TRAINING NEEDS ASSESSMENT
A Qualitative Study on Community Attitudes and Perceptions on Disability in Gilgit-Baltistan
A Qualitative Study on Community Attitudes and Perceptions of Disability in Gilgit-Baltistan

A Training Needs Assessment

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INTRODUCTION
The concept note for the TNA and tools for Focus Group Discussions were developed by Usman Ali and Reem Khan, under the guidance of Aga Khan University – Human Development Programme. Training and supervision of field teams during the TNA was done by Reem Khan and Sumra Ahmed, as was the initial data entry in the field. The data cleaning and sorting process was completed by Sumra Ahmed and Sher Salman Baig, once again under the guidance of AKU-HDP. The NOWPDP team would like to extend a special thank you to Dr. Ghazala Rafique, Seema Lassi and Dr. Sayeeda Amber at AKU-HDP for their advice, guidance and support with the development of tools and for training the NOWPDP team in data analysis on NVivo.

Data analysis using NVivo was carried out by Sumra Ahmed, and the final report was written by Reem Khan.

The NOWPDP team would like to thank the EDIP donor AusAID, for giving us this opportunity to conduct an attitudes and perceptions study regarding disability. We would also like to thank the lead partner AKF for their support and guidance, Dr. Moladad at PDCN for his invaluable input in the selection of field teams for the TNA, and Mr. Niat Wali for his ever-lasting support, advice, and concern. We would also like to extend a hearty thanks to Mr. Maqsood and Mr. Sher Dil at PDCN for driving us to our many destinations, for being excellent company along the way, ensuring we stayed on track, remained safe, and for pointing out all the key landmarks along the beautiful journey.

We would also like to thank our excellent field teams for their professionalism, motivation, and dedication to the task. Field team spent long hours with the NOWPDP staff after each FGD (Focus Group Discussion) to ensure that the translating and transcribing process was completed efficiently.

Finally, we would like to extend a warm and heartfelt thank you to our participants, for speaking freely, for sharing their stories, problems and difficulties, and providing key insights which helped ensure the NOWPDP training sessions on Disability Sensitization and Inclusive Education were relevant and acceptable in the local context.

Sincerely,

Amin Hashwani
President, NOWPDP
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1. ACRONYMS

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<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AUSAID</td>
<td>Australian Aid</td>
</tr>
<tr>
<td>AKDN</td>
<td>Aga Khan Development Network</td>
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<tr>
<td>AKES,P</td>
<td>Aga Khan Education Services, Pakistan</td>
</tr>
<tr>
<td>AKF</td>
<td>Aga Khan Foundation</td>
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<tr>
<td>AKPBSD</td>
<td>Aga Khan Planning and Building Services</td>
</tr>
<tr>
<td>AKU-HDP</td>
<td>Aga Khan University – Human Development Programme</td>
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<tr>
<td>AKU-IED</td>
<td>Aga Khan University – Institute for Educational Development</td>
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<tr>
<td>CSRC</td>
<td>Civil Society Resource Center</td>
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<tr>
<td>CWD</td>
<td>Children with Disabilities</td>
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<tr>
<td>DDE</td>
<td>Deputy Director of Education</td>
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<td>EDIP</td>
<td>Education Development and Improvement Programme</td>
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<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>GB</td>
<td>Gilgit-Baltistan</td>
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<tr>
<td>GoP</td>
<td>Government of Pakistan</td>
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<tr>
<td>HI</td>
<td>Hearing Impairment</td>
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<tr>
<td>ID</td>
<td>Intellectual Disability</td>
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<tr>
<td>IDI</td>
<td>In-depth Interview</td>
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<tr>
<td>LD</td>
<td>Learning Disability</td>
</tr>
<tr>
<td>LLI</td>
<td>Local Level Institutions</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<tr>
<td>MT</td>
<td>Master Trainer</td>
</tr>
<tr>
<td>NOWPDP</td>
<td>Network of Organizations Working for People with Disabilities, Pakistan</td>
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<tr>
<td>PD</td>
<td>Physical Disability</td>
</tr>
<tr>
<td>PDCN</td>
<td>Professional Development Centre North</td>
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<tr>
<td>PWD</td>
<td>People with Disabilities</td>
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<tr>
<td>TNA</td>
<td>Training Needs Assessment</td>
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<tr>
<td>ToT</td>
<td>Training of Trainers</td>
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<tr>
<td>TT</td>
<td>Teacher Training</td>
</tr>
<tr>
<td>VI</td>
<td>Visual Impairment</td>
</tr>
</tbody>
</table>
2. OPERATIONAL DEFINITIONS

Attitude

a: a mental position with regard to a fact or state
b: a feeling or emotion towards a fact or state

Children of school-going age

Children between 7 and 18 years of age

Disability Sensitization

The sharing of knowledge (types, causes, characteristics, levels of severity etc.) regarding disabilities with a group of people with the aim of bringing about a different, more positive, reaction to disability and persons with disabilities due to increased understanding. Directly addressing common misperceptions is also helpful in the process of disability sensitization.

Family

Refers to not only the nuclear family (i.e. mother, father, siblings), but also to the extended family (i.e. grandparents, aunts, uncles, cousins) in the context of Gilgit-Baltistan where joint-family households are common.

Focus Group Discussion

A gathering of people from similar socioeconomic, cultural, educational, and linguistic backgrounds who share a common interest in a topic. The topic is discussed in the gathering for a certain period of time during which common ideas, perceptions, beliefs, and debates within the group emerge. Focus Group Discussions often have a moderator (sometimes two - the dual moderator approach) and a note-taker.

Inclusive Education

Inclusive Education is a process of increasing the participation of all students in schools, including those with disabilities. It is about restructuring the cultures, policies and practices in schools so that they respond to the diversity of students in their locality.

Inclusion implies that the system should be flexible enough to adapt to and accommodate a child with disabilities as opposed to the prevalent system which expects that the child with disabilities must adapt to the existing system.

Moderator

Leader of the Focus Groups Discussions who was responsible for initiating discussion by asking key questions and encouraging participation. Part of the field team.

Perception

The way in which something is regarded, understood, or interpreted.

Training Needs Assessment

A study through which the training requirements of a specific group regarding a specific topic are researched in terms of their present level of understanding, along with the general understanding of the community. Involvement of the community provides additional context.

Training of Trainers (ToT)

A training in which participants of the training are prepared to become trainers themselves. ToTs often cover material, as well as training techniques.

NOWPDP conducted a three-week ToT with 18 master rainers from across GB, who then went on to conduct 21 training sessions on the same topic in various districts.

Translator/Note-taker

Individual responsible for recording the entire Focus Group Discussion and taking detailed notes over the two hour session. Part of the field team.
3.1. Introduction to Education Development and Improvement Programme (EDIP)

The Education Development and Improvement Programme (EDIP) was launched in July 2010 and is funded by AusAID. The programme has a “whole-school improvement” approach and will be implemented in 106 schools across seven districts of Gilgit-Baltistan (GB) over a period of three years. EDIP partners include –

- The Aga Khan Foundation (AKF)
- Aga Khan University – Institute for Educational Development (AKU-IED)
- Aga Khan Education Services, Pakistan (AKES,P)
- Aga Khan University – Human Development Programme (AKU-HDP)
- Aga Khan Planning and Building Services, Pakistan (AKPBS,P)
- AKU-IED Professional Development Center, North (PDCN)
- Civil Society Resource Center (CSRC)
- FOCUS Humanitarian
- Network of Organizations Working for People with Disabilities, Pakistan (NOWPDP)

3.2. Introduction to Network of Organizations Working for People with Disabilities, Pakistan (NOWPDP)

NOWPDP is a non-profit organization that aims to make a significant difference to the quality of life and welfare of people with disabilities. NOWPDP conducts its programs regardless of faith, origin or gender, and has been working towards the achievement of its vision since its launch on 9th May 2008 as an initiative of the Aga Khan National Council for Pakistan.

Composed of civil society and disabled persons organisations from around Pakistan, NOWPDP works in the following areas to provide opportunities for people with disabilities to be an integral part of society:

- Foster collaboration and capacity-building of relevant stakeholders
- Facilitate employment opportunities for people with disabilities
- Advocate for the rights and needs of people with disabilities
- Generate a greater level of awareness about the abilities and rights of people with disabilities

3.3. NOWPDPs role in EDIP

As part of the whole-school improvement programme, NOWPDP will be implementing teacher and community awareness events in disability sensitization and inclusive education for children with mild to moderate disabilities.

Prior to conducting Teacher Training Sessions, NOWPDP completed a Training Needs Assessment (TNA) to understand the existing community attitudes and perceptions towards people with disabilities. The TNA was instrumental in providing a background for the development of culturally sensitive and relevant training materials.

Teacher trainings will provide teachers with the basic tools/skills they require to identify potential indicators of disability in their classes and to work effectively with disabled students in their mainstream classrooms.

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1 At the time this report was printed, programme activities had not yet commenced in one district of GB (Diamir) due to security concerns.
4. EXECUTIVE SUMMARY

The first part of the report focuses on general finding regarding the concept of disability as defined by participants in the Focus Group Discussions (FGDs), as well as the way disability is viewed in their communities. The second part of the report highlights the views and opinions of participants regarding three specific areas in the lives of children with disabilities (CWDs) and people with disabilities (PWDs) – education and employment, home and family life, and social integration.

When asked to describe the term disability, participants did not use “group” designations like jismani mazoori (physical disability) or zehni mazoori (intellectual disability); instead, specific descriptions of disabilities were provided, such as “those who cannot use their arms or legs”, “those people who have weak bones”, “people who cannot see or hear”. Participants in nearly all FGDs held in all four districts concluded that a disability was present when “any part of a person’s body did not function”, thus preventing them from doing simple things in their everyday lives. Participants also often described disability in the context of a person's ability to “work” or fulfill their roles as mother, wife, husband, provider etc. Many participants agreed that “those who could not work” or “those who were not useful” due to their disability were more prone to being thought of as disabled, whereas those who could, despite their disability, were sometimes not seen as having a disability at all.

The causes of disability that participants described were divided into two main groups by the NOWPDP team and participants: medical and non-medical. Medical reasons for disability included factors such as poor nutrition, lack of vaccinations, illness, poor hygiene etc., while non-medical reasons included topics such as punishment for sins, jadoo (magic), fate, and a test of patience for parents of disabled child etc. The reasons for disability also had an impact on the actions taken by parents of CWDs upon discovering their child’s disability, usually within the first two years after birth. The actions taken by parents upon the discovery of disability varied greatly between parents in Gilgit and Ghizer when compared to parents in Skardu and Ghanche. While all parents appeared to know the medical causes of disability, parents in Ghanche and Skardu seemed to give more weight to the non-medical causes which often prompted them to seek traditional methods of “cure” including spiritual healers or pirs.

