochistan.

Khyber Pakhtunkhwa Rights, Rehabilitation, Accessibility and Empowerment of People with Disabilities Act, 2018.

**Figure 4.1. Timeline of the Laws and policies for the rights of Person with disability**



This shows that Pakistan has all sorts of legislation and policies and there is partial implementation in process of further progress and implementation. Pakistan has a high level commitment for improving wellbeing of PWDs and Task force is already in place. Further on assistive technologies are another component, which focuses on physical disabilities like cochlear implants and wheel chair, Brails and other assistive educational technologies. In health, action plans as SDG agenda vulnerable are well covered and mental health is included in essential package of health services for Universal Health Coverage.



## Chapter 5

# Taking Care of the Physically Disabled

According to the United Nations Convention on Rights of Persons with Disability (CRPD), disability care should be person specific rather than segregating it. This stands correct as there are many different types of disabilities which needs varied type of management. Even if two or more people face the same type of disability, the extent of its impact on their lives may vary significantly, hence their care needs would vary too. There are numerous organizations worldwide that either provide overall care and support to our differently abled fellow human beings or work for a specific group of people facing a certain kind of disability.

The entire phenomena of facing a disability makes the life of a person completely different in terms of their needs and potential opportunities. These dimensions include general lifestyle, education, work, family life, harassment and crime, legal rights, sports, transportation and skill development. In addition to these is housing and long-term care, as many PWDs need full me assistance/ care even in carrying out daily life tasks such as eating food, transporting themselves and managing natural needs (WASH ).Therefore, by now it is important to identify the significance of highlighting the difference in kinds of disabilities and the different dimensions of life it may have an impact on. Once these are identified then person-specific support is identified and provided. Usually across the world, in every nation there are some institutions which are working on some of these kinds of disabilities while others are working to improve the overall lifestyle of PWDs by targeting certain aspects of their lives. The difference mostly comes in adequate provision and targeting of both. Another very important challenge faced by PWDs is poverty. The poor may not have anyone to look after their child, finance his/her financial and medical needs.

Pakistan is a philanthropic nation. On the individual as well as organizational levels, there is extensive welfare work being carried out. Edhi Foundation comes among the most prominent national names in this regard, it maintains the record of having world's largest volunteer ambulance service. Others include Chhipa Welfare Association, Ansar Burney trust International and more. These national organizations have very vast scope when it comes to coverage in terms of beneficiaries. Be it emergency support in case of accidents like building collapse, providing home to the homeless or food to those in need, such organizations work in all aspects. They provide support to women, children, old and PWDs. For differently abled persons, there are broadly three types of institutions.

- Special education schools catering children with intellectual limitations disabilities.
- Disability shelters which provide all sorts of support need including residence.
- Training schools/institutes.

There are about 270 local organizations/facilities for the disabled persons in Pakistan and around 4 international organizations working towards betterment of PWDs.

### 5.1. Different models of taking care of disabled persons

It is observed that socioeconomic environment of PWD make a difference in becoming a useful citizen of country.

Just compare a child with impaired hearing in poor and rich family

#### Hearing impaired

Poor	Rich
<ol style="list-style-type: none"> <li>1. Delayed diagnosis Mal Nutrition</li> <li>2. Exposed to Childhood diseases</li> <li>3. Not vaccinated</li> <li>4. No Educational facilities</li> <li>5. Assistive technologies not available</li> <li>6. No Social protection</li> <li>7. Permanent Disability</li> <li>8. Sent to shelter</li> </ol>	<ol style="list-style-type: none"> <li>1. Early identification well nourished</li> <li>2. Less exposure with childhood diseases</li> <li>3. Vaccination completed</li> <li>4. Educational &amp; care facilities available</li> <li>5. Assistive technologies available</li> <li>6. Leading almost normal life</li> </ol>

- The best management is done by parents who can judge and respond to the needs of children and try maximum to provide but their social, educational, economic limitations can impact the final outcome.
- Second model is professional caregivers (such as nurses). This is an option, that is mostly available for those who can afford it. The positives with this is that, in most of such instances proper provision of required support is ensured.
- Next, we have differently abled persons who are managing on their own, these are the ones usually facing a physical limitations like post injury disability. Overtime they train themselves to carry out daily life tasks.
- Another group is those who are in government, charity or private led disability support centres. These are either those who have no one to take care of or those who are facing severe disabilities and require constant professional care and observation.

