



DISABILITY AMONGST CHILDREN - A SITUATION ANALYSIS OF GILGIT-BALTISTAN



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EXECUTIVE SUMMARY

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The Global Burden of Disease study estimates that 93 million children (5.1%) aged 0–14 years, experience “moderate or severe disability”, with 13 million (0.7%) children having severe difficulties.

There is very limited evidence available on disabilities for children in Pakistan and it is therefore essential to have accurate data for informing policy, designing intervention strategies and developing support programmes for children with disabilities.

The Education Development and Improvement Programme (EDIP) is being implemented in Gilgit-Baltistan (GB) under the auspices of Aga Khan Foundation, Pakistan (AKF,P) funded by Australian Agency for International Development (AusAID). The main goal of EDIP is to contribute to the overall socio-economic development of GB through enhancing access and equity in education; improving the quality and relevance of education and strengthening governance and management of the education sector. An important guiding principal of EDIP is 'a commitment to working with diversity and developing an inclusive approach which includes the poorest and most disadvantaged and those with disabilities'.

This population based disability survey is part of EDIP and was designed to adequately provide a situational analysis of children with disabilities in GB under fifteen years of age, assessing not only the prevalence but also exploring issues and challenges faced by these children. The basic purpose of this survey is to help move towards developing more inclusive approaches to education, an integral part of a pluralistic approach that welcomes diversity and addresses all types of social and economic exclusions. Specific objectives of the applied research included:

- To assess the burden of disability in children less than fifteen years of age in the GB region.
- To explore perceptions of various stakeholders such as parents, teachers, community members and NGOs regarding disabilities in children.

A cross-sectional, population based survey was undertaken in four districts of Gilgit-Baltistan region for assessing the prevalence of disability among children aged 0-14 years. The sample size was estimated to be 3,003 children. For qualitative component, 27 Focus Group Discussions (FGDs) were conducted with various stakeholders in GB and 07 semi-structured Interviews (INTs) with children with disabilities.

Quantitative Data – Key Findings

Socio Demographic Status

- The estimated total population of District Gilgit, District Astore, District Ghizer and District Ghanche, based on Census (1998) was 592,585 with 52,445 Households.
- The survey covered 22,732 people, 2939 households and 3194 children. Children, birth to 14 years comprised 44% of the total population with a gender ratio of 107 males for 100 females.
- Twenty-eight percent of people live in Katcha/sheltered construction. The mean \pm SD number of

rooms available within a HH was 2.7 ± 1.4 and average number of people within a household was 7.7 ± 3.0 . Ghanche is the most deprived district and has the poorest sanitation facilities with 93% HH having open drainage system and less than 4% HH having a flush toilet.

- Literacy rate in GB is 66%, lower literacy rates were observed for both males and females in District Astore and Ghanche. One-third of the population in GB had never received any formal education.
- At least 20% of children of school going age are out of school in GB. The lowest enrollment rates were found in Astore, where more than one-third children were not enrolled, followed by Ghanche, with 21% out of school children.
- The results of the survey indicate that 70% of the households have only one earning member and 20% have two members contributing to the family income. Among the employed population almost one-fourth (26%) are engaged in agriculture and related works. The second most common profession is the category of “Clerical and related workers” (16%), mainly employed with government service. Employment rate for women 18 years old and above is only 09%. The average monthly income in GB is PKR $20,220 \pm 17,115$, showing a highest to lowest gradient from Gilgit to Ghizer, Astore and Ghanche respectively.

Basic Information of Target Children 0-14 years

- The sample included 54% boys and 46% girls less than 14 years of age.
- Consanguineous marriage is common in GB and overall 34% of the parents of indexed children were either related as a first cousin or second cousin.
- Forty-four percent women were reported having at least 4 antenatal care visits (WHO recommendation) with index pregnancy.
- Breast feeding Practices - Pre lacteal feed was given to 8.3% children after their birth. The prevalence of breast feeding was very high (more than 98%), however exclusive breast feeding up to 6 months was reported as 58%.
- The most common illness found among children during the last 15 days of survey was fever (9%) followed by gastrointestinal problems (4%) and respiratory tract infections (4%). In case of illnesses, mothers were consulting either hospitals (69%) or private doctors (12%).
- Malnutrition – Rates of malnutrition were found very high (stunting - 50%) among children aged 0-5 years. Highest prevalence of malnourished children was found in District Ghanche followed by District Astore.
- Complete immunization status for children under 1 year was reported as 11% and for 1 to 05 years as 15%.

Disability Status of General Population

- The overall prevalence of disability amongst the surveyed population of GB, based on self-reporting, was found to be 4.6%. District Ghizer had the highest rates (7.8%) of people with disability. Majority of disabilities were reported for the category of physical impairments (1.4%), followed by vision impairments (1.2%) and hearing impairments (0.7%). Mental impairments were the least reported category with an overall prevalence of 0.3%.

- Twelve percent of the surveyed population was also reported with more than one disability.
- The highest disability prevalence was found in population >55 years of age (17%).