Overall, the reaction of parents, family, and community members to the birth of a disabled child ranged from very negative (sorrow, grief, sense of devastation, isolation, and CWD viewed as curse) to positive (supportive, encouraging, engaging, and CWD viewed as lucky omen to family). Attitudes, perceptions and behaviors of community members towards CWDs/PWDs are also highlighted in this section – it was reported that while some were kind to CWDs/PWDs, many preferred to stay away from them and their families.

When discussing education and employment many parents of CWDs indicated the lack of trained teachers or special schools, and were hesitant to send their children to mainstream schools. Parents of non-disabled children as well as teachers were also hesitant to mainstream CWDs into regular schools, claiming that CWDs have special needs which cannot be met in a regular classroom. All three groups also highlighted the lack of employment opportunities for PWDs; many indicated that, without the possibility of employment, education of CWDs served no real purpose. Participants also stated that those PWDs who did find some form of employment were often dependent on the goodwill of employers and were vulnerable to poor treatment. The home and family life of CWDs/PWDs was also discussed, and participants all agreed on the importance of role fulfillment. Those PWDs who were seen as “useful” were sometimes encouraged to marry, whereas those who were seen as completely dependent were discouraged. Isolation was a main underlying theme in this discussion as PWDs were seen as being isolated from their communities. Many faced ridicule and constant taunting, and no opportunities in terms of family life, marriage, and real integration into society.

The final sections of this report address the emerging findings and observations requiring action; some of these have been addressed by NOWPDP through field activities, while others require a differently structured approach. For such findings, recommendations have been made.
5. METHODOLOGY

5.1. Aims and Objectives of Research Study/TNA

Training Need Assessment was conducted to determine community attitudes and perceptions towards disability in Gilgit-Baltistan. The basic objective of the study was to identify and meet the needs of children with disabilities (CWD) in schools and communities by developing a comprehensive training program for teachers and communities of the program area.

This study allowed NOWPDP to gain an understanding of the existing social barriers faced by CWDs prior to the preparation of the teacher training manuals on Disability Sensitization and Inclusive Education in which findings from the study were directly addressed. It also explores the potential social barriers to CWDs with regard to access to education. The study focuses on parents of children with disabilities of school-going age, teachers, and parents of non-disabled children of school-going age.

5.2. Study Design

The TNA was a qualitative study which explored attitudes and perceptions of communities in the target area through Focus Groups Discussions (FGD).

5.3. Sample Size

The population size was based on the number of targeted schools/school catchment areas, which were the unit of intervention and measurement. Based on this, NOWPDP selected 20% of the total population (106 schools/catchment areas) as a sample size. As a result, a sample size of 21 schools/school catchment areas was established for the qualitative study.

Considering budget and time constrains, NOWPDP selected four districts to be a part of the study based on their traditional/non-traditional status, as well as on distance, remoteness and ethnicity. The four districts which were included in the NOWPDP qualitative study were Gilgit, Skardu, Ghanche, and Ghizer.

In order to ensure proper representation of each district, the total sample of 21 school catchment areas were proportionalized to match the number of schools/catchment areas per district. NOWPDP held FGDs in 50% of the clusters in each district. As a result of this proportion, data was collected from 15 school catchment areas in Ghizer (which has a total of 51 schools/catchment areas) and from two (2) catchment areas in each of the three selected districts (Skardu, Ghanche, and Ghizer with a total of 8 schools/catchment areas).

Focus Group Discussions were conducted separately with parents of children with disabilities, parents of non-disabled children, and teachers. FGDs with teachers included both male and female teaching staff, while FGDs with parents were segregated by sex (except for two groups in Ghizer where male and female participants did not object to attending a mixed gender FGD).

As a result of the sampling used, NOWPDP was required to conduct 21 FGDs (15 in Ghizer, 2 each in the remaining three districts) in 21 school catchment areas across 7 clusters in 4 selected districts.

<table>
<thead>
<tr>
<th></th>
<th>Parents of CWD Male</th>
<th>Female</th>
<th>Teachers Male</th>
<th>Female</th>
<th>Parents of NDC Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
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<tr>
<td>Skardu</td>
<td>10</td>
<td>0</td>
<td>5</td>
<td>4</td>
<td>10</td>
<td>0</td>
<td>50</td>
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<td>2</td>
<td>7</td>
<td>0</td>
<td>9</td>
<td>50</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>18</strong></td>
<td><strong>46</strong></td>
<td><strong>27</strong></td>
<td><strong>31</strong></td>
<td><strong>16</strong></td>
<td><strong>52</strong></td>
<td><strong>190</strong></td>
</tr>
</tbody>
</table>

2 The term ‘school-going age’ included children from 7 to 18 years. However, some mothers with children younger than 7 years of age also participated in the FGDs.

3 Traditional districts are those in which the AKDN has been operating for a period of time. Non-traditional districts are those in which the AKDN has recently begun operations.
An analysis of each discussion was conducted by NOWPDP staff and the field teams at the conclusion of each session. As a result of these discussions, the NOWPDP team decided that a point of saturation had been reached after FGD number nineteen (19).

Each FGD had a minimum of eight (8) participants and a maximum of ten (10) participants.

Due to time constraints caused by the delay in the approval of the Project Implementation Plan, NOWPDP was unable to conduct In-depth Interviews as originally planned.

5.4. Sampling

NOWPDP used purposive sampling by using the project baseline data regarding disability enrolment for the selection of clusters and schools/catchment areas. This process ensured that all the villages in a cluster were represented, as well as eliminating the likelihood of situational bias (choosing the villages closest to the road, easiest to access etc.)

5.5. Instrument of Investigation

Detailed guidelines and unstructured/open-ended questionnaires were designed by NOWPDP for the FGDs, with feedback and guidance from AKU-HDP.

5.6. Field Teams

Field teams (moderators and translators) went through a rigorous interview and shortlisting process. Advertisements for local field teams were placed through PDCN in each district to be included in the study (Jamaat-Khanas, community centres etc.); the first round of candidates were shortlisted based on the experience listed in their CVs and their knowledge of local languages.

Phone interviews were held with shortlisted candidates in order to understand the nature and relevance of the experience they had listed; candidates also received detailed information about the project, the tasks required from field teams and the compensation being offered.

A second round of candidates was shortlisted upon the completion of these interviews. The final candidates were selected upon the successful completion of a second interview with the EDIP programme manager at NOWPDP. All selected candidates were well versed in the local languages of each district and had past experience with qualitative studies and conducting focus group discussions.

Upon signing their TORs, field teams were provided with names of schools/clusters (taken from the baseline survey) around which they were to identify participants for the FGDs (catchment areas). Teams were given at least two weeks to identify and mobilize participants prior to the arrival of the NOWPDP team in the district. Upon arrival in a district, the NOWPDP teams provided a one-day refresher training to field staff on qualitative data collection, since all field team members had previous experience with qualitative data collection. All FGDs were conducted in the presence of the NOWPDP team and in the local language of the district. FGDs with teachers were conducted in Urdu; however, participants were able to communicate in any language they wished during the FGD. All FGDs were recorded with the permission of participants; recordings were destroyed upon the completion of data analysis in accordance with suggested ethical practices regarding confidentiality.
5.7. Data Collection and Analysis

AKU-HDP provided training to NOWPDP staff on basic qualitative data collection as well as data analysis using Nvivo software.

FGDs were conducted by experienced moderators and translators from each of the participating districts. One focus group was held per day for a period of 22 days.

Upon the completion of each FGD, the moderator, translator, and NOWPDP staff translated and transcribed the information gathered during the discussion. FGDs were recorded with the consent of participants, and these recordings were used for the translation and transcribing process.

All quotes included in the report have been translated from the local language into Urdu, and then from Urdu to English. Some excerpts are rough translations; such excerpts have been identified in the report. No names have been used in this report upon the request of participants.

5.8. Use of Results

The results of the study were used for the development of training materials for teacher training sessions which were held in the summer of 2011. Results of this study will also complement the disability prevalence survey which will be conducted by AKU-HDP.
6.1. Map of Gilgit-Baltistan

The area of Gilgit-Baltistan (formerly known as the Northern Areas) is diverse, with the population comprised of 35% Shias, 35% Sunnis, 25% Ismailis, and 5% Nurbakhshis. There is also diversity in the languages spoken there; Shina (with several dialects) is the language of 40% of the population, spoken mainly in Gilgit, throughout Diamer, and in some parts of Ghizer. Balti is spoken by the entire population of Baltistan. Wakhi is spoken in upper Hunza, and in some villages in Ghizer. Khowar is the major language of Ghizer. Burushaski is an isolated language spoken in Hunza, Nagar, Yasin (where Khowar is also spoken), in some parts of Gilgit and in some villages of Punyal. Domakki is spoken by the musician clans in the region. Pashto is also spoken by a small minority.

6.2. District Profiles

6.2.1. Ghanche

Ghanche is the eastern-most district of Gilgit-Baltistan. According to 1998 census, the population of Ghanche is 88,366 with about 80% Nurbakhshis, 10% Sunnis, and 10% Shias.

6.2.2. Ghizer

Ghizer District is northernmost part of the Northern Areas of Pakistan. Ghizer is a multi-ethnic district where major languages are spoken. According to the 1998 census, the population of Ghizer is 120,218 with nearly 100% Ismailis.

6.2.3. Gilgit

Gilgit lies at an elevation of 1500 metres in the North East of Pakistan. According to 1998 census, the population of Gilgit is 243,324 with about 60% Shias and 40% Sunnis.

6.2.4. Skardu

Skardu, home to the famous K-2 and several other high peaks, is the largest district in Gilgit-Baltistan. It has an interesting topography; the Indus becomes wide and still here, and Skardu town is surrounded by dry rugged mountains and sand dunes. According to 1998 census, the population of Skardu is 214,848 with about 55% Shias, 20% Sunnis, and 25% Nurbakhshis.
7. GENERAL FINDINGS

The general findings of the perceptions, attitudes and behaviors regarding disability as expressed by participants through discussions regarding definitions of and reasons for disability as understood in the local context are presented here. Reactions to disability, and actions taken upon the birth of a child with disabilities (CWD) are also discussed. Each of these areas provides insight into the overall attitudes and perceptions that exist in each community when talking about people with disabilities (PWD).