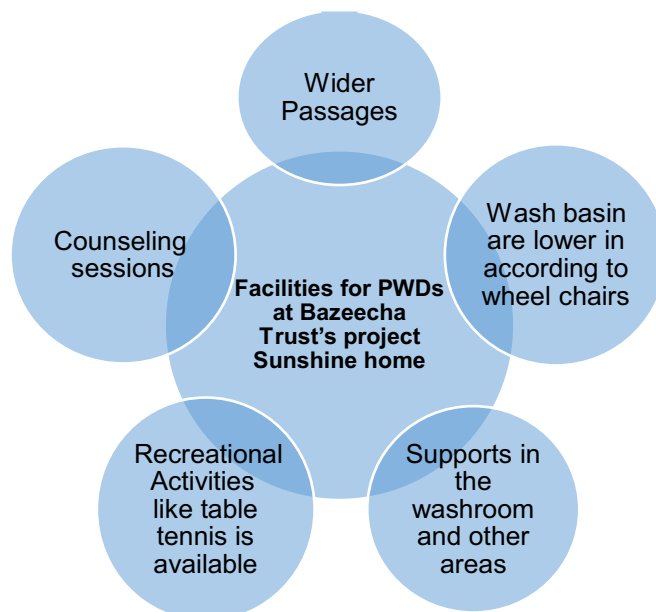
In Pakistan, Bait ul mal is a public social assistance institution and assistance to PWDs is one of it (shelter, Health assistance). There are trust run institutions, which came into existence in response to natural disasters like Earthquake in 2005 and these shelter homes and NPOs are still working and contributing to improve the condition of PWDs. Here is a case study of Sun Shine Home run under Bazeecha Trust Rawalpindi.

## 5.2. Bazeecha Trust: A Case Study

Established post 2005 earthquake in Pakistan to provide shelter for children orphaned. It was purely on self-support and initiated by collecting funds from friends and relatives. Bazeecha Trust provides home to more than a hundred women in different cities of Pakistan. Bazeecha trust welcomes all people in need with inclination towards women in need, PWDs and orphans. They welcome women from any caste, culture and religion. Initially they targeted young girls but they remained their doors open to others too and with time they become an organization that deals with problems of women and many dimensions. The trust provides a home to women who have been abused, who have nowhere to go, and persons with physical disability. At these centres, Bazeecha Trust not only provides more than satisfactory living conditions (food, shelter and basic necessities), they support the girls in their education, skill development and life skills.

The Bazeecha Trust team tries to cater the needs of their beneficiaries collectively and individually too. One of their centre called Sunshine Home is located in Rawalpindi and is hosting the six paraplegic girls. This infrastructure is purpose built for these girls so that these girls can move around freely on wheel chairs and can do their daily chores like washing, self care cooking food, eating. Even provision for recreational activities like table tennis is there. Passages are wider, there are supports in the washroom. Besides their physical care their mental health is also important to mainstream them in order to face the challenges of disability. So, Sunshine also arrange counseling sessions every week virtually. They are also given the opportunity and supported to get admission in better educational institutions. Moreover, they are taught life skills, inter personal communication and harmonization. All of them can take care of themselves for carrying out daily tasks. Their Health status is evaluated frequently and demand basis and given particularly required treatments. Director of the Sunshine home is personally interested and involved in motivational activities over the weekends as well.

