

Exploring ways to encourage earlier detection of hearing loss
in Hazaribag, Jharkhand, India.

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A dissertation submitted in part fulfilment of the requirements for the degree of M. Ed

(Inclusion and Special Educational Needs)



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September 2012

Abstract

Every child deserves a fair start in life, with the very best opportunity to succeed. To have a fair start in life, children with hearing loss (CWHL) need to be identified at an early age. The early detection and management of hearing loss is vital to alleviate the consequences of deafness. This study attempted to provide a deeper understanding of the issues and concerns regarding early detection and intervention of CWHL in Hazaribah, Jharkhand, India.

Objective: To sensitise and empower the people with hearing loss (PWHL) and their families in rural areas in gaining support and access to their rights. It also endeavours to provide some useful information about support services.

Method: This research was designed around an expert consultation approach involving a multidisciplinary team, using multiple methods. A questionnaire –based survey, drama presentation and interviews to get feedback on the drama were conducted.

Results: The results from fifty-eight respondents (82%), six Skype interviews and five email responses indicate the late detection of early-onset hearing loss, due to inadequate infrastructure and equipment. Moreover, PWHL are poorly educated, unemployed, and vulnerable are unable to access their rights. The females with hearing loss are even more likely to be socially marginalised, abused and devalued. The drama presentation has raised awareness on the issues of hearing loss that affects the quality life of PWHL and their families.

Conclusion: It is required to have proper implementation of the government policies on support services for PWHL, particularly the universal neonatal hearing screening (UNHS) in all the health care facilities. Community support groups and networking among people could promote the awareness and enhance the chances of rehabilitation.

Acknowledgements

I would like to thank the International Ford Foundation Program (IFP) for the sponsorship to further studies overseas.

I am deeply indebted to my supervisor, Dr. Linda Watson for her professional guidance, comments, advice and support; these have contributed enormously to my success in completing this research. I also acknowledge the efforts of my tutor, Michele Pipe for constant encouragement throughout the course.

I must say that the proposal of this project was commented as highly 'ambitious'. However I made all the proposed ideas possible with support of my supervisor and the team members in India.

I specially render the words of gratitude and my appreciation to the team members who carried this research on my behalf, all the respondents for their information and all who have helped me in one way I wish to say thanks a million and God's blessings.

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ACRONYMS

CWHL	-	Children with hearing loss
EHDI	-	Early hearing detection and intervention
EDHL	-	Early detection of hearing loss
GOVT	-	Government
HL	-	Hearing loss
JCIH	-	Joint Committee on Infant Hearing
NGO	-	Non–Government Organisations
NSS	-	National Sample Survey
NDCS	-	National Deaf Children's Society
NIDCD	-	The National Institute on Deafness and Communication Disorders
NSSO	-	National Sample Survey Organisation
PWD	-	Persons with Disabilities
RCI	-	Rehabilitation Council of India
SEN	-	Special Educational Needs
SSA	-	Sarva Shiksha Abhiyan
UN	-	United Nation
UNCRPD	-	United Nations Convention on the Rights of Persons with Disabilities
VOI	-	Voice over internet

Chapter 1

Introduction

Hearing is critical for development of speech, language and learning. One of the most amazing things that a child learns in their lifetime is a language. A hearing impairment greatly affects a person's life and those living with them. The earlier the hearing loss occurs in a child's life, the more serious the effect on their development. Similarly, the earlier the hearing loss is identified and intervention begun, the better the possibilities of rehabilitation. Several researchers have found that the early detection of hearing loss coupled with appropriate intervention is essential for the child's development (Jackson et al., 2010; Kumar and Mohapatra, 2011). For these reasons, many states and countries are undertaking aggressive efforts to screen all newborns before they are discharged from hospital (Olusanya, 2001).

However, in rural areas such as Hazaribag where a large number of children are born at home, or small nursing homes, they do not have access to hearing screening. In addition, hearing loss is a hidden disability, which uninformed parents find difficult to detect during the early stages of their child's life. Even the recent research in Jharkhand presents that it is often not identified until a child is 3 years of age (Vaani, 2012). The deaf babies timely intervention seems to be rather difficult as there are no early intervention centres in many of these areas. The poor awareness of disability amongst the families and the community is common and the delay in acquisition of speech and language is a matter of dismay and shock to the family. Many studies in India on etiology and prevalence show that due to a poor economic background, the rural population has been more affected than the urban population (Verhaert et al., 2008; Marchbank, 2011; RamaDevi and Naushad, 2004). Due to poor nutrition and lack of parental care might lead to develop infections of the ear.

The delay in detection and intervention affects communication and interaction between the hearing and non-hearing. This affects the majority of CWHL who could achieve remarkable outcomes, but are left frustrated, unsatisfied and become a burden to their family and society (Subirendra, 1997). Therefore, the early identification and effective management of hearing loss is vital, as it alleviates the negative impact on poor educational achievements, socio-psychological development and vocational success of children with hearing loss (CWHL). (Jackson et al., 2010; Finitzo et al., 1998).