The following sections of this report will explore the existing attitudes, perceptions and behaviors regarding specific areas of the lives of PWDs such as education and employment, home life, and integration into the community.

7.1. Describing disability through role fulfillment

Participants in all Focus Group Discussion (FGDs) indicated that there were numerous cases of disability in their villages; nearly all participants (not including parents of children with disabilities) said that they either personally knew someone with a disability, or knew of someone who had a person with disabilities living in their home.

When asked what they considered to be a disability, participants did not use “group” designations like jismani mazoori (physical disability) or zehni mazoori (intellectual disability); instead, specific descriptions of disabilities were provided, such as “those who cannot use their arms or legs”, “those people who have weak bones”, “people who cannot see or hear”, “people with no tongue or who cannot speak”, or “people with crooked faces who look different” amongst other descriptions. Many participants also alluded to learning difficulties as being disabilities – “those who cannot learn”, “those who have trouble reading, learning or remembering”. When talking about intellectual disability, it was very clear across all FGDs that people did not make a distinction between intellectual disabilities and mental illness, often grouping them into the same category using words such as pagal (crazy/insane) or mentally upset to describe people with intellectual disabilities—

*There are some children who are mentally upset and can harm others.*

*Teacher, Oshkhandas, Gilgit*

After discussions that involved describing disabilities, participants in nearly all FGDs held in all four districts concluded that a disability was present when “any part of a person’s body did not function”, thus preventing them from doing simple things in their everyday lives.

Stemming from the above concept of disability, participants often described disability in the context of a person’s ability to “work” or fulfill their roles as mother, wife, husband, provider, etc. Many participants agreed that “those who could not work” or “those who were not useful” due to their disability were more prone to being thought of as disabled, whereas those who could, despite their disability, were often not seen as having a disability at all—

*Those [people] who can work or support themselves are not disabled.*

*Teacher, Chatorkhand, Ghizer*

Examples were provided of Deaf women who could take care of their husbands and families, and do housework as effectively as women without a hearing impairment. Participants often insisted that such people could not be called disabled as they were still able to fulfill their roles as wife and mother, and were useful to others around them.

Similarly, participants from three separate FGDs in Ishkomen valley in Ghizer spoke about a blind man in the area who owned and ran a shop, and was able to identify currency denominations simply by touching the money. Many participants agreed that while this man did in fact have a disability due to the fact that his eyes did not function, he was still able to work and provide for this family and therefore was not considered completely disabled.
However, while the definition of disability generally evolved over the discussion from a physical description to a person’s ability to fulfill roles, there were a few examples of perceived disability provided in some districts, often with the same FGD, which contradicted this idea.

In Gilgit, one mother indicated that she, her family, and her community considered her son to be disabled due to the fact that he was born with the condition called Albinism and looked different from other children. The mother indicated that even though her child was very intelligent, performed well at school and had no physical disabilities, he was still thought to be disabled simply because of his white skin and hair. In a separate FGD for teachers in Gilgit, a teacher also referred to the same child with Albinism and stated that the child was most definitely disabled due to the fact that his white hair and skin made him very different from other children; the teacher acknowledged the child’s intelligence and good performance, but still considered him to be disabled. Coincidentally, another teacher in the same FGD was also born with Albinism and spoke about his own experience at being considered disabled as a child, despite being very bright in school and having no physical difficulties. He was employed as a government school teacher based on the two (2) percent government quota for people with disabilities.

Similarly, a few participants indicated that people with ‘hunchbacks’, ‘squints’ and even those who were left-handed were often considered disabled, even though participants agreed that none of these perceived ‘disabilities’ had an impact on a person’s ability to learn, work, or fulfill roles.

In a FGD held in Skardu with fathers of children with disabilities, one father spoke about his son; even though his son had no intellectual disability and was able to learn, speak, see, hear, work, and fulfill many roles he was considered disabled due to the fact that he was unable to fulfill his ‘marital duties’ after marriage and did not bear children. This further reinforced the concept of role fulfillment as being an important benchmark for the definition of disability, along with the physical appearance of a person. The concept of infertility (in both men and women) as a disability was not explored further in the Training Needs Assessment (TNA).

NOWPDP Insights on ‘definition of disability’

The ability to fulfill expected roles (for example husband/provider, mother/wife) appeared to be a key determinant of whether a person was considered disabled. However, while a person with disabilities was described as someone who was “unable to use any part of their body” (including mind), the very same people who fit this criteria were often not considered ‘completely’ disabled if they were able to fulfill their designated roles.

At the same time, those who were able to fulfill their familial/social roles but had distinctive features (for example white skin and hair, hunchback etc.) were often considered disabled. These two concepts of disability appeared to exist in contradiction, but were found to be widespread across all FGDs.

Therefore, disability seemed to be a fluid concept (unlike western group designations such as physical or intellectual disability) which changed from person to person, and not necessarily perceived according to the actual impairment present but according to the characteristics, impact and level of functionality of the impairment.

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4 From the Latin word albus, meaning “white”. Albinism is a congenital disorder characterized by the complete or partial absence of pigment in the skin, hair and eyes due to absence or defect of an enzyme involved in the production of melanin. An organism with a complete absence of melanin is known as an albino, although the term albino is not preferred way to address someone with Albinism.
7.2. Causes of disability

Participants were asked to talk about what their community commonly believed was the cause of disability. Upon the conclusion of that discussion, participants were asked to discuss what they thought were the causes of disability. The answers given for these two similar questions were often very different.

The causes of disability that participants described could be divided into two main groups: medical and non-medical. Medical reasons for disability included factors such as poor nutrition, lack of vaccinations, illness, poor hygiene etc., while non-medical reasons included topics such as punishment for sins, jadoo (magic), fate, and a test of patience for parents of disabled child etc.

While both medical and non-medical reasons were provided in all four districts of the study, FGD participants in Ghanche and Skardu appeared to lay more weight on non-medical causes, and those in Gilgit and Ghizer focused more on medical causes. This also had an impact on the actions taken by parents of CWDs upon discovering their child’s disability, usually within the first two years after birth. Actions taken will be discussed further in this section of the report.

**NOWPDP Insights on ‘medical’ vs. ‘non-medical’ causes of disability**

It was observed that when discussing the views of their community, participants would often highlight non-medical reasons while providing medical reasons when talking about their own views on the causes of disability.

It may be useful to bear in mind that even if participants believed in the non-medical causes of disability, they were more likely to put forth medical causes in order to come across as “progressive”. This became apparent when those who stated medical reasons as the causes of disability, but would first turn to non-medical methods – spiritual healers etc. – when attempting to ‘cure’ their child’s disability.

This suggests the existence of medical syncretism in GB, where both biomedical and traditional sectors are sometimes accessed simultaneously in the hopes of finding a ‘cure’ for disability. This topic is explored further in the section titled Discovery of Disability: Actions taken by parents and families.

It was in anticipation of the existence of two simultaneous systems that NOWPDP divided questions on causes of disability into self and community views when developing tools.
7.2.1. “Medical” causes of disability

Participants in FGDs across all four districts under study provided similar reasons for both medical and non-medical causes of disability. It was believed that poverty, poor nutrition, improper hygiene, illness, attempted abortions, and use of certain medications during pregnancy could affect the fetus and cause a disability. Lack of access to clean water and vaccinations for pregnant women were factors which were discussed across almost all FGDs.

Poverty as a cause of disability proved to be an interesting topic for discussion during FGDs. Some participants argued that poverty brought with it limited access to nutrition, hygiene, and health care, which sometimes resulted in the birth of a child with disabilities or the emergence of disability due to illness in early childhood. Others argued that the birth of a disabled child actually initiated poverty, thus initiating the cycle of poverty and disability, due to the high financial costs of managing disability.

Another medical reason for disability included birth asphyxia\(^5\), which participants commonly believed to be the cause of intellectual disability. Many participants also indicated that a child may become intellectually disabled due to extreme psychological trauma or stress. One participant provided an example –

“One child went to Karachi to study and because of the extreme stress caused by violence and bombings that take place there, he came back intellectually disabled.”

*Father of non-disabled child, Shigar Khas, Skardu*

Another participant spoke about her young child –

*I left my daughter with my mother-in-law when I went to my parents’ house to attend a funeral. My daughter didn’t get enough love and attention from her grandmother while I was away and had become intellectually disabled by the time I returned.*

*Mother of a child with intellectual disability, Gupis, Ghizer*

Similar thoughts emerged repeatedly across all four districts showing that there exists confusion between intellectual disability and mental illness, resulting in a tendency to group both into the same category.

Severe illness during early childhood including polio, genetic conditions inherited from parents, and accidents were amongst the other causes of disability which were identified by participants.

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**NOWPDP insight regarding relationship between poverty and disability**

It was noted by the NOWPDP team that, especially in Gilgit, Ghanche and Skardu, participants who had children with disabilities appeared to belong to a lower socio-economic group than other participants. This observation was based on the following –

1. The physical appearance of participants in these FGDs; participants were often dressed in old, torn clothes.
2. While only 8 to 10 participants were required in each FGD, there would often be many more people wanting to participate in the session for Parents of CWDs. The reason given was that word had spread regarding refreshments and travel compensation provided at the FGD; many families of CWDs wanted to be a part of these sessions for that reason and would bring their children along as well. Unfortunately, NOWPDP was not able to accommodate additional participants, and only those who had been identified in defined catchment areas and invited through field teams were allowed to remain in the FGD.
3. Some parents also brought their CWDs as they believed NOWPDP was holding an information session where they could get advice on the treatment of their CWD.

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\(^5\) Birth Asphyxia (also referred to as Perinatal Asphyxia or Asphyxia Neonatorum) can result from inadequate supply of oxygen immediately prior to, during, or just after delivery.
7.2.2. “Non-medical” causes of disability

The non-medical causes of disability put forth in the FGDs emerged across all districts. A common theme was “punishment” where participants stated that the birth of a disabled child was considered to be a punishment from God for the sins committed by the parents of that child. A father of a child with disabilities in Skardu expressed his views –

If a person commits a sin, then their child absorbs that sin while in its mother’s womb and becomes disabled.

Father of a CWD, Shigar Khas, Skardu

Another theme that emerged, especially in Skardu, was the idea that those families that do not live strictly according the teachings of Islam are often punished by the birth of a disabled child. One participant in the FGD in Skardu stated that disability can be found in those households that do not strictly follow the “Islamic” way of life. Such beliefs alluded to the idea that disability only happens to ‘bad’ people, or occurs in families that deserve punishment.