**Figure5.1. Facilities for PWDs at Bazeecha Trust's project Sunshine home**



### Case study of Safina

Safina 27 years old is one of the paraplegic girl at Sunshine Homes, faced the spinal injury at the age of 14 years. At age of 14 she undergone back bone surgery due to tumor and is paraplegic since then. She belongs to a middle class family. It was very difficult time period for her. After Sunshine Home team motivation she was realized that she is equal to others. The Sunshine Home team taught her to perform her day to day activities by herself. She lives in the sunshine center and motivate her other mates towards independent living. Safina attained the education at the intermediate level and now she wants to get the bachelor degree in special education. Besides education she also have computer skills. During studies she had to face some difficulties as according to her, educational institutes does not cooperate with the special person and does not facilitate them as the environment is not adapted for wheelchair users and physical environment was a barrier like staircases . She is also learning fashion designing. She love cooking so she spend her spare time in cooking. She has interest in sport activities and she love cricket. In the sunshine center they have a coach who teach them to play table tennis. She have a very good bonding with her mates and she is satisfied with all the facilities provided to them at sunshine home. Currently, she is working as an intern in an organization that works for Canadian immigration. The major problem that Person with disability have to face according to Safina is generally the inappropriate infrastructure (particularly transport infrastructure) for PWDs. Besides this, negative societal behaviour of general public and colleagues at the work place also demotivate them. So there is need to make aware people about how to treat the Differently abled person.

## Facilities at Bazeecha Trust's project Sunshine home



The team has insured a properly equipped infrastructure at the Sunshine Homes centre residential facility for paraplegic girls. Washroom facilities accessible at wheel chair height, wheel chair ramps and widening doors so that wheelchairs can cross easily.





## Skill Development at Bazeecha Trust's project Sunshine home



Sunshine Home fully supports any girl sheltered at their centres who wants to continue her education or attain a skill. From among the sheltered woman, one has the skill of sewing clothes, she sewed all the Eid clothes for the rest of the residents. One of them is pursuing her bachelor's degree from Riphah International University, while one works at a bank. The difficulty they face was highlighted during the interview was lack of professional sports trainer for paraplegic girls. The directors believe in the potential of these girls and say if they are trained properly, they can represent Pakistan on international platforms.





### 5.2.1. Common Challenges faced by PWDs

The challenges that come in addition to the physical difficulty include mental health issues, social stigmas and economic challenges. Differently abled persons require additional financial support to fulfil their additional medical needs and for improved physical mobility. Often people are not aware of sensitivity of differently abled persons due to which in addition to the physical challenge, they have to face social alienation too. Feeling like an outcast, have people staring at you when you go out in the streets, hence finding it difficult to blend in. This in turn may cause depression, anxiety and may give rise to insecurities, even leading to more severe mental health issues.

In Pakistan, mainstreaming PWDs is another challenge. They are unaware of their rights, suffer from low self-esteem, feel themselves as unfit and end up being wrongly treated by the people around them. Differently abled persons, especially young girls or women are more vulnerable to abuse and neglect. By close conversation with women at Sunshine home it was revealed that these women left their home voluntarily due to mock and abuse they face at home and in society or they are forced to leave the home. Therefore, lack of awareness of their rights and availability of wider fit to purpose support system and poverty are the main reasons, which increase the challenges faced by an average PWD.

From this group, children are more vulnerable, as they are not physically strong and mentally mature to understand or sense the bad intentions, they find it difficult to speak up against mistreatment. It is difficult for them to find a person around who they can trust and ask for help. It is also a social stigma that people often treat differently abled persons as inferior.

Overall, an enabling environment is one that provides adequate financial arrangements, socio-cultural acceptances, government support, legal framework, institutional arrangements, skills and capacity building opportunities. It is unfortunate how for PWDs in Pakistan, all dimensions of an enabling environment are inadequate. Therefore, it is paramount to identify the challenges PWDs have to face in addition to the medical issue they face due to their disability. Poverty is on the rise, there is little or no socio-cultural acceptance, government support is limited and partial implementation of legal framework raises many questions. There is need for provision of universal social protection for these strata of population of Pakistan.

## Chapter 6

## Institutional Challenges of PWDs during Covid-19

Covid-19 pandemic has a huge impact on lives of the people and especially it has caused severe health threats to millions of people around the globe. In accordance with this pandemic, countries around the globe have taken some measures to curtail the flow of pandemic through lock downs, closure of institutions and introducing the policy of social distancing. Persons with disability, who are already vulnerable to discrimination even in non-pandemic times, were at higher risk as the pandemic effects.

