

Whispering Through Obstacles: Unveiling the Journey of Parents Raising Hearing and Speech Impaired Children in Charsadda. Khyber Pakhtunkhwa (KPK)

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Abstract

This article examines the challenges faced by parents raising hearing and speech-impaired children in Charsadda, KPK Pakistan. It highlights emotional distress, societal stigma, communication barriers, limited special education institutions, lack of inclusive education, financial constraints, healthcare difficulties, and uncertainty about future education. Medical treatment and consultation with doctors also create hurdles for parents. Furthermore, their parents are passing through psychological and emotional distress especially their mothers while attending family gatherings and different functions. The theoretical framework of the study is based on the social model of disability. The study used qualitative research methods, interviewing twenty families and conducting a thematic analysis. Recommendations include establishing dedicated support systems, improving healthcare accessibility, promoting community involvement, advocating for government initiatives, collaborating with NGOs, and organizing parental empowerment workshops. Addressing these collaborations is crucial to enhancing the well-being and prospects of hearing and speech-impaired children and their families.

Keywords: Social stigma, Sign language, Inclusive education, Special education institutions, Emotional distress, Communication barriers.

1. Introduction

Encyclopedia Britannica defines parenting as “the process of nurturing and socializing the children along the provision of social protection and care to ensure healthy transition to adulthood” in addition to these other words and phrases used for nurturing the child include, taking care of the child in every aspect such as feeding, nourishing, nurturing, parenting (father/mother) which shown that parenting is not an easy process requires a significant amount of energy, time and emotional strength. However, it becomes more challenging when being a parent you have to raise a differently able child and children, especially hearing and speech-impaired children who are deprived of hearing and speaking (Abbas et al., 2023; Kretchmar-Hendricks, 2023).

Having the ability to listen, speak, and react to different circumstances is an invaluable asset to any person. However, some individuals are not blessed enough to retain these abilities. In this scenario to raise a differently able child face a lot of difficulties and obstacles in everyday life to later in life, including communication barriers, access to basic and higher education, lack of training to prepare for employment, psychological problems, economic dependency and face physio-psychological abuse. These common problems and challenges

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become worse when these children are raised in poor families where their parents are not able to provide basic facilities of medical treatment and education, which further leads to other problems because the nature of these above-mentioned problems varies from country to country and region to region depending on their economic prosperity and their policies and approaches towards these differently able children (Kretchmar-Hendricks, 2023).

In Pakistan a more polarized and poor society, hearing and speech-impaired children and their parents have been facing a lot of challenges and problems in raising a child and children like, proper training and education, after separation, there were only three schools for special people. The historical view of the institutes was that the first school was established before the independence of Pakistan in 1906 for visually impaired children, while the second school for deaf and speech-impaired persons was established in 1920 in Karachi. The families of these special people formed a society called the Deaf and dumb welfare society, later on, it became a school by the name of Gung Mahal (Palace of Deaf) (Akram and Bashir, 2012). Similarly, for the uplifting of these special Children, NGOs and other humanitarian organizations have worked properly (Hameed, 2003). After the independence, the National Commission of Pakistan for the first time presented the agenda for Special people education. After the evaluation of the agenda in 1983 – 1992, the UN recognized this period as the Decade of Special People. The national policy for the education and rehabilitation of the disabled in 1985 improved after the evaluation in 1988. During this period, a directorate was established on a federal level to run the model special education institutions in the whole country. Moreover, a national institute of special education was established to train the teachers of these institutions. Later on, this policy was approved in October 2002.

In light of (the National Policy for Persons with Disabilities, 2002) the total population of Disabled was 2.49% in 1998. Of this disabled population, 7% are deaf, 8% are blind, 19% are crippled, 6% are insane, and 8% are mentally retarded while 52% are others. In addition, most parents tend to hide the disabled child during the census or negate the existence of disability in their children. Moreover, (the Social Protection Resource Centre, SPRC 2021) Report stated that according to the census 2017, the total population of disabled people increased to 6.2% which is considered to be a high ratio.

The Sindh provincial government has increased the Special person's budget from 800 million to 1.7 billion in 2022-23 FY to provide better facilities in special education and rehabilitation centers. The KP government provided a budget of 6068 million for the Social welfare department in FY 2022-23. Furthermore, a monthly stipend of Rs 2000, free conveyance, and lunch are provided to these special students by the Sindh government. Additionally, Rs 250 million was apportioned for these special people under the social protection policy (The Express Tribune, June 12, 2022). According to WHO (2021), globally the Mild hearing loss population is 1.5 billion people, among these 430 million people have a severe level of hearing loss. Furthermore, the hearing thresholds of more than 20 DB indicate clinical hearing loss and should be cured in the clinic. Unless the disease is not identified appropriately, people are more expected to experience negative effects in the healthier hearing ear. If the hearing loss problem is not treated on time, then it can negatively affect multiple aspects i.e. Communication, language development, speech problems, education, interpersonal relationships as well as mental health problems. Additionally, the WHO also predicts that if the problem is not taken seriously then it will affect more than 2.5 billion people by 2050 of which 700 million will have moderate hearing loss, which needs proper treatment and rehabilitation. There are various hearing loss i.e. hearing loss up to 40 decibels is Mild hearing loss. Hearing loss above mild hearing loss of up to 60 decibels is moderate hearing loss, hearing loss more than Moderate which is up to 80 decibels is