However, there was also a strong opposing viewpoint within the same FGDs in Skardu; one participant indicated that children with disabilities could more often be found in homes which strictly followed the teachings of Islam. He believed the reason for this occurrence was that children with disabilities were born to test their family’s sense of justice, patience, and fairness. Therefore, children with disabilities are born to those who claim to live strictly by the teachings of Islam in order to test this very claim.

The concept of ‘balanced marriages’ also emerged a few times in a number of FGDs, especially in Ghizer. Participants believed that marriages should take place between people who have similar characteristics in terms of physical appearance, education, family history, religion etc. Many were of the view that two disabled persons often produce able-bodied offspring due to their ‘balanced’ union, whereas if one person in the marriage is disabled while the other is not, then they are more likely to have a child with disabilities.

This belief, however, can be limiting to people with disabilities when it comes to home and family life. This topic will be discussed later in this report.

Other non-medical reasons provided by FGD participants to explain the causes of disability were nazar (the evil eye or envy of others), the presence of kudakan (supernatural forces which possess human beings especially pregnant women, causing the birth of a disabled child), possession of the child by evil spirits, and tish (intellectual disability/mental illness resulting from extreme fear caused by evil spirits of supernatural forces).

This very common belief regarding tish once again highlights the widespread confusion between intellectual disability and mental illness.
7.3. Discovery of disability: Actions taken by parents and families

Parents of CWDs indicated that they discovered their child’s disability usually within the first two years of the child’s life. Many participants had other children and therefore had an idea of childhood development milestones which allowed them to become aware of the disability when milestones were not reached. In some rare cases, parents became aware of their child’s disability at a much later stage, when the child was up to seven or eight years old.

Congenital physical disabilities, which are often obvious at birth, were noted right away by most parents. One father shared his observations –

*I saw my child’s tongue when she was born and realized that she would not be able to speak properly.*

*Father of a child with speech impairment, Gupis, Ghizer*

However, less obvious physical disabilities or those resulting from illness (e.g. polio) manifested themselves at a later stage and became obvious when the child began to crawl/walk. One parent stated –

*When my child started walking at the age of one, I realized that there was something wrong with his legs as he was unable to stand properly.*

*Mother of a child with a physical disability, Oshkhandas, Gilgit*

Less obvious disabilities such as visual and hearing impairment, as well as intellectual disabilities, were usually discovered between the ages of eight months to three years. One mother described her experience with her visually impaired daughter –

*It was only at the age of three or four that we realized our daughter couldn’t see properly. She would go to the wrong person when told to go to me or her father.*

*Mother of a child with visual impairment, Oshkhandas, Gilgit*

Another mother in Oshkhandas, Gilgit, spoke about her five children. Her first four children were born deaf, so when her fifth child was born, she immediately tested his ability to hear –

*I made a loud sound next to [my child’s] ear using a tin glass and a spoon. When he did not react I knew he was also the same [Deaf].*

*Mother of a child with hearing impairment, Oshkhandas, Gilgit*

The actions taken by parents upon the discovery of disability varied greatly between parents in Gilgit and Ghizer when compared to parents in Skardu in Ghanche. As mentioned previously, while all parents appeared to know the medical causes of disability, parents in Ghanche and Skardu seemed to give more weight to the non-medical causes which had a clear impact on their actions upon discovering their child’s disability.

A majority of the mothers of CWDs in Ghanche indicated that they took their child to a *pir* (spiritual healer) upon discovering their child’s disability as they believed the child to be under *nazar* (evil eye caused by the envy of others). One mother spoke about her reaction to her child’s disability –

*We immediately took our child to a pir to get the jadoo (magic) removed. It was successful.*

*Mother of a child with intellectual disability, Khaplu, Ghanche*

Some parents indicated that they prayed in order to rid the child of evil spirits which were causing disability.
We took our child to a pir who gave us a taweez\(^6\) and we prayed.

*Father of a child with an intellectual disability, Shigar Khas, Skardu*

A majority of the parents of CWD, especially in Ghanche, indicated that they did nothing at all upon discovering their child’s disability -

*We [the family] did not do anything as it is the will of God.*

*Mother of a child with an intellectual disability, Khaplu, Ghanche*

While only one parent of children with disabilities participating in the FGD in Ghanche claimed to have taken her child to a doctor upon discovering the child’s disability, parents of CWDs in other districts spoke of their attempts to receive a diagnosis and treatment for their children. Most times, these efforts weren’t successful due to the high costs involved as well as the lack of facilities in Gilgit-Baltistan. One father in Skardu shared his story –

*I spent approximately five or six lakh\(^7\) of rupees to get my child treated at AKU in Karachi. Nothing came of our efforts.*

*Father of a child with intellectual disability, Shigar Khas, Skardu*

The father went on to talk about how the medical costs of managing his child’s disability were too high, which prohibited him from going back to the doctor. Yet another father in the same FGD agreed; he decided to take his child to Lahore for treatment, but was unable to continue treatment due to the high costs involved. It was observed that in Skardu, many parents who attempted to have their child’s disability diagnosed managed by a professional but were discouraged due to the financial costs involved also eventually turned to spiritual healing methods. Participants lamented the lack of disability-specific services and facilities in their area.

A slightly different trend was observed in the districts of Gilgit and Ghizer. While some parents in these two districts also turned to spiritual healing methods, most parents of children with disabilities, especially in Gilgit, indicated that their first action upon discovering their child’s disability was to take them to a doctor. Unfortunately, once again there were very few positive outcomes due to the limited availability of services and professionals in the region. One mother angrily spoke of her experience with a local well-known eye hospital where she took her daughter as soon as she suspected a visual impairment –

*The doctor said that my child’s vision would improve gradually in 10 years and that we should bring her back then. We took her back some years later, but then the same doctor said that her eyes had become worse and could no longer be treated in Pakistan.*

*Mother of child with visual impairment, Oshkhandas, Gilgit*

Many parents in Gilgit and Ghizer, like their counterparts in Skardu, indicated that they had to discontinue treatment or management of their child’s disability due to the expenses involved or lack of accessible services.

A few parents did talk about how their child’s disability was confirmed through diagnosis by a professional. One father in Gupis, Ghizer indicated that his child’s intellectual disability was diagnosed at an early age due to his family’s persistent efforts to understand the disability. However, even with a diagnosis, management of disabilities continues to remain a problem due to the lack of services and facilities available.

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\(^6\) A taweez or talisman is a). an object help to act as a charm to avert evil and bring good fortune b). something producing apparently magical or miraculous effects. The Merriam Webster Dictionary - http://www.merriam-webster.com/dictionary/talisman

The taweez mentioned in this report is an amulet containing pieces of paper with verses from the Quran.

\(^7\) PKR 100,000 is referred to as one lakh
NOWPDP insights on disability management vs. ‘cure’

While some mild physical disabilities (e.g. clubbed feet, cleft lip/palate) can be “treated” or “cured”, most disabilities are not “curable” and will remain with a person throughout their lives.

Most participants who had children with disabilities placed great emphasis on “curing” their child’s disability through treatment, which meant that the presence of a disability was often not accepted and the importance of diagnosis and management of the disability overlooked. This was noted by the NOWPDP team and addressed in teacher training sessions across Gilgit-Baltistan.

The idea that disability can be ‘cured’, either through biomedicine or through traditional treatment (or both) also appeared to encourage parents of CWDs to seek the advice of doctors and/or traditional spiritual healers. Once again, there appeared to be little focus on understanding the disability and learning how to manage it.

7.4. Discovery of disability: Reactions of parents, family and community

Overall reactions to the birth of a child with disabilities varied in each district. Parents of CWDs spoke about their own reactions to their child’s disability as well as about the negative and positive reactions from their families, friends and communities. The reactions of parents and family/community are presented separately.

7.4.1. Reaction of Parents

Parents of CWDs often described feelings of intense sorrow and grief at the birth of their disabled child. Many said they felt pity for their CWD when comparing them to other able-bodied children. Parents also reported feeling consumed with worry when thinking about their child’s future and the lack of opportunities available to people with disabilities. Many parents expressed fear about their child’s future once they were no longer alive to take care of their CWD. Dialogues about employment opportunities for people with disabilities often stemmed from these concerns and will be discussed further on in this report.

Some parents reported feelings of acceptance and love for their newborn CWD. These parents indicated that it was God’s will and that they accepted their children for what they were. One father in Skardu iterated this sentiment –

God does everything for a reason so it would be wrong to blame Him in anger.

Father of a child with disabilities, Shigar Khas, Skardu

Not surprisingly, those parents who had supportive families and communities largely appeared to overcome their initial feelings of grief faster than those who didn’t, and were able to approach their child’s disability with a relatively positive attitude. Reactions of family and community to the birth of a child with disabilities are discussed in greater detail below.

7.4.2. Reaction of Family and Community

The reactions of family and community members, as depicted by parents of CWDs, ranged from very positive and supportive to extremely negative.

In Chatorkhand, Gupis and Pakora, some participants indicated that a child with a disability was viewed as a “blessing” or a “lucky omen” to the family. A participant in Gupis spoke about how people in her community come to visit her disabled daughter whom they believe can predict the future. They hold her in high esteem and believe that she brings good luck.
Similarly, some participants in Chatorkhand also spoke about the birth of a disabled child as a good omen, which would bring luck and “an abundance of food” to the family. Others in Pakora, Ghizer and Oshkhandas, Gilgit said that a child with disabilities was a gift from God and should be treated as such.

_Some of us believe that good spirits choose to come to earth in the body of disabled children as a test of their patience and goodness. So we must treat children with disabilities with love and respect as they are innocent spirits._

_Mother of non-disabled children, Oshkhandas, Gilgit_

In Gupis, Ghizer, parents of children with disabilities indicated that people would react very negatively to a person with disabilities in the past; however, this has changed and people with disabilities are now generally treated with kindness. Participants in this particular FGD believed this change in reaction is due to a greater, more positive understanding of disability than in the past, and a decreased tendency to link disability with negative thoughts such as punishment to the parents or possession by evil spirits.

Some parents of CWDs also indicated that their families extended a lot of support to them when their child was born. Extended family often provided advice on treatment and management of the disability –

_When our child was born our family encouraged us to seek treatment and was very supportive._

_Father of a child with physical disability, Shigar Khas, Skardu_

Participants talked about how members of their extended families would often help take care of a disabled child shortly after its birth; grandparents were often cited as being the ones who would encourage parents to seek medical advice.