Persons with disabilities are already facing the challenges like affordability or accessibility of required health care. COVID-19 has exacerbated the problems of the PWDs<sup>44,45</sup> (United Nations ESCWA and World Health Organization, 2020, World Health Organization, 2020b). During COVID-19; services are shifted toward the online mechanism by using the telecommunications technology<sup>46</sup> (WHO, 2020). This policy is effective in the developed areas where the internet facility is available<sup>47</sup> (Jalali et al., 2020). Person with disability are facing the awareness and accessibility barrier regarding the technology. Moreover, some people with disability have the concern about their privacy in the online treatment process or session<sup>48</sup> (Goyal et al., 2020).

Mental health services are highly affected during the COVID-19 pandemic. There is a reduction in the mental health services as well as the psychosocial support during this period of COVID-19. According to a study by United Nations, in Madrid nearly 70% beds for mental health patients reserved for the COVID-19 patients<sup>4</sup>. Studies also find that ,COVID-19 create the huge mental stress among the people for example in China nearly 40% of the people have physiological problem during the COVID-19 period<sup>49</sup> (Liang et al., 2020). As closure of educational institutions in general and switching over to online instruction has aggravated challenges for PWDs individually and at institutional level due to limitations and accessibility. Keeping in mind the barriers of non-availability and affordable technology individually by special educational and medical care institutions, SPRC has done a small qualitative study on COVID-19 impact. This study has focused on problems faced by administration of institutes for switching over to alternatives and impact of interruption in learning process on skills, training and treatment of PWDs.

<sup>3</sup><https://reliefweb.int/report/world/covid-19-and-its-impact-persons-disabilities>

<sup>4</sup> <https://unsdg.un.org/sites/default/files/2020-05/UN-Policy-Brief-COVID-19-and-mental-health.pdf>

## Methodology

Three dedicated institutes of varied types of intellectual disability and mental health disorders were selected as convenient sample/case study. In depth interviews were conducted and certain observations were combined which helped in bringing out themes in making case studies.

**Table 6.1 Institutional Profiles**

Institutions	Description
<b>Al-Harmain Rehabilitation Center</b>	Al-Harmain Rehabilitation center (AHRC) is located in Malot, near Bahria Enclave Islamabad. It provides services in domains of social work, Clinical Rehabilitation, counseling, extensive Psychotherapies and Drug Addiction through therapy sessions with PWDs, recommend medication, exercise, and training.
<b>Step to Learn</b>	Step to Learn (STL) is an organized set up for children with disability located in Sector I-9 Islamabad. STL focuses on Behavior, Communication, Academics and Daily Living skills. STL domains of work includes; Autism, Slow learning, Down syndrome, Hearing Impairment, Cerebral palsy, Delayed speech, Mentally challenged and Multiple disorders. STL provide services in special Education, therapies in Speech and Language, Behavior, Physical, Sensory and Cognitive areas.
<b>Hassan Academy Special Education</b>	Hassan Academy Special Education (HASE) is a non-governmental organization located on Park Road, Chak Shehzad been providing the education to the children with hearing impairment and Mental disorders. HASE provides auditory training, speech development, language development, speech reading, sign language, finger spelling, written language, reading skill and writing skills.

Above mention are the key domains in which all three dedicated institutions are providing services to the persons with disability. Table 3.2 shows the socio-demographic characteristics of the respective institutions.

**Table 6.2 Demographic Profile of Institution**

Institutions	Enrolled PWDs	Age (years)	Male	Female	Socioeconomic Status
Al-Harmain Rehabilitation Center	25	21-45	25	-	Middle to Poor
Step to Learn	63	3-24	44	19	Higher to Poor
Hassan Academy Special Education	30	7-16	20	10	Middle to Poor

## Interviews

Data was collected using semi-structured interview guide having open-ended questions. In-depth interviews were conducted to get the understanding of the challenges faced by PWD's during the lock down period. The administration of all the three institutes was interviewed separately. The researcher recorded interviews and for that, prior consent was taken from the respondents.