severe, and more than these three levels, profound hearing loss, which is also called deafness. Thus, what challenges are faced by parents of hearing and speech-impaired children while raising their children?

2. Literature review

One of the persistent problems that have a significant detrimental impact on deaf and speech-impaired children and their families. Nadir, Akhtar, and Ali (2006), conducted a study in Deaf and speech-impaired schools in Faisalabad (Pakistan). They have provided hearing aids to 100% of students for smooth learning but unfortunately, there is no proper training for the understanding of sounds. During the study, they found multiple barriers. Among those barriers, some are personal and some are social. From the data, 11.6% showed a likeness to making friends and relations, 29.2% were glad to attend social functions and 59.2% felt nervous in social gatherings and functions. Furthermore, these personal barriers declined the comprehension of deaf and speech-impaired students. As a result, 63.3% of the students show difficulties in maintaining their academic standards while 36.7% of the students did not show any development in academics.

Additionally, these students are pleased to make close relationships with disabled relatives. Due to the obstinate attitude and difficulties in communication, these students only keep relations with deaf and speech-impaired people. Only 10.8% of deaf and speech-impaired respondents received preference over other siblings by their parents while 15% showed ignorance from their sibling. It results in social exclusion and isolation among deaf and speech-impaired students (Nadir, Akhtar, & Ali 2006).

In Ghana, people with special abilities face multiple negative perceptions of the nature of their special abilities. Habitually, these stigmas and irrational beliefs were made according to the nature of the disability. Deafness in Ghana demonstrates some irrational philosophies like these were a sign of annoyance from the gods as well as the witch grandfather of the deaf person. Earlier, in Ghana, these special persons were considered a sacrifice of gods or had been killed at birth. Nevertheless, some negative perceptions create these rumors in communities. Afterward, the development of Christianity and Western education in Ghana, these stereotypes and killing traditions were no longer (Avoke, 2002).

Deafness and speech impairment are not only problems for affected people but it is also communication barriers for the people who want to communicate with these people (Bachman, Vedrani, Drainoni, Tobias, & Maisels, 2006). A study was conducted at the National Institute for Deaf (NID) regarding the healthcare problems of these special people in South Africa. The data highlighted that the signing language for the deaf is not a universal language as the students from different African countries did not understand the signing of each other and healthcare practitioners face a chronic problem during communication with the deaf. In the institution, there are different types of sign language used i.e. sign language, tactile sign language, and finger spelling. Due to the multiple sign languages, a gap is created during communication in healthcare settings. Moreover, deaf students are destitute of proper healthcare facilities. The main barriers to healthcare facilities are considered socio-economic factors, communication, and inaccessibility to mass media, which adversely affect all aspects of their personality (Kritzinger, 2011).

Additionally, in 2006 there were only four professionally trained translators who have a piece of proper knowledge and training of Deaf people. During the study, it was understood that Worcester (a City in South Africa) faces a deficiency of well-trained translators, if a translator then they have a permanent job which will be negatively affected by giving time to NID (Heap & Morgans, 2006). Besides, Bubbico et al, (2007), stated that in every

thousand children, seven children were born with severe deafness and hearing loss/impairment. The diagnosis of deafness and hearing loss is hard to find in the initial stages of birth and it is difficult to appear in a child's appearance. Furthermore, the disability/impairment can be recovered in the initial stages but, if the family is not able to find out the disability in the initial stages they can diagnose it after three or four years of the birth.

Moreover, deafness and hearing loss adversely affect the child's cognitive development/IQ, academic achievements, and language development. Multiple pieces of research show that deaf and hearing-impaired children in intelligence and cognitive development are normal, but psychologists believed that the normal result of these children was due to the inappropriate test taken from deaf and hearing-impaired children. However, recent tests show that the deaf and hearing-impaired children were normal in intellectual and cognitive development but their IQ level was very low. Regardless of the natural cognitive ability and intelligence, the academic achievements of mostly deaf and hearing-impaired children were low to normal students (Gharashi, 2015). According to Paul and Jackson's report, there is an inverse relation between hearing loss and the academic achievements of the child. The more severe the hearing loss, educational achievements will decrease.