While there were numerous discussions on the positive attitude and support extended to the families of children with disabilities, many parents also spoke about the negative reaction their family, friends and community members had to the birth of their disabled child. One parent in Gupis, Ghizer indicated that when her child was born disabled, community members blamed her of having been sinful in the past and believed that she was rightfully being punished by God. This concept of punishment was also discussed by fathers of non-disabled children in Skardu –

_Some people think it is good that the parents are being punished for their sins._

_Father of non-disabled children, Shigar Khas, Skardu_

One participant in Khaplu, Ghanche said that some people in her community looked upon the birth of her disabled child as a curse on the family and therefore began to isolate them. Parents of non-disabled children reinforced this concept of isolation by indicating that they often worried their able-bodied children would become “inflicted” with a similar disability if they came too close to a child with disabilities. One participant with non-disabled children stated that she preferred to stay away from families with disabled children for this reason.

In Chatorkhand, Ghizer, a participant described how her community viewed the birth of her disabled child as a “catastrophe” on the household; she spoke about how members of her community offered their condolences to her family instead of celebrating the birth of her child.

Many parents of CWDs reported being isolated and neglected by their community members after the birth of their disabled child –

_People prefer to stay away [from families that have a PWD living in the home]._

_Mother of CWD, Pakora, Ghizer_

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8 This quote has been translated from Shina to Urdu, and then roughly translated from Urdu to English.
While some parents believed this occurred due to the fact that they themselves became more involved in caring for their disabled child, many parents of CWDs felt this occurred due to the overall negative attitude of people towards disability.

The discussion on reaction to the birth of a disabled child can be linked with the discussion on general attitudes and behaviors towards people with disabilities.

### NOWPDP insights on the topic of ‘sin and punishment’

Interestingly, over the course of the FGDs it could be noted that women were more likely to be accused of being sinful and therefore blamed for their child’s disability than men across all districts. Most examples of sinful behavior were about women; women were accused of sins such as greed, dishonestly, and indiscretion, leading to the birth of disabled children.

### 7.5. Disability: Attitudes and Behaviors

The discussions on attitudes and behaviors of people towards children with disabilities as described by the parents of CWDs, parents of non-disabled children, and teachers proved to be an interesting topic with many contradictions. Opinions stated by participants in the each of the three FGDs held in each district provided a wide range of insight into the prevailing attitudes and behaviors towards people with disabilities.

In FGDs with parents of non-disabled children and teachers, participants were of the opinion that children with disabilities should not be excluded from society and should be treated with kindness. They often spoke about how people in their community are nice to children with disabilities and accept them for who they are –

*A child with disabilities is not only a child of that family, but a child of the community.*

*Mother of non-disabled children, Oshkhandas, Gilgit*

The need for educational and employment opportunities for CWDs was also expressed in FGDs with parents of non-disabled children across all study districts. However, while a majority of the participants in these FGDs spoke positively about children with disabilities and stressed the importance of education, many were not comfortable with the idea of CWDs going to the same school as their own children. It therefore became apparent that a majority only supported inclusion when it didn’t interfere with their own lives –

*Incomplete people should be kept separate.*

*Mother of non-disabled children, Khaplu, Ghanche*

While some participants supported inclusion of CWDs into mainstream society, leading to interesting debates within the FGD, many seemed to stress separation by insisting that it would be best for people with disabilities to stay separate from others. Many believed that PWDs and CWDs suffer from low self-esteem and confidence, and frequent interaction with non-disabled people would only reinforce their feelings of inadequacy and low self-esteem.

A large majority of parents of non-disabled children believed that the presence of a CWD in a mainstream school would cause various problems for non-disabled children. This proved to be in contrast to the overwhelming support most participants displayed in the initial stages of the FGD regarding the equal treatment and education of children with disabilities. Education will be discussed further on in this report.

Overall, in FGDs with parents of non-disabled children, the general attitude towards CWDs appeared to be positive at a surface level or “from a distance”; it quickly became apparent during discussions that participants
were not comfortable with the idea of CWDs closely interacting with their own children, and often harbored quite a negative attitude towards people with disabilities. Parents of non-disabled children indicated that they some times allowed their children to play with CWDs in their neighbourhood, but preferred to limit interaction since they believed CWDs were usually unhygienic and unruly, and could cause harm to their child. Others stated that non-disabled children did not like to play with CWDs and would make fun of them and their disability. Such attitudes led people to advocate for separate parallel systems for people with disabilities.

Parents of CWDs also shared their observations regarding the attitudes and behaviors of community members towards people with disabilities. This group was of the opinion that the kindness of people towards CWDs did not extend beyond surface level interactions; people were kind as long as CWDs were kept separate and away from their own children. According to parents of CWDs, when interaction does occur, people begin to show negative behaviors towards CWDs. Many parents of CWDs across all districts spoke about how people do not like to meet CWDs, do not allow their children to play with CWDs, are uncomfortable visiting the home of a PWD, often make jokes about disability, and sometimes taunt the parents of CWDs about their child’s disability. One parent summarized these sentiments that exist in her community regarding CWDs –

There is a lack of compassion, love, and sympathy.

Mother of child with disability, Chatorkhand, Ghizer

Yet another mother of a CWD in the same discussion spoke about the attitude people had towards disabled children –

I think people hate CWD [children with disabilities].

Mother of child with disability, Chatorkhand, Ghizer

One mother even discussed her own feelings of hatred for her three disabled daughters. While the mother was aware of the fact that all three girls had intellectual disabilities, she said she hated them because they didn’t understand anything –

I sometimes get really angry at my daughters and beat them as they are useless and don’t understand anything.

Mother of three daughters with intellectual disabilities, Pakora, Ghizer

A number of parents admitted to feeling ashamed and embarrassed of their disabled children, and some admitted that they looked upon CWDs as a burden. A few parents, like the one quoted above, spoke about extremely negative feelings towards their disabled child and blamed them for the social isolation they experienced. One woman spoke about the pain of being abandoned by her husband after she gave birth to their third disabled child. Her husband married another woman in the same village, leaving her to care for all three disabled children without any support.

Extended families sometimes shared these negative feelings; a mother of a CWD described the reaction of her family when she wanted to take her child for treatment shortly after its birth –

When I decided to take my child for treatment my family got angry. They said I was wasting money on my disabled child instead of spending it on my other, non-disabled children.

Mother of a child with a physical disability, Gupis, Ghizer

These feelings of negativity often caused the parents of CWDs additional grief and sorrow, and made it harder for them to accept their child’s disability.
This section of the report includes findings on specific areas pertaining to the lives of people with disabilities. These areas include education and employment, home life, and integration into society.

Participants in FGDS were asked open-ended questions regarding the three broad areas mentioned; the answers provided by teachers, parents of CWDs, and parents of non-disabled children had many similarities, but also some key differences.

8.1. PWDs: Education and Employment

Education was a topic of discussion in FGDS on which a majority of the participants had very strong opinions. All three groups openly shared their views on education; access, availability of opportunities, and the pros and cons of inclusive education were some of the topics discussed.

Stemming from the topic on education, the discussion in FGDS would evolve to employment opportunities, or lack thereof, for PWDs.

The following section on education has been divided into two parts: parents’ perspective (which includes parents of CWDs and parents of non-disabled children), and teachers’ perspective.

8.1.1. Education of children with disabilities: from a parent’s perspective

8.1.1.1. Parents of Children with Disabilities

Nearly all participants in FGDS across all four districts agreed on the importance of education for CWDs. Parents of disabled and non-disabled children alike agreed on the need to send CWDs to school in order to ensure that they receive an education and have the opportunity to study, learn, play and interact with other children. However, when discussing inclusive education, participants had some insights and perspectives.

Despite expressing a desire to send their child to school, a majority of parents of CWDs did not do so due to a lack of special schools in their area. When the topic of inclusive education was brought up in the FGD with parents of CWDs, many stated that they were hesitant to send their children to regular schools; bullying, taunting, lack of proper facilities, poor knowledge of disability management, and lack of attention by teachers were the main reasons cited for not sending CWDs to regular schools. In fact, the negative attitude of teachers towards CWDs was the most sited reason for dropouts by parents of those CWDs that had been enrolled in school. For this reason, nearly all parents of CWDs agreed that they would prefer separate schools with trained and sensitized teachers who would be able to manage their child’s disability. Some parents did recognize the lack of such facilities in their area and were ready to send their CWD to a mainstream school, provided the teachers were sensitized to disability. One mother articulated her views –

*I would only send my child to a regular school if the teachers are trained and soft-hearted.*

Mother of child with disabilities, Gupis, Ghizer

A very common perception that emerged from discussions on inclusive education with parents of CWDs was that the parents of non-disabled children would not like the idea of sending their child to the same school that disabled children attend. Parents of CWDs were certain that not only would non-disabled children tease and taunt their children, but their parents would also complain about the presence of CWDs.

Access to education was also highlighted as a problem. Most parents of CWDs stated that even if there were special schools for children with disabilities, access to these schools would be a problem. Many students - especially those with visual impairments, and physical and intellectual disabilities - would find it difficult to get to school on their own. The mountainous region makes travel difficult for those with disabilities, and most
families did not have the means to arrange and pay for transport. This issue was raised in NOWPDP teacher training sessions where participants were asked to think of creative solutions in the context of their own villages and communities which would allow CWDs to access schools with greater ease. As part of the training, teachers were given the responsibility of coordinating with their community, parents of CWDs, and the school to establish a solution to transport issues in their clusters so that children with disabilities are able to attend school.

However, the reason why some parents wanted to send their CWD to school proved to be unexpected. Many admitted that they needed a break from caring for their child and school provided the perfect respite. Other parents spoke about how their CWDs want the opportunity to go to school like their non-disabled siblings. When discussing education opportunities for CWDs, parents worried not only about the lack of special education schools, but also the lack of employment opportunities available to PWDs after schooling. Many parents were therefore of the opinion that schools for children with disabilities should be free of cost as they do not really help PWDs gain meaningful employment later on in life. Instead, there should be separate vocational training centers where PWDs can be taught a skill which they can use to support themselves. This view will be discussed in more detail further on in the report.

8.1.1.2. Parents of Non-disabled Children

Parents of non-disabled children also shared their insights on inclusive education. As mentioned previously, nearly all parents of non-disabled children supported the idea of educating CWDs. However, for many participants, these views changed when the topic of inclusive education was raised.