## Data Analysis

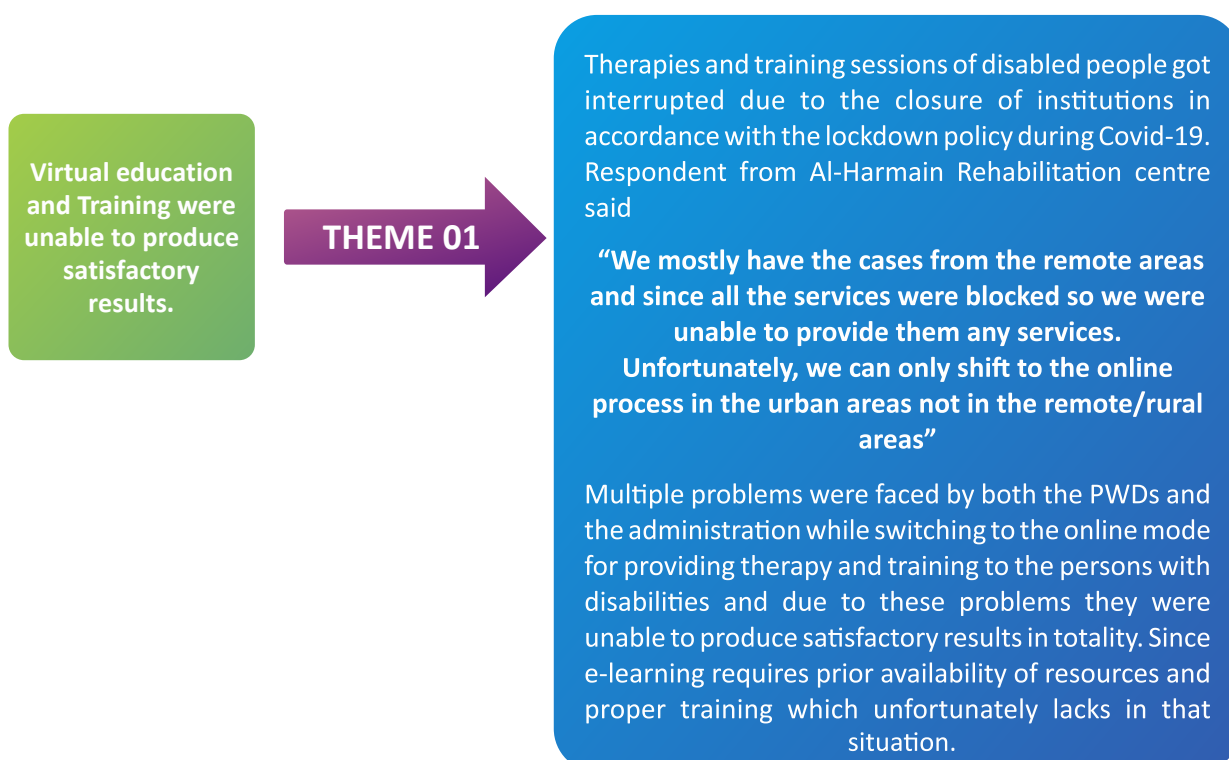
In accordance with the qualitative approach, the analysis was done to explore the challenges of Persons with Disabilities. Furthermore, data was analyzed using inductive thematic analysis. Data was coded and themes were identified. It was made sure that the themes are consistent with the data. Keeping themes in view, a narrative description was produced accordingly.

## Themes

After analyzing all the three interviews, four major themes emerged.

1. Effect of Virtual education and Training on satisfactions and results
2. Effects on PWDs health due to disruption in designed nutrition.
3. Effect on learning process of Self-care of the PWDs
4. Effect on PWDs and their families during pandemic.

## General effect of pandemic on PWDs, Families and Institutions Thematic finding



PWDs health got worsen due to inadequate nutrition.