3. Theoretical framework of the study

This study is based on the social model of disability which focuses on the societal structure, social barriers, and attitudes of the people towards disabled persons. This model explores the social barriers and challenges of any society therefore we employ this model in our study to incorporate the social barriers and challenges face by these parents and children.

4. Method and Procedure

This research study was conducted at "*Government Institute for Children with Hearing and Speech Impairments District Charsadda KP*". The main objective of the study aligned to explore the challenges faced by the parents of hearing and speech-impaired students. Keeping the sensitivity of the problem, the study nature was qualitative which helped to get rich, deep, and reliable data regarding the objectives of the study. Being a social caseworker in the said institution, I have the information data set of all families whose children are admitted in our institute. Out of them twenty families were contacted and took their consent for data collection. After visiting their homes in-depth interviews were conducted for the accomplishment of the study. In-depth interviews and observation with open-ended questions were the tools for data collection. The close-ended questionnaire cannot achieve the targeted information regarding the study.

5. Analysis and Discussion

After conducting interviews with twenty families and analyzing case histories, it has been concluded and examined the challenges faced by parents of hearing and speech-impaired children from their perspectives. The majority of parents expressed that they underwent a deeply distressing period upon determining their child's disability. Which include an inferiority complex, unsatisfying future of their children, psychological distress, and the stigmatizing behaviors of the community towards the parent of such child. Additionally, parents face hurdles regarding communication methods, most of the parents adapt to the use of sign language with their child which is effective to some extent, but it creates difficulties in conveying significant messages regarding the development of their children. Especially, the mothers who are busy in their daily routine work in houses, it is difficult for them to purchase items for their children due to communication barriers.

Moreover, medical treatment and consultation with doctors also create hurdles. It becomes a huge obstacle for parents that they cannot overcome.

A significant number of parents express the burden of social, emotional, and psychological impacts which involve emotional and psychological grief. Particularly, mothers express depression and frequent tears as a sign of psychological distress and try to alleviate it through religious practices. Parents of such children avoid social gatherings and events which becomes the reason for sadness and loneliness for them. Because of their child's silence and loneliness in events increases their emotional and psychological distress.

Education becomes an emerging hurdle for the parents of hearing and speech-impaired children. They expressed hardship in providing proper education to their children because of limited resources and are unable to send them to private or government schools. Lack of inclusive education and a limited number of schools become barriers to their children's educational development. While high-level school exists in the country, they are very limited in numbers and some of them are private, and the parents are unable to send their children far away to that institution due to financial and social barriers. i.e. in Charsadda a private high-level school, Azam Khan special education school for hearing and speech-impaired children exists but it is financially inaccessible for most of the parents, while there is no government high school for such children. The lack of governmental support and effective policies for these children increases the parents' concerns about their children's academic future.

Healthcare is worth listening hurdle, for the parent of hearing and speech-impaired children. Initial treatment is done in local clinics and hospitals. But lack of professional and diagnostic capabilities frequently refers them to Peshawar for specialized tests. Financial limitations avert them from achieving proper healthcare and daily medical visits. Although recommendations from medical experts for hearing aids and cochlear implants, most parents avoid such facilities due to high financial expenses. The lack of governmental and non-governmental interventions leaves the parents to uplift these burdens on their own.

Lack of proper government initiatives for the parents and their children except for one primary school which is unable to cover the whole district due to limited resources. Besides, in government hospitals these children are treated like normal people, there is no proper facilitation and diagnostic lab for these hearing and speech-impaired children. Likewise, there is no proper initiative to provide free hearing aids and cochlear implants and also these children in the Sehat Card program.

In summary, the result shows the uncountable barriers faced by the parents of these children who are trying to provide significant rights and care to adjust their children in society. These obstacles are particularly pronounced for economically disadvantaged parents, who struggle to provide even primary healthcare, testing, and necessary medications.

Theme 01: Navigating Early Challenges and Emotional Resilience

Parents of hearing and speech-impaired children (HSIC), who have gone through very difficult times, carry significant social and psychological burdens. When we interviewed a respondent who is the father of four H&SI children, regarding the early stage of identifying his child's hearing loss and the emotional rollercoaster experienced while seeking appropriate communication methods and resources, we examined multiple families facing the same distress one of them shared:

“When we noticed our first female child's disability at the age of 8 months, it was

an extremely challenging time for us. We both experienced intense mental stress and had numerous concerns about her future. Our minds were filled with uncertainties, and we were distressed by the thought that she would be constantly dependent on others. We continue to worry about our children, as they are unable to express their feelings, complaints, or desires. Most people and family members struggle to understand their expressions and sign language, leading to frustration and shouting. This pattern continued to escalate as we discovered the disabilities in our second, third, and fourth children. Now, our hearts have grown weak, and we feel emotionally drained."