There were a number of parents who stated that they would not mind having CWDs in the same class as their child. They insisted that they would teach their children how to interact positively with CWDs and would encourage them to be sympathetic and kind. This group of parents, who supported inclusive education, appeared to appreciate that inclusive education would give all children an opportunity to learn from one another –

*They will get used to each other and learn from each other.*

*Mother of non-disabled children, Khaplu, Ghanche*

This sentiment was supported by another parent –

*[Inclusive education] can create a friendly environment.*

*Mother of non-disabled children, Khaplu, Ghanche*

However, alongside these few positive comments, a majority of parents of non-disabled children were afraid that CWDs would have an overall negative impact on classroom environment in regular schools. This group at first claimed to be comfortable with the idea of inclusive education; however over the course of the discussion, their true views would emerge. Many were of the opinion that children with disabilities should be kept separate from non-disabled children, due to the difference in intellectual capacities. Some participants believed that CWDs were generally violent and could harm their child –

*It would be dangerous to send our child to school with an insane child.*

*Mother of non-disabled children, Chatorkhand, Ghizer*

Others were afraid of the “contagiousness” of disability and feared for the health of their children –

*Non-disabled children may catch the illness of a child with disabilities.*

*Mother of non-disabled children, Gupis, Ghizer*
Some parents also spoke about the different learning abilities and special needs of children with disabilities; they believed that a CWD would slow down the pace of a classroom, which would have a negative impact on other students.

*They [children with disabilities] should be taught in a class with children of their own level.*

*Father of non-disabled children, Gupis, Ghizer*

One father of non-disabled children in Skardu enthusiastically promoted the importance of education of CWDs; however, when he was asked if he would be comfortable if his own children went to the same school as CWDs, his response was clear –

*No, we would not be alright if children with disabilities were in the same class as non-disabled children.*

*Father of non-disabled children, Shigar Khas, Skardu*

Parents of non-disabled children also expressed their worry for CWDs who they believed would be teased by non-disabled children, which would cause low self-esteem and lack of confidence. Many stressed the fact that children are often harsh with each other and with those who are ‘different’, which would have a negative effect on CWDs.

One parent in an FGD in Ghanche raised a topic which was explored in other FGDs as well. She spoke about the importance of sending children with disabilities to school, but felt that schools for such children should be separate from regular schools and should be free of cost –

*Why should fees be wasted on children with disabilities?*

*Mother of non-disabled children, Ghanche*

When asked to explain further, the participant explained how children with disabilities would not be able to achieve much in life and it would therefore be a waste to spend money on school fees. This idea that educating children with disabilities is of little use emerged repeatedly throughout numerous FGDs, including those with teachers and even parents of children with disabilities, and will be discussed further in the section on employment.

Over the course of various FGDs with parents of non-disabled children, it became clear that there exists a lack of clarity regarding disability, especially mild to moderate disabilities, which led to numerous unfounded concerns. These concerns were summarized and addressed in teacher training sessions conducted by NOWPDP, and will also be addressed in Local Level Institution (LLI) trainings to be carried out by Civil Society Resource Center (CSRC).

8.1.2. Education of children with disabilities: from a teacher’s perspective

The insights which emerged in FGDs with teachers were extremely interesting and invaluable in developing the NOWPDP teacher training manual on Disability Sensitization and Inclusive Education. Teachers were very honest about their views and were able to explain their thoughts and reservations regarding inclusive education from a teacher’s perspective, keeping in mind resources and time constraints, administrative support, and other essential factors.

During discussions about educating children with disabilities all teachers unanimously agreed that all children, disabled or otherwise, should have the opportunity to go to school. However, their views were different when discussing inclusive education specifically; one teacher who initially strongly supported the education of CWDs
made her views on inclusive education very clear when asked if she would be willing to teach CWDs in her own class –

*It would be a waste of time.*

*Inclusive education would be bad for everyone [students and teachers].*

*Teacher, Gupis, Ghizer*

This comment was a good summary of the sentiments expressed by a majority of teachers in FGDs. Even though the participant who made the above comment had appeared to be highly supportive of providing CWDs with educational opportunities, she became adamant that CWDs should be kept separate when asked if she, as a teacher, was willing to help mainstream CWDs into regular schools.

A common argument against inclusive education was that the parents of non-disabled children would not like their child to be in the same classroom as a disabled child. Many teachers agreed with this sentiment, and put forth many examples of situations where parents became upset at the fact that their child was in the same classroom as a CWD. A teacher in Khaplu, Ghanche, shared her story –

*There was a disabled child with a very small head in my class. The parents of the [non-disabled] child who sat next to him got very angry when they found out that their child sat next to a child with disabilities.*

*Teacher, Khaplu, Ghanche*

Most teachers were concerned about having to manage CWDs alongside non-disabled children; they were not willing to spend extra time with CWDs at the expense of non-disabled children, which indicated a lack of understanding of the concept of inclusive education. There was also a lot of emphasis on the separate needs of CWDs –

*It is not possible to teach children with disabilities and non-disabled children together as they have separate needs which cannot be met even if their teacher is trained.*

*Teacher, Pakora, Ghizer*

The overall consensus was that the presence of CWDs in a classroom would slow the pace of learning. They also addressed the issue of bullying of CWDs by their non-disabled peers which would cause distraction and disturbance in the school environment. One teacher provided an example –

*Other children do not like to do group work in class with children with disabilities as they think they lack intelligence and tease them. They [non-disabled children] also do not like to play with them [CWDs] as they cannot keep up and slow down the game.*

*Teacher, Pakora, Ghizer*

However, there was a small group of teachers across the four districts who acknowledged the lack of special education schools in the area and agreed that CWDs must be mainstreamed into regular schools as this was the only way they would be able to receive an education –

*Since we do not have separate schools we will teach children with disabilities as we cannot leave them sitting at home.*

*Teacher, Pakora, Ghizer*
This group also voiced their concerns regarding inclusive education; however, they agreed that with the use of proper tools and teaching aids, it would be possible to include children with mild to moderate disabilities into classrooms. The teaching aids the group highlighted included audio-visual tools such as posters, maps, pictures, recorders, educational toys, and other such tools which would allow a teacher to include children with various impairments in their lectures. This group of teachers also pointed out the “overlap” or similarities between teaching methods used for multiple-intelligence and those that could be used to teach children with disabilities.

Teachers in this group also provided encouraging examples of children with mild to moderate disabilities that were present in their schools/classrooms and were able to not only keep up with the pace of teaching, but had also established strong relationships with their peers. One teacher shared her experience –

*There is a [physically] disabled child in my class; his [non-disabled] class-fellow carries his school bag home for him every day because he himself cannot.*

*Teacher, Khaplu, Ghanche*

A small group of teachers in Skardu also shared this sentiment and highlighted the fact that a teacher is responsible for ensuring and maintaining positive relationships between students. They strongly believed that failure to control student behavior resulting in any taunting of CWDs by other students is a weakness on the teacher’s part.

Out of the three groups that took part in FGDs, and with the exception of a small group who expressed support, teachers were the most outspoken against inclusive education and believed that students with disabilities should be kept completely separate. In fact, many teachers were of the opinion that a completely separate school for CWDs would be better than separate classes within a regular school. However, irrespective of their views on inclusive education nearly all teachers agreed that they should receive an introductory training on inclusive education so that they have a better understanding of disability.

**NOWPDP Insights on the discussion on Inclusive Education**

*Even though participants exhibited some understanding of the disabilities (and different levels of severity) that exist, when discussing education, it appeared as though participants were not able to separate intellectual disabilities from other impairments. This assumption of “multiple disabilities” – when a person with any impairment is also assumed to have a lessened intellectual capacity – is often common and may be the reason why participants did not believe inclusive education was a good option.*

*Also, the discussion on inclusive education was in the context of the instinctive assumption that all disabilities are severe; there was often little consideration of mainstreaming children with mild or moderate disabilities. Even when reminded of the different levels of severity, participants would revert back to their original idea of disabilities being severe or profound, which would cause them to believe that inclusive education is a very difficult option.*

*Finally, the mistaken assumption that all disabilities are severe led teachers to believe that inclusive education would be very demanding of their time and resources, and could only happen at the expense of non-disabled students.*
8.1.3. Employment: opportunities for PWDs

While built into the FGD questionnaire, the discussion on employment usually evolved very organically, stemming from the discussion about education of CWDs.

Lack of opportunities was the topic most discussed when talking about employment of PWDs. Participants across all three groups interviewed highlighted the prejudice and discrimination that prevents PWDs from obtaining employment, in spite of the two per cent employment quota set by the government. A FGD participant in Ishkomen shared a story to illustrate this point –

There was a job opening for which a qualified man with disabilities applied, but he was rejected and the job was given to a [non-disabled] person from Gahkuch instead.

Teacher, Pakora, Ghizer

Other participants in the FGD agreed and stressed the fact that the two per cent quota reserved for PWDs is usually given to non-disabled people. In the event that a PWD is given employment using the two percent quota, the process takes a long time and often requires the assistance of human rights lawyers, something which most PWDs do not have easy access to nor can afford. One teacher in a FGD in Gilgit, who has Albinism and weak eye-sight as a result of the condition, illustrated this point through his own experience –

I finished my studies and started looking for jobs in 1996. I applied with the police force and the army, but was rejected because of my eye-sight... There were no other opportunities for me... Finally, a lawyer helped me get a job as a teacher and I was employed in the two percent quota [for PWDs].

Teacher, Oshkhandas, Gilgit

While this individual was able to eventually find employment, many PWDs remain unemployed. Due to the fact that PWDs are seen as being completely dependent on the goodwill of potential employers and are almost never employed based on skill, merit, or talent, many FGD participants questioned the point of educating CWDs. FGD participants explained that while it is important for a CWD to go to school at a young age, and interact with other children, there was no real use in educating a CWD in the context of creating employment opportunities later in life. Vocational training centers for PWDs were thought to be a better option; participants, especially parents of CWDs, believed that vocational training would teach PWDs skills and give them a competitive advantage which would allow them to start home-based businesses or even seek employment with skill-centered organizations/establishments, where they would not be discriminated against based on their disability.

There were a few encouraging examples of PWDs finishing school and finding gainful employment, as provided by one mother –

Children used to make fun of my son and call him names in school, but he completed his studies and now works for an NGO.

Mother of Deaf child, Khaplu, Ghanche

However, such success stories were rare; the common consensus was that PWDs take whatever menial jobs they are given and can manage. Also, there were certain disabilities that were considered more “employable” than others. People with intellectual disabilities were often viewed as being completely “useless” and unemployable.

9 Under the Disabled Persons (Employment and Rehabilitation) Ordinance (1981), a two percent quota is reserved for persons with disabilities in all government and private sector establishments.

