

Delayed Diagnosis, Delayed Hope

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To what extent does the absence of a national newborn hearing screening (NNHS) program in Pakistan affect the age at which congenitally deaf infants are identified and subsequently referred for cochlear implantation, compared to countries with established NNHS programs?

Executive Summary

This policy brief addresses the important hearing gap in Pakistan caused by the absence of a National Newborn Hearing Screening (NNHS) program. Today, infants with congenital deafness are often diagnosed well beyond the optimal window for intervention, leading to distorted speech, poor language speaking skills, and low education understanding. This analysis is based on a mixed-methods approach, integrating a cross-sectional survey of 74 parents of cochlear implant recipients in Lahore with grey literature on healthcare barriers.

The findings reveal that logistical hurdles including distance to specialized clinics (71.6%), travel costs (51.4%), and a lack of health insurance (66.2%) severely hinder an infant's diagnosis journey. Yet the most profound barrier remains the lack of a formal system to catch hearing loss at birth. Clinical research suggests that identifying hearing loss by six months is vital for normal development, yet in the limited pool of Pakistan's healthcare spending of 2.52% of GDP, many children are left without this essential service. This policy brief recommends that the Ministry of National Health Services should order universal newborn hearing screening and allocate specific funds to consolidate these services into existing infant health frameworks.

Introduction

Audiology is an important field of healthcare focusing on assessing, treating, and rehabilitating hearing and balance conditions. According to global norms, the approach to congenital hearing loss involves screening within one month, diagnosis within three months, and treatment within the next six months also known as the 1-3-6 Rule. It is vital to follow this schedule because it provides an infant with optimal chances for achieving positive results of acquiring language skills and cognitive development.

Nevertheless, there is no official national program of NNHS in Pakistan. Hence, hearing loss is detected only when children do not show expected language skills several years after birth. This is a devastating consequence because those who are detected later, need intensive and expensive rehabilitation programs and are unable to reach the same level of mastering languages as those who were detected earlier. Besides, the problem is caused by the healthcare system of Pakistan. With the spending on healthcare at 2.52% of its GDP, it is far below the global indicator of 5%. The existence of cultural barriers, lack of trained professionals in the relevant field, lack of

infrastructure, lack of government funding and lack of awareness about the problem are additional hurdles that further add to the existing challenges. Hence, by studying the barriers faced by families whose children have gone through the entire process of receiving Cochlear Implants (CI), gives us insight into the problems of the systems that fail even before the child becomes known about. Understanding such barriers like the expensive cost of transportation and the shortage of local experts, will equip policymakers with the knowledge of why an organized screening program right from birth is needed.

Methodology

The policy brief is guided by a mixed methodology approach that comprises primary data collection along with a comprehensive literature review. Primary data is obtained from a cross-sectional survey consisting of 74 parents/guardians of children having congenital hearing impairment and undergoing Cochlear implant treatment. Participants were chosen using a non-probability sampling method at significant locations of Lahore city including Hamza Foundation Deaf Academy. The data collected from this sample has been analysed to find out the statistical pattern of demographic barriers and service accessibility.

In addition, the policy brief uses information gathered from an ongoing study being conducted for understanding the point of view of the professionals regarding referral delays and diagnosis delay. Literature review has been carried out using Pakistan Journal of Medical Sciences (PJMS) and WHO reports.

Limitations: The most significant limitation is related to the geographical and socio-economic limitations of the collected data. Specifically, the survey was conducted in urban areas of Lahore, which is expected to have more access to various resources compared to the rural areas in Pakistan. In addition, due to the small number of respondents from the group of healthcare specialists (5-8 people), the obtained information is partial and does not cover all possible obstacles within the system. Finally, since the survey was conducted among families with cochlear implants, there might be a selection bias towards wealthier families.

Key Findings

Impact of Delayed Diagnosis on Speech and Language Outcomes: It is important to understand when an individual should get a CI as there exists a "prime window" when the development of speech and language skills coincides with the period of childhood development.

Implanting Under Age 2: Detection and diagnosis of hearing loss prior to six months will ensure that the child gets the "full benefit" of the procedure at their optimal stage of development. Early detection is associated with better preschool speech intelligibility and vocabulary skills, which predict future linguistic success.