Theme 02: Educational Advocacy and Access to Support

While providing education is a fundamental right and a parental as well as state responsibility, it presents a significant challenge for parents of H&SI children. One of the respondents shared:

"It was incredibly difficult to witness our child growing up without access to basic education. Seeing other children attend school is painful for us. We understood our child's desire for education. However, when we attempted to enroll our child in both government and private schools, we consistently encountered disappointment from school administrations and teachers. They repeatedly advised us to send our child to a special education institute."

Another respondent discussed interactions with medical professionals:

"At DHQ Hospital Charsadda, there was no testing facility available. We were referred to ENT specialist Dr. Shahid Masroor, a renowned doctor in district Charsadda. However, even he directed us to Dabgari Garden, Peshawar, for hearing loss diagnostic tests. The tests and travel expenses were a substantial burden, especially considering my husband's daily wage labor. Following the diagnostic tests, the doctor recommended a hearing aid, which proved to be too costly for us. We lacked information about available government services and assistance and did not receive help from anyone."

Theme 03: Community, Coping, and Future Aspirations

Parenting is already a challenging journey, and raising hearing and speech-impaired children becomes even more difficult due to hurtful comments and stigmatization from family members and relatives. One mother of two special children shared her feelings:

"One of my female family members once commented that Allah knew why He gave me two disabled children. Another female member openly told me that I was unlucky (using the Pashto word 'SPERA'). They see this as a punishment for my actions."

When asked about coping strategies, one respondent shared:

"Religious practices and recitations provide me with hope and some solace. I have consulted religious scholars multiple times. After my last visit to a doctor who informed me that my child's condition was unlikely to improve without a major surgery involving cochlear implants before the age of five, I stopped seeking medical opinions. Religious practices are my main source of support."

Additionally, a father of two hearing and speech-impaired daughters shared his future aspirations:

"I am immensely grateful that your institute offers free education, pick-and-drop

services, and vocational training. We and all parents of such children are gratified and honored that our children are being educated like other normal children. Our happiness is concerned with our children's well-being and we are now hopeful for their secure future."

Lastly, a bunch of barriers faced by the parents of hearing and speech-impaired children in the form of lack of proper education, daily household tasks, medical problems, communication challenges, ambiguous futures, stigma, and societal pressure. which later on contributes to psychological and mental distress that affects their social, emotional, and psychological life. Irrespective of these challenges, with the intervention of government initiatives, special education institutions and community support became a ray of hope for society.

6. Conclusion

This research article explores the severe barriers and challenges faced by the parents of hearing and speech-impaired children. The study also highlights the parents who remain the victim of emotional imbalance, communication problems with children for their proper socialization, limited educational opportunities, especially high school, college, and higher studies, and social stigmas. While having these barriers, these parents show notable resilience and adopt a surviving mechanism, habitually following religious teachings and practices for mental peace and satisfaction. The result of the study stresses the immediate comprehensive support system, inclusive education, and affordable healthcare services to decrease the psychological pressure on such parents. Despite the barriers, a ray of hope is present in the form of specialized education institutions and community-based programs aiming for a bright future and improved well-being for both hearing and speech-impaired children and their parents.

7. Recommendation

To start a comprehensive support system for parents of these children which comprises psychological counseling, guidance, and mentorship programs to make them enable to cope with emotional distress while raising these hearing and speech-impaired children. Additionally, Access to education is a fundamental right of every child irrespective of disability, race, caste, and ethnicity. Therefore, to start inclusive education programs and initiatives in the existing educational institutions to make access to education possible and easy for these children. Furthermore, to improve access to healthcare facilities for these hearing and speech-impaired children by expanding hearing loss tests in each government hospital and offering affordable interventions such as hearing aids and cochlear implants through governmental agencies like Baitulmal, Zakat, and NGOs, especially for poor children because these modern and technological treatment is very expensive. Likewise, to start a community engagement initiative to promote awareness, discourage misconception and misinterpretation, and support and develop a stage for the parents of these children to share experiences, coping strategies, and mutual support while raising these children wholeheartedly.

Similarly, to engage and enhance partnerships with local and international NGOs working for these people for desirable results in education, healthcare, and emotional and psychological support for these children and their parents. In the same way, all those governmental initiatives should be advocated which provide financial aid, subsidies, and support to all these speech-impaired children especially poor families. Lastly, policy advocacy for raising hearing and speech-impaired children to engage and influence policy-making and policy change at regional and national levels to ensure the right to education .

and well-being of these hearing and speech-impaired children and their parents.

Ethical consideration

Research ethics of participants consent, confidentiality and cultural competence was maintained by the researchers.

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