10 Please note that this quote has been roughly translated from Urdu to English and was extracted from a conversation with the person speaking.
A majority of the FGD participants were of the view that deaf persons have the most opportunities in terms of earning money; they can be employed as manual labor, sweepers, chowkidaars, construction workers, toilet cleaners or for other low-paying jobs. Since they are physically fit and able to do almost any task, they are often hired out as labor by their families, or given the task of completing all household tasks. One woman shared her observations of a family with a Deaf daughter –

**A family in our village makes their [Deaf] child do all the housework.**

*Mother of non-disabled children, Chatorkhand, Ghizer*

However, the treatment of Deaf employees was reported to be poor. Participants highlighted the fact that Deaf persons are not only paid very poorly for their work, but are often cheated out of any payment at all; often times employers would withhold payment upon the completion of the task.

While Deaf persons are most likely to find some kind of employment, usually in the informal sector, participants agreed that this group is very extremely vulnerable to poor treatment by employers. It was also generally agreed that people with visual impairments, physical, and intellectual disabilities are largely unable to work and support themselves by finding jobs, even if they are adequately qualified. Being unable to bring in any monetary assistance for the family therefore makes PWDs a burden on their families and communities, a theme which will be discussed in the next section of this report. However, participants believed that teaching PWDs a useful skill, such as sewing, embroidery, carpentry, etc, would greatly increase their chances of income generation.
8.2. PWDs: Home and family life

When discussing home and family life of PWDs with participants, there were many different things which were highlighted. The most prominent theme was that of ‘burden’ where PWDs were considered a burden on their families, both socially and financially.

While all three different groups were asked the same questions, parents of CWDs were asked additional questions regarding the home and family lives of CWDs. Parents were quick to talk about how they worried for their child’s future, especially once they themselves were old and unable to provide care to their disabled child, and how they suffered a degree of isolation from their communities due to their child’s disability.

The following section is divided into two parts – childhood: the current situation and adulthood; looking into the future. The portion on childhood looks at the current situation faced by the parents of CWDs who participated in the FGD. Since only those parents with children of school going age were selected for FGDs, it was assumed that parents of CWDs present in the FGD had young children whose current situation they could share.

8.2.1. Childhood: the current situation

Parents of CWDs spoke about frequent disagreements over the care of disabled children, especially in joint family systems where resources are scarce. In terms of food and nutrition, parents of CWDs were adamant in stating that they did not prefer their non-disabled children over their CWD and treated both equally. However, in terms of material goods, mothers spoke about how they often bought new clothes for their non-disabled children who went to school and had to look presentable, but were unable to do the same for their CWD due to financial constraints. For those few CWDs who were enrolled in school, their parents indicated that they preferred to send their child to government schools which were free of cost, while their non-disabled children were sent to private or AKES,P schools which are thought to offer better quality education. Parents stated how they preferred not to “waste” school fees on CWDs, who may not have access to opportunities later on in life. Aside from a few parents who reported unequal treatment in terms of clothing and education, most parents indicated that they treated their disabled and non-disabled children equally.

Parents of non-disabled children had very different observations; many believed that CWDs were not treated equally to their non-disabled siblings and did not receive the same care and attention. Numerous FGD participants, both parents of non-disabled children and teachers indicated that the CWDs in their villages were seldom sent to school, had poor hygiene, and often looked dirty, unkempt, and uncared for. This was cited as one of the main reasons why parents of non-disabled children did not let their own children play with CWDs. This will be discussed further in the section on Integration into the Community.

Parents of CWDs also sometimes reported tension in relationships within the immediate and extended family; these tensions were often caused by disagreements over the care or management of the CWD, or over the CWDs interaction with other family members. A father of a CWD in Skardu talked about how he would often fight with his brother over the poor treatment of his CWD by his brother’s children. A mother of a CWD stated that her extended family is embarrassed of her CWD in the presence of guests; her family wanted to hide her CWD when guests visited, which would often lead to hurt feelings and disagreements within the family –

*When guest visit the house, I have to hide my child in another room.*

*Mother of CWD, Khaplu, Ghanche*

According to mothers of CWDs, the task of caring for a child with disabilities fell entirely on the mother, often with very little help from other family members. One mother of a CWD spoke about juggling household chores and caring for a disabled child –
If a child has a minor disability then they can be put to one side while household tasks are completed. If the disability is severe then it is more difficult to complete household tasks.

Mother of child with disabilities, Khaplu, Ghanche

Caring for a CWD, while also being solely responsible for household chores caused mothers of CWDs to experience high levels of stress, grief, and isolation in their daily lives. They spoke about how they had lost touch with other people in their community because they seldom had any free time.

While some parents of CWDs indicated that their children did have the opportunity to play, they were seldom allowed to go outside and often played with an older sibling or cousin within the home. In many cases how ever, slightly older CWDs remained isolated as siblings or cousins did not include them in their games. A parent shared her story involving her CWD and his non-disabled younger brother; the non-disabled boy hated his disabled older brother and preferred to stay away – he refused to play, spend time or even eat with his older brother. This led to the isolation of the CWD, and created tensions between siblings, with the mother bearing most of the stress caused due to discord amongst family members. Isolation was a bigger issue for those children with intellectual disabilities; a mother of an intellectually disabled girl shared her experience –

No one wants to play with her and they make fun of her, so I don’t let her go outside to play...

Pakora, Ishkomen Valley, Ghizer

In terms of expectations of CWDs, most indicated that they did not involve their CWD in housework or assign any responsibilities to them. While there were a few mothers who claimed that their CWDs, usually girls, took on a large share of household chores despite their disability, most parents assumed their CWDs would be unable to contribute or manage anything.

A common theme when discussing home and family life of a CWD was sorrow and pity. Mothers and fathers of CWDs often highlighted their feelings of grief when considering their CWD in relation to others around them. A mother stated her feelings –

I feel pity for my child [with disabilities] when I look at my other [non-disabled] children…. He will not have the same opportunities and cannot do the same things.

Mother of child with disabilities, Oshkhandas, Gilgit

NOWPDP insights on home and family life of PWDs

Alongside these negative feelings, a few families of CWDs also highlighted some positive aspects of the home and family life of CWDs. Some parents stated that the CWD had encouraged cooperation and compassion in the family; their CWD had also taught them to feel compassion for other PWDs. Some spoke about how their CWD helped with household chores and in the upbringing of younger siblings.

However, these feelings were not shared openly or right away. Instead, numerous prompts and questioning were necessary before parents of CWD shared these positive feelings.
8.2.2. Adulthood: looking into the future

When discussing opportunities, parents highlighted the fact that they worried about the limited opportunities available to their CWD in terms of home and family life. Due to the fact that people with disabilities are viewed as dependents and therefore a ‘burden’, the option of marriage is often not available to them.

The discussions on marriage and family life for PWDs emerged from the concept of ‘role fulfillment’; the idea that a male PWD should marry only if he is able to financially support his spouse and family, while a female PWD must only marry if she is able to bear her responsibilities as a wife and mother. By becoming a criterion for marriage and family life, this concept provided an additional layer to the earlier discussion on role fulfillment when defining disability.

However, many participants were also of the opinion that even if a PWD is able to fulfill their roles, he or she must only marry another PWD. This idea comes from the concept of ‘balanced marriages’ (which was previously discussed in the section of causes of disability), which dictates that a PWD should preferably marry another PWD. While a large number of participants reinforced this belief of balanced marriages or unions, which also applied to non-disabled people, there were a number of people who believed that a PWD should be able to marry freely given that they are able to fulfill their roles. It was unanimously agreed that a PWD must not marry if they are unable to fulfill their roles.

Another important topic emerged from the discussion on marriages; a number of FGD participants stated that the families of PWDs, especially siblings, often willfully prevented the marriage of PWDs in order to retain control of family inheritance. Since PWDs are often dependent on their families, it is not uncommon for a non-disabled sibling to control their inheritance; many PWDs are prevented from marrying so that the inheritance remains in their sibling’s control. This was reported across all FGDs in all four districts as being a very common practice amongst families of PWDs.

8.3. PWDs: Integration into the community

The views of parents of CWDs were often in stark contrast to those of parents with non-disabled children when it came to the integration of CWDs into the community.

As seen before, parents of non-disabled children were enthusiastic in highlighting the willingness of community members to welcome children (and people) with disabilities. Participants in the FGD with teachers and parents of non-disabled children spoke about how people are kind to CWDs and feel sympathy for them and their families.

However, the views of parents of CWDs were quite different. As mentioned earlier in the report, many spoke about the isolation of families that have children with disabilities; they believed that their communities did not like to interact with PWDs and preferred to stay away. One father in Skardu spoke about taking his disabled son to the mosque to pray; once at the mosque, people demanded the child be kept in the back of the mosque. The father sharing his story indicated how it is common practice to encourage the elderly, weak, and disabled to pray in the front of the mosque, but due to the fact that others felt uncomfortable by the presence of a disabled child, he was asked to remain in the back where he could not be seen by others.

Another parent of a CWD shared her experience of taking her disabled daughter to a wedding. She described how other wedding guests stared and laughed at her daughter, which resulted in her CWD feeling uncomfortable. The woman then went on to explain how her disabled daughter seldom leaves the house or interacts with the community and prefers to stay at home where she isn’t subject to the ridicule of others.

Another parent of a CWD indicated that her physically disabled son is never included in happy occasions such as marriages or other celebrations because people make fun of him when he goes out.
A common theme was one of disability as a form of ‘entertainment’; parents of CWDs said that people in the community make fun of people with disabilities, especially those who are Deaf or intellectually disabled.

There were also numerous stories and incidents of PWDs being teased and taunted in their community. A FGD participant in Skardu shared his story –

*When my [intellectually disabled]\(^{11}\) brother goes to the bazaar, people give him drugs instead of cigarettes because he cannot tell the difference. They laugh at him and call him names.*

*Father of CWD/brother of person with intellectual disability, Shigar Khas, Skardu*

Another FGD participant spoke about his observations regarding the treatment of PWDs in public spaces in his village.

*[People with disabilities] are teased and provoked by people until they get angry. One disabled woman in our village gets called names when she is in the market and when she gets really angry, people laugh at her even more.*

*Father of non-disabled children, Chatorkhand, Ishkomen*

This concept of disability as a source of entertainment was reinforced by all three groups participating in the FGDs. A participant in Gilgit also spoke about similar incidents in the market of her village.

*There is an intellectually disabled young boy in our village who gets teased by other children in the market. When he gets angry he throws large rocks at people, and now everyone is scared of going near him.*

*Mother of non-disabled children, Oshkhandas, Gilgit*

Yet another participant in Skardu spoke about how, even though it is common practice for people in their community to share meals and eat together, people do not like to eat in the presence of a PWD/CWD. She added that this was due to that fact that PWD/CWDs are considered “unclean”. Parents of non-disabled children also spoke about how CWDs often appeared dirty, unhygienic, and uncared for, which is why they preferred to keep their children away from them and discouraged them from playing together.