Implanting Over Age 3: Individuals who were diagnosed and received a CI later on (such as over the age of 3) are likely to have worse results since they missed the critical period of natural language speech development. These individuals need more costly and difficult rehabilitation in an attempt to catch up with their development.

Primary Healthcare System Barriers

There are several system-related factors that lead to the delay in identifying deaf children who can undergo cochlear implants:

Infrastructure and Policy: Currently, there is no paediatric hearing screening service run by the Ministry of National Health Services. This indicates a lack of systematic approach to the problem, which means that the problem is detected accidentally or on the parents' initiative once major development landmarks have been missed.

Workforce and Accessibility: The survey results indicate that accessibility is one of the key barriers; 51.4% of families had trouble accessing audiologist clinics, while 71.6% were struggling to visit ENT clinics. There are also numerous barriers related to hospital management and health administration priorities concerning neonatal screening.

Financial Barriers: Pakistan is one of the countries with the lowest expenditures for healthcare in the world. From the individual perspective, the barriers include expensive transportation (mentioned by 51.4% of respondents) and scheduling problems (by 48.6%).

Cultural Barriers: Cultural barriers and low awareness are the factors that prevent people from recognizing the problem especially while being based in Pakistan. Even just the concept of accepting the diagnosis can come up as controversial, making the life of a deaf individual full of hardships when instead they can be filled with opportunities.

Projected Cost-Effectiveness of a National NNHS Program

While implementing a national program requires an initial investment, the sources suggest it would be highly cost-effective in the long term:

- **Reduction in Rehabilitation Costs:** Because later-identified children require significantly more intensive and expensive long-term rehabilitation, detecting hearing loss by six months through an NNHS program would reduce the overall lifetime cost of care per child.
- **Optimized Resource Allocation:** Clearer referral pathways established by an NNHS would allow audiologists and surgeons to prioritize infants during their most responsive years, ensuring that expensive technology like cochlear implants provides the maximum possible return on investment in terms of the child's future productivity and integration.
- **Economic Justification:** Providing concrete data on the benefits of early identification serves as a justification for government investment, potentially shifting the burden from reactive, expensive clinical care to proactive, efficient screening.

Logistical and Financial Barriers

The absence of a national program creates a vacuum where early detection is left to chance rather than protocol. Additionally, 51.4 percent of parents said that the distance to an audiologist is a difficulty. An even higher number, 71.6 percent said that the distance to an ENT clinic is a barrier. This is a critical issue since in a country like Pakistan, specialized care is mostly found in major cities. Therefore, families from peri-urban areas have a hard time getting their kids diagnosed early. Distance also adds up to the cost.

Travel and Opportunity Costs are also an issue. 51.4 Percent of parents said that the cost of traveling to appointments is a problem. These costs, combined with the hassle of scheduling appointments, which 48.6 percent of parents mentioned often lead to missed follow-ups and delayed treatments.

Insurance Gaps are a challenge. 66.2 Percent of parents said that not having health insurance is a challenge. When there is no private insurance to cover hearing screenings and assistive devices the financial burden falls on the parents. Many of these parents (46%) earn between \$587 and \$650.

Structural infrastructure gaps:

Detection and Referral Delay: Without the NNHS, children get diagnosed after age one, which prevents them from starting the process of acquiring their language. The absence of organized paediatric screening provides no path for newborns to get timely assistance.

Lack of Human Resources: About 52.7% of parents revealed that they do not have any speech therapists or professionals who are engaged in rehabilitation close to them. This situation is worse in rural areas where educational institutions provide rehabilitation services.

Urban and Rural Divide: Urban children may have greater chances to reach a health facility compared to rural children leading to lack of access to critical services such as speech therapist appointments, follow up OAE tests and increased transport costs.

Socioeconomic and Educational Influences

Moving through the existing fragmented system relies heavily on parental resources.

Education as a Navigator: The study found that a high proportion of parents with graduate level education (33.8%) were able to obtain CIs for their children. Thus, the complex, uncoordinated healthcare system in Pakistan requires a level of “health literacy” and persistence that less-educated parents may not be able to provide.

Psychological and Cultural Resistance: Socio-psychological problems, including denial of hearing loss, often cause delays in treatment. These delays are prolonged because parents wait for the child to "grow out of" perceived speech delays, without a formal, obligatory screening at birth.