## THEME 02

PWDs need extra dietary care because their diet has direct impact on their long-term health. More the diet is balanced better the overall condition will be. Respondent from Al-Harmain Rehabilitation Centre narrated that;

*“We discharged one of our client and at that time his weight was 70-72 kg and when after visiting home he came back again at that time his weight reduced to 58-60 kg.”*

Health of PWDs declined when they went home in period of Covid-19. Similarly, respondent from Step to Learn told that;

*“We do not let them eat the sugary or bakery items and also advise the parents to follow that and we also strictly follow this plan as these items have major impact on these students behaviour as it increase the hyper activities”*

Management of the institutions tried to follow the plan and direct the parents in the time of lockdown, to avoid sugary items in diet of children with disability because it triggers them toward hyper activities, extreme emotions and aggressive behavior.

Self-care of the enrolled includes their social interaction, skill building and other learning self-care skills. It has been noted that particularly this area of self-care of the PWDs has been effected much more than the rest of the things. Respondent from the “Step to Learn” told about the self-care they have been providing;

*“We work on the basic skills like attention, eye contact then we move to behaviour modification and communication skills in which we focus on the verbal skills along with behavioural changes of the student. Then we work on the self-help area in which we teach these children about the daily living skills like how to open the bottle etc. and motor skills that includes sign motor movements and gross motor movement (bending walking, running etc.). Last areas is of academic skills that include reading and writing.”*

All these basic self-care routine and training were affected by lock down and a respondent from Hassan Academy told that; “one thing is noticed that learning process became much slower among the students when they came back after lockdown”

## THEME 03

Self-care of the patients was highly compromised.

Patients and  
the families  
both suffered  
in pandemic.

#### THEME 04

Persons with Disabilities are already considered as a burden on the family and the resources, in the current situation when the families have been facing the worst financial constraint, PWDs became none other than an unpleasant responsibility. Respondent from Al-Harmin Rehabilitation Centre said that;

*“We have cases where due to family discrimination during the COVID-19 some of the client's condition became worsen and they died. Discrimination in the sense that the family considered that they are already suffering and are not contributing to family income and COVID-19 has aggravated the situation, like income loss. So families are unable to take care of these special persons properly as these patients are not considered as the productive member of family”.*

Even mostly parents remained in denial state of mind towards disability of the child and some of the parents consider it a taboo for themselves, so their behavior with a disabled child remained different from that of normal. Due to poor communication and least training provided to the patients, they developed some serious mental issues which mark long term impact on their health.



## Results and insights

Covid-19 has brought change in social life of the people which made it difficult for the pre-existing setup to adopt new mode of living and communicating. The situation got even worsen when it comes to persons with disability. Participants of the study talked about the difficulties in their interviews with SPRC researcher, that disability institutions and persons with disability have faced while shifting from regular mode of education and training to virtual mode without any prior and necessary arrangements and it ultimately results in lack of communication between clients and their regular therapists. In urban areas where institutions managed to conduct e-sessions, clients were unable to get their commands even from this mode and this thing further increased the level of stress and anxiety in them. Those who were residing in rural areas were simply cut-off due to non-availability of internet.

Nutrition plays vital role in overall progress of a person with disability along with all other therapies, at studied institutions daily nutrition plan is being followed, which contains the division of foods with all the required calories for the client. But when they went back to their homes in the time of lock down, parents failed in fulfilling the basic dietary needs of the PWDs. One acceptable reason for this incompetency can be the economic challenge that most of the lower income households were facing, secondly families were not aware of importance of full filling dietary needs so they did not pay attention and this thing has led to long-term negative effects on persons with disabilities.

Social interaction and learning skills of children with disability are so much important in their self-care that it sets a base for their further progress, because it includes sensory learning, object identification, symbolic interaction and taste development. As an example, if we talk about taste development, similar diet has been using for a week to develop the taste of that diet into the mind and senses of the patient. This type of learning is the most sensitive part of the process which needs to go in a flow, but in the time of lock down when the flow of this self-care learning disrupted, and parents at home were unable to follow the guidelines of the institute and therapists, that disruption ultimately results in hyperactive behavior of the enrolled which has led to extreme emotions, aggression and sharp mood swings.