This theme of isolation of PWDs stemming from negative interaction was one which surfaced across all four study districts. Participants were unanimous in their views that PWDs were often the victims of negative treatment by community members, which ultimately led to their isolation from the community. Even participants, who initially highlighted the presence of good will and compassion towards people with disabilities in their communities, agreed that PWDs were often isolated from their communities due to poor treatment by people.

When discussing the treatment of PWDs by society the topic of “name-calling” was raised. Participants were asked to highlight some of the words used to address people with disabilities. It was noted that all the commonly used terms were extremely derogatory and demeaning, and were said to be frequently used when talking to or about a person with disabilities. Many participants also claimed that name-calling had led PWDs in their village to stay away from others and had further isolated them from society.

\(^{11}\) The participant who shared this incident used the phrase “mentally retarded” to describe the child’s disability. However, due to the fact that the term has been replaced by Intellectual Disability, NOWPDP made a change in the quote.
Apart from isolation, there was another theme of fear of disability which was noted in some of the study districts. In Ghanche, participants explained how people often show kindness to PWDs only out of “fear of God”, as they do not want to be cursed with a disabled child, and not out of genuine compassion.

A participant in Pakora also shared this view –

*My brother has a physical disability. When he was young, he would get teased about his disability by a boy in our village. When that boy grew up and got married, he was unable to have children.*

_Mother of non-disabled children, Pakora, Ghizer_

The concept that making fun of PWDs would result in future ‘punishment’ of some form of disability is one which also emerged repeatedly in FGDs, portraying disability as a ‘curse’ and something to be feared. This also reinforces the concept of disability as ‘punishment’ for sins, which leads to the portrayal of PWDs in a very negative context.

**NOWPDP Insights on Integration into the Community**

_FGDs with participants suggested that while people are kind and sympathetic towards young children with disabilities, these sentiments are not extended to older CWDs or adult / young adult PWDs in the same communities. The taunting and ridicule many older CWDs are subject to leads to their isolation from the community (isolation of the CWD as well as their family). This isolation leads to less interaction between mainstream society and PWDs, resulting in a further de-sensitized community where the integration of PWDs becomes even more difficult._
9. EMERGING FINDINGS WITH ACTIONS TAKEN/RECOMMENDATIONS

9.1. Disability sensitization

Observation
There was a considerable lack of clarity regarding the differences between disabilities. When thinking of disability, it was noted that participants appeared to envision severe and profound cases only. Mild to moderate disabilities were not often envisioned in the context of discussions, which prevented participants from realizing the ease with which most children with mild to moderate disabilities can be integrated into mainstream schools.

As well, mental illness (which can be ‘cured’ with the help of medication and therapy) was almost always confused with Intellectual Disability (which cannot be ‘cured’ but can be managed). This confusion can limit the opportunities available to children with Intellectual Disabilities due to the fact that the negative, often violent, characteristics of mental illness were associated with Intellectual Disability. This led to concerns about safety of non-disabled children in an inclusive classroom.

Overall, disability was view as something to be feared, and often as a ‘punishment’ for the ‘sins’ of a family. While participants indicated that the inclusion of these children into society was important, many were hesitant to take the first steps (inclusive education) to make that happen, due to the general lack of understanding and information regarding disability.

Action
NOWPDP has incorporated a unit on Disability Sensitization in the teacher training manual used in Teacher Training (TT) sessions across Gilgit-Baltistan. This unit outlines the most common disabilities found in class rooms including Learning Disabilities, Intellectual Disabilities, Physical Disabilities, Visual Impairment, Hearing Impairments, Speech and Language Impairments, Autism, Down’s syndrome, and Chronic Illnesses. The causes of each disability are explained in detail, which addresses common misperceptions regarding disability that emerged in the TNA. The unit of Disability Sensitization also highlights common characteristics exhibited by CWDs which a teacher can expect to observe in the classroom. Finally, teachers were given tips and suggestions on how to manage these characteristics and behaviors in order to support students with each type of disability in an inclusive classroom.

The difference between Intellectual Disability and mental illness was highlighted and stressed upon. It is made very clear that people with intellectual disabilities do not usually behave violently unless provoked, whereas those with mental illness may or may not do so, depending on the type of mental illness.

The NOWPDP training manual also clearly highlights the different levels of disability, ranging from mild to profound. Participants in the training sessions were taught hands-on teaching methods and strategies that would not only effectively include children with mild to moderate disabilities in the classroom, but would benefit other students as well. The training manual was used to train and sensitize teachers, LLI members, and the community.

9.2. Lack of understanding about inclusive education

Observation
There was a clear lack of understanding regarding the concept of inclusive education and the mainstreaming of children with mild to moderate disabilities in regular schools. While many of the teachers participating in FGDs indicated that they had students with mild to moderate disabilities in their classes, a majority were hesitant when asked if they were willing to teach CWDs in their class. This relates to the previous observation regarding disability sensitization, where most participants envisioned only severe and profound cases when discussing disability, while often forgetting about the existence of mild to moderate cases. Teachers were also concerned about the special needs of CWDs, which would require extra one-on-one time with the teacher at the expense of other children in the classroom.
Parents of non-disabled children were also hesitant to accept the concept of Inclusive Education. Once again, it was noted that most participants referred to severe and profound disabilities when citing their reasons for not accepting Inclusive Education. Additionally, the confusion between mental illness and intellectual disability made parents fearful for the safety of their child around a child with intellectual disabilities who is ‘violent’.

**Action**

In order to address this lack of clarity regarding the concept NOWPDP included a session on Inclusive Education. Training participants were first introduced to the concept of Inclusive Education and were given a chance to put forth their concerns and fears. These concerns and fears were not only discussed and addressed during that session but also addressed in greater detail as other aspects of Inclusive Education were covered over the course of the five-day training.

Teachers were encouraged to be mindful of the various levels of disability, and the ease with which children with mild to moderate disabilities could be mainstreamed into regular schools through the use of simple teaching methods that would benefit the entire classroom.

The concerns of parents will be addressed through NOWPDP community awareness events which will take place in the summer months of 2012. Here, parents will be informed about disability and the inclusion of children with mild to moderate disabilities into schools.

9.3. Negative attitudes towards the capabilities of PWDs

**Observation**

Many participants in FGDs assumed that CWDs were incapable of learning or getting an education. They would then proceed to assert that PWDs are unable to find employment because not only because they lack education, but because despite being educated, opportunities were not open/available to them due to discrimination and stigma in their communities.

**Action**

NOWPDP challenges negative attitudes towards CWDs by reminding training participants that those with disabilities are still able to learn, including those with intellectual disabilities. They may require different techniques much like the methods used to address multiple intelligences. The assumption of multiple disabilities (i.e. someone with a physical impairment also being intellectually disabled) should be avoided.

NOWPDP will also begin the long process of sensitizing community members (specifically parents of school going children with and without disabilities) through community awareness events, where guest speakers will include persons with disabilities who are successful and have achieved many things.

However, it is important to keep in mind that the process of community awareness and sensitization is a long one; NOWPDP community awareness events are simply a ‘first contact’ with the community; we do not expect long term behavior change simply with one event. We do, however, aim to begin the groundwork for a more supportive school community for CWDs.

9.4. Vocational Training

**Observation**

Many parents of children with disabilities (as well as other FGD participants) shared their desire for the presence of a vocational training center in their area where they could send their CWD. Many parents were of the opinion that PWDs are unable to find employment, even with an education and relevant skills, and that they would prefer for their CWD to learn a vocation which will allow them to support themselves later in life.
The Karakoram Area Development Organization (KADO) was referred to in nearly all of the FGDs across the study districts and participants stressed the need for a similar organization that trains and employs PWDs in other areas of GB.

Recommendations

NOWPDP suggests bringing vocational training opportunities to other areas of Gilgit-Baltistan. This can be done by establishing linkages between the AKDN and local disability organizations in the area, a concept which has been initially considered by NOWPDP. While extensive research remains to be done in terms of specific needs assessment, skill selection, production, marketability of products, etc., NOWPDP is willing to take a lead on this potential project in the future with the support of other AKDN organizations.

10. LIMITATIONS

Due to the time constraints faced as a result of the delay in the Project Implementation Plan, NOWPDP was unable to conduct one-on-one in-depth interviews with the parents of CWDs, parents of non-disabled children and teachers, as planned. In-depth interviews would have provided rich insight into the lives of CWDs, as well as a candid look at the perceptions and attitudes of teachers and parents of non-disabled children towards disability.

Due to the uniqueness of each district in Gilgit-Baltistan, conducting FGDs across all seven districts would have allowed NOWPDP to customize the training manuals for each district. Unfortunately, time and budget constraints made this impossible. As well, activities in Diamir had not yet commenced due to security concerns; including Diamer in the study would have been worthwhile as it is the most conservative district in Gilgit-Baltistan and is likely to have different needs compared to other districts.

Due to the lack of disability prevalence data, NOWPDP was unable to draw a sample size of parents of CWD which would reflect the true population of people with disabilities in the area. Sample size was therefore based on EDIP clusters in each district (see methodology for more details).

11. CONCLUSION

The results of the TNA were extremely useful in the development of NOWPDPs teacher training manual on Disability Sensitization and Inclusive Education. There were many existing misunderstandings regarding the causes of disability which perpetuated a cycle of fear, apprehension, incorrect assumptions about disability, ridicule, and isolation of PWDs and their families. This isolation of PWDs and their families has led to misgivings and hesitations regarding the mainstreaming and inclusion of CWDs into regular schools, which was discussed in the FGDs.

Perceptions of disability as seen in the FGDs ranged from positive and inclusive (very seldom) to extremely negative and isolating. The idea of disability as ‘punishment for sins’ is widespread which leads to disability being viewed as a result of sinful actions and therefore as ‘deserved punishment’ eliciting little support or empathy. PWDs are often ostracized in their communities along with their families and do not have access to education, recreational activities or a regular family life.

By addressing the major underlying misconceptions about the causes of and reasons for disability in the Disability Sensitization and Inclusive Education training manual for teachers, NOWPDP has taken the first step in laying the foundations for an inclusive school community. Our goal is to improve the existing environment for students with disabilities already enrolled in EDIP schools as well as sensitize their teachers, parents, and the extended school community.
Network of Organizations Working for People with Disabilities, Pakistan

The painting on the cover of this report was made by a student named Kashif Ali. NOWPDP’s heARTwork project exhibits paintings made by children with disabilities.