Recommendations:

To the Ministry of National Health Services, Regulations and Coordination (MoNHSRC):

1. UNHS Program Order: The ministry should develop a policy to mandate all public and private maternal hospitals to conduct OAE (Otoacoustic emissions) screening of all newborn babies prior to discharge from hospital. If OAE testing has no major response it is also important to make Auditory Brainstem responses mandatory so that a proper diagnosis is identified. In case OAE has already been performed this would be part of the routine infant care along with other vaccinations and screening procedures.
2. National Registry and Referred Testing Program: In order to address the issue of delayed hope, the government needs to establish a central registry where information regarding

babies that have failed their first hearing screening test is recorded and connected with regional audiology clinics in order to conduct ABR (auditory brain stem response) test within three months of age. By establishing such registries, the problem of patients getting lost for follow ups won't come up leading to proper treatment in an organised manner leading to better results and a better economy for the in the future.

3. **Dedicated Fund for Audiological Infrastructure:** The government needs to allocate additional funding for the health sector based on 5% GDP that is the international benchmark; and particularly for the purchase of the equipment for screening in the rural districts. It would be done through either subsidy or insurance coverage for the diagnosis and cochlear implant rehabilitation for which the 66.2% families lack resources at present.
4. **Training:** The government needs to give incentives to the training of speech-language pathologists and audiologists through scholarships with the condition that the professionals need to practice in the rural districts for a certain number of years. Through such training around 52.7% parents can access better speech therapy services which were not present before. Many parents think that after their child has received the Cochlear Implant, the treatment has been successfully wrapped up, however the real burden starts when speech therapy has to be conducted in public hospitals in Pakistan professional behaviour is rare leading to expensive surgeries also being meaningless.

Conclusion

Absence of a nationwide newborn hearing test screening in Pakistan becomes a silent disaster as it robs thousands of children of their ability to hear, speak, and become a healthy individual. Judging by the figures provided, the current approach to the parent-based diagnostics is hampered by the unaffordability of costs, remoteness to the clinics, and lack of proper infrastructure. In the moment when the diagnosis is made, there is no possibility for the child to utilize the time of the fastest brain development. The implementation of a national screening program is not only an issue of health care, but also the one of making sure that the child's ability to hear and speak does not depend on his or her family's financial status or birthplace.

This survey of eight clinical audiologists in Pakistan demonstrates the significant gap between the international standards for hearing healthcare and local clinical practice. Although the international guidelines suggest that the diagnosis should be made at the age of 3 months, most of the interviewed specialists state that only less than 10% of their patients meet these standards.

Based on the findings above, it is evident that the price of cochlear implant and surgery remains an absolute barrier to the timely provision of the services because it has been identified as an issue for all the respondents. It is also worth noting that there is no suspicion that children may have a problem with hearing until they reach between 7 and 24+ months of age. This brings about "a very large gap of several years," unlike the situation in the United States of America or Austria, the country where most of the hearing aids are manufactured (Med-el products).

Summary of Professional Perspectives on Newborn Hearing Screening (NNHS) in Pakistan:

Metric / Category		Key Finding	Survey	Professional Consensus & Data Points
Typical Suspicion	Age of 7 to 24+ Months			Most infants are only suspected of hearing loss after failing major speech milestones.
1-3-6 Compliance	Benchmark < 10% of Patients			Five out of eight audiologists report that fewer than 10% of patients are diagnosed by age 3 months.
Average Implantation	Age of 25 to 48+ Months			Most children receive cochlear implants well beyond the ideal developmental window.
Primary Bottleneck	System Cost of 100% of respondents	identified financial barriers as the single biggest hurdle after diagnosis.		
Loss to Rate	Follow-up 31% to 60% of Cases			62.5% of clinicians report that patients are "frequently" lost between diagnosis and evaluation.
Primary Driver of Late ID	Infrastructure & Policy			While parental awareness is a factor, lack of screening equipment and government policy are cited as the root causes.
Perceived Gap vs. Global Standards	"Very Large Gap"			Clinicians perceive a difference of several years between Pakistani practice and international norms.
Recommended Step	First Urban Programs	Pilot		Establishing universal screening in major urban tertiary hospitals is seen as the most feasible starting point.

Source: Based on primary survey data from clinical audiologists in Pakistan (July 2026).

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Primary research: Google Form survey conducted with responses from audiologists both working in private healthcare institutes as well as public hospitals.