Disability among Children 0 to 14 years

- The prevalence of disability among children under 15 years (based on screening) in the four districts of GB was 7.5%. The highest number of disabilities were found in district Astore (12.6%), followed by Ghizer (8%), Ghanche (6.3%), and Gilgit (5.5%).
- In all districts except District Gilgit, disabilities were reported to be higher amongst boys as compared to girls. In District Gilgit, girls were at higher risk (53%) for disability as compared to boys (47%).
- Age distribution of children with disabilities revealed 23% children to be under 5 years, 42% were aged 5-9 years, and 35% children were in the age group 10 - 14 years.
- Disability was found significantly associated with increasing age of child, consanguineous marriage among parents (more disabled children with inter marriages), women with more than 04 pregnancies and home as the place of delivery.

Qualitative Data – Main Findings

Issues and Challenges Associated with Disability

- Knowledge on causes, classification and practices of Children with Disabilities (CWD) was poor and reflective of the experience with CWD rather than their acquired learning. The knowledge on disabilities prevention, early detection and interventions was limited among all participants.
- Household members of disabled children found themselves in a particularly difficult situation. The burden of caring for a disabled family member was very heavy and often carried solely by a female caretaker, commonly mother of the CWD.
- It was noted during FGDs that the caretakers (mothers) stressed out, being both physically and psychologically exhausted due to the responsibility of taking care of the CWD. In many cases, they had to lift and carry their disabled child because of lack of aids (wheelchairs, ramps, elevators, etc.) and transport adapted for the needs of disabled people.
- Mainly due to illiteracy, the parents failed to understand the disability of the child, got irritated and considered CWD as a burden and a curse on them. There were apprehensions in parents regarding the future of a child with disability.
- Children with disabilities in GB experienced discrimination and negative attitude from others and developed low self-esteem. There were limited employment opportunities for the disabled population.
- Poverty was proved to be one of the main hindrances to integration and at the same time a consequence of the lack of integration. Most of families of CWDs could not afford medication, medical treatment such as surgery and rehabilitation procedures due to their exorbitant costs. The need to struggle for basic survival precluded household members of disabled persons from providing necessary care and finding time for social activities.

Major Difficulties in Schooling

- Children with disabilities seldom had education beyond the primary school, mainly due to three reasons; they were not accepted in the 'regular' schools, the family was not able to pay the fees and was not able to provide for or pay for transportation.
- Children with mild and moderate disability at times got a chance to go to school, however, when they were unable to cope with the demands of the school and faced peer scorn and mockery, these children simply dropped out.
- Most of the time abilities of CWD who enrolled in mainstream schools were not developed. In general the number of teachers in schools was less as compared to the number of students and in particular teachers rarely had formal training to teach children with disabilities.
- School buildings were not adjusted to mobility-impaired pupils and suitable learning materials for CWD were not available. A special school complex was located in GB, however, many disabled children were unable to join that because their parents, especially those living in remote areas did not want or could not afford to bring their children to Gilgit.

Barriers to Mainstreaming

The following barriers were identified by the Focus Group Discussion participants and CWD that were considered to be the main factors hindering mainstreaming of children with disabilities:

- Social Barriers – Involuntary seclusion of CWD from social life, inability to leave home or communicate, and lack of educational and vocational trainings prevented the CWD from developing and maintaining viable social networks.
- Mobility and Commuting Barriers –Transportation was identified as a major problem for CWDs in GB. There was no transportation available which was adapted to their needs. Therefore, finding the balance between taking risks and maintaining health and safety was not easy for the parents, and mostly resulted in limitations to play and education opportunities for the child with disability.
- Physical accessibility Barriers–There were many architectural barriers and lack of supplies related to physical adjustment in school buildings and for socializing such as ramps, rails and toilets that led to exclusion of CWD from everyday life activities.
- Education Barriers –In addition to inability to cope with peer ridicule and physical barriers, lack of trained staff, lack of specialized study materials and lack of adequate knowledge about teaching techniques for disabled children all contributed to the failure of the education system in GB to educate a disabled child.
- Economic Barriers - The family's economic security was untenable to meet the needs to care for the CWD without formal support and without sustainable earning capacity of the parents.
- Healthcare and Rehabilitation Service Barriers – Therapeutic support, counseling, surgical and rehabilitation services were underdeveloped and almost non-existent in GB, largely preventing CWD from receiving timely and quality health care and rehabilitation services.

In conclusion, the findings of this survey reveal that prevalence of childhood disability in GB has

increased considerably as compared to the 1998 census report. The data suggests that children with disabilities in GB are particularly prone to discrimination and neglect, have reduced access to basic health, education and social services, as well as lack recognition of their equal rights by their families, peers and communities. Furthermore, policies and programmes that address the specific needs of CWD are sporadic and limited in scope. Much needs to be done to develop supporting policies and increase institutional capacity and inclusiveness in GB for improving chances of differently abled children to enjoy equal benefits of education and development as their counterparts i.e. children without disabilities.