Role of parents in this situation was very important but they were neither trained for this situation nor did they have any previous idea about how to handle such situation with person with disability. Although the disability institutions have tried to guide the parents and arrange training sessions for them to teach how to manage the situation and take care of the patients in the most meaningful manner but those sessions turn out to be unsatisfactory, the situation becomes a sort of burden or compulsion for parents in the times of economic crisis. This thing affects the parents as well, disturbs their mental stability as well but the most serious damage that it has done is that it worsen the condition of the persons with intellectual disability by making them more vulnerable, increased the level of stress and anxiety in them at an alarming rate, slows down their learning speed to the dead level and inculcates a feel of neglect and loneliness in them.



## Conclusion & Policy Recommendations

Pakistan a populous LMIC country with 10.7% functional limitations (PSLM 2019-20) Functional limitation includes 3.4% disability and 7.3% some difficulty. During the preparation of this report lack of data overall is big barrier in providing assistance to PWDs with equity. It is very well realized that policy level interventions /allocations are based on counting of PWDs and declaration of their status by registration with NADRA. In this report, it is found that there is big gap in actual number and registration with NADRA to gain maximum support from Government as Sehat Card. On other hand at Legislation and policy level national Government has responded well to the international commitments but implementation and true benefit to this vulnerable population is still not in place. As 30 % of PWDs are diagnosed in less than 6 years of age, which needs lifelong care and there is no mechanism of universal social protection through life course approach, protecting against vulnerabilities. Health and education is a provincial subject post 18th amendment and provinces also need to adopt inclusive approach.

Physical disability either as inborn or manmade needs enabling environment to make them productive member of society. In this regard, compensations, social protection, health support and employment can also make a positive difference. Intellectual disability is the area that needs early intervention and still not properly focused on, as early detection and interventions can improve their life skills & reduce their vulnerabilities. Educational institutions and teachers are the ones who can be the light bearer & source of change. Mental health either as part of disability or due to lack of social protection (unemployment ,neglect, social response) especially in younger population is become another area of attention.

Government of Pakistan provides institutional arrangements for PWDs with different mechanisms like Bait ul mal and Ehsaas programe has taken some measures to provide better facilities for PWDs.

Review of legislation and policies has given the insight that all basics are there and need political will and prioritization and harmonization (national /provincial, public /private) with monitoring mechanisms. COVID-19 pandemic was another test, though there was huge expansion in IT sector for educational support but PWDs were deprived of this due to lack of capacity of special educational and rehabilitative institutions to switch over as mentioned in impact of COVID-19 chapter, It is realized that leaving no one behind, shock responsive social protection mechanisms are the answer as adopted by many countries.

Robust social protection system can build resilience and provide support in uncertain conditions like pandemic through better anticipation, adaptation and absorption. Shock responsive social protection system against idiosyncratic & covariate shocks may be the solution as it keeps the ability to absorb the shock, and it keeps disaster risk considerations incorporated in its design, so that it can respond flexibly in times of crisis. Countries that have shock responsive social protection system have just need to enhance the productivity of same program rather than launching a new program of cash transfers in such times.

As SPRC teamwork has shown certain gaps in management of PWDs and there are some recommendations which can be implementable and result oriented.

- As data is lacking on localization of disability and disparity in counted and registered PWDs scale up the registration process.
- PWDs should be benefited from existing social security (SSP) benefits by increasing registration with NADRA.
- Registry of all public and private institutional arrangements for PWDs is to monitor and harmonize services according to standards so that they can provide services with equity.
- Disability benefits should be provided as individual, rights-based entitlements in a life course social protection system backed by international frameworks.
- Programs should be multi-tiered, a combination of adequate, guaranteed benefits and higher-rate benefits for those required to pay contributions which include supplemental family allowances to support the families of persons with disability. So, that their on-going progress (education, training sessions, self-care and nutrition) could not be disrupted and even families can be able to take care of them in times of crisis.
- A citizenship paradigm should be encouraged instead of charity and approach should be universal in nature to strengthen all the persons with disability.
- Training and awareness of Health Care Workers in early detection of disability. Strengthening of existing institutions and scaling up.
- Awareness about legal rights of PWDs and establishment of disability forums to make their point and seek legal help.
- Universalization of social protection inclusive of caregivers.
- Inclusion of PWDs in preparing emergency preparedness like future pandemics.
- Advocacy and facilitation for higher up take of routine and COVID-19 vaccination.



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