1.1 Aims of the research

Over the last ten years of my experience with deaf children in the rural area of Jharkhand in India, highlights the above challenges which need to be considered. Firstly, the impact of

delay identification of deafness and lack of subsequent intervention. Secondly, the majority of children with disabilities who live in rural areas do not benefit from services offered to them by the government. These are concentrated mostly in the big cities or those close to district headquarters. Thirdly, most of their families do not have adequate information about their child's particular disability and provisions.

Therefore, the main aims of this research project were:

1. To sensitise and empower rural families in gaining support for CWHL and access to their rights.
2. To recognise the barriers to early detection and exploring ways to overcome them.
3. To reach the unreachable (CWHL) and to create positive attitudes among community members towards People with Disabilities (PWD).

1.2 Research questions

It is a great concern as there is a lack of access to services offered by the Government (Govt) and Non-Government Organisations (NGO). Consequently, taking this into consideration, the research questions that I seek to answer are:

1. What are the ways of giving information to the families about the provisions for disabled children?
2. How can the use of drama encourage the earlier detection of hearing loss in rural areas? And what are barriers of early identification and intervention?
3. How can I reach the unreachable (i.e. deaf children in remote areas) and include them in the mainstream?

To achieve the aims and answer the above challenging questions in depth, I carried out a research study through a questionnaire-based survey, drama presentation and Skype interviews. The expert consultation approach was adopted using a multidisciplinary team to carry out this research in three districts of Jharkhand as directed by me. The drama was the key device in fulfilling the thesis's aims.

1.3 Purpose of research

The purpose of this research was to gain a deeper understanding and wider knowledge in the issues and concerns related to deafness and the quality of education given to CWHL. As head-teacher of the school for deaf in Hazaribag, I am inspired by its mission and vision to be a ray of hope or an agent of transformation in some way to the underprivileged section of our society through this research study and its follow up. This research is to support and enhance the PWD, specifically CWHL to participate as equal members of their families, communities and societies. Thus, I intend to encourage earlier detection of hearing loss which will have an impact on their quality of education, inclusion in society and access to jobs so that they become an integral part of human society.

To live with dignity, value and self-esteem is the right of every person including those with disabilities. As noticed, these rights are not accessible to a deaf girl in many parts of India. She is ill-treated, uneducated, abandoned, segregated and left on street. This reality provoked me to write and present a drama to highlight social issues specifically regarding deafness. The use of drama aimed at briefing and exploring ways to sensitise the villagers of Hazaribag District and raising an awareness of early detection of hearing loss. The main theme of the drama was “a right to dignity, value and self-esteem” and its sub-themes were gender issues in disability, undervaluing a girl with hearing loss and denying her access to education. The report from the interviews indicated it had a great impact on villagers.

1.4 Brief overview of the context:

India is a country of diversity with a multicultural, multi religion and multilingual society. It has been and continues to be a predominantly rural country, with almost 75% of its population living in villages. Jharkhand, the 28th state of the Indian Union, was brought into existence by the Bihar Reorganisation Act in 2000. It is still one of the least developed states of eastern India. Table 1 indicates the total population of India and Jharkhand with a disability (See table 1.1). Jharkhand has 32 tribal groups, and although Hindi is the State Language, the people speak a number of languages. Hazaribag is one of 24 districts of Jharkhand.

Table 1.1 Total Population (census, 2011) PWD and PWHL population (census, 2001)

India/ State	Total Population(2011)	Disability	Total(2001)	Rural	Urban
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India	1,210,193,422	PWD	21906769	16388382	5518387
		PWHL	1261722	946291	315431
Jharkhand	32,96,6238	PWD	448377	348928	99449
		PWHL	28233	23552	4681

The Hazaribah, Kodarma and Ramagdh districts of Jharkhand (as seen on the map) were chosen for this research study, mainly because most of the children with hearing loss (CWHL) are from these remote areas and it houses the special school I work at.

Figure-1. Map of India-Jharkhand-Hazaribag.



Most of the CWHL in these areas seem to be doubly disadvantaged in regard to receipt of services. They are being deprived and their rights violated or neglected in almost all areas of their lives. This includes medical, educational and transport facilities, community and social amenities. Most of the members in the families are illiterate, so they are neither aware of provisions for their disabled children nor do they try to get the information. Consequently they remain in their limited world, which affects the development of their disabled children.

At this point I will consider the literature that explains more on the impact of early detection and intervention of CWHL and other issues related to my inquiry. The following chapter on the review of literature covers these concerns.

Chapter 2 Literature review

Introduction

Early detection of hearing loss (EDHL) and the appropriate early intervention is essential to speech, language, and cognitive development. These abilities are the foundation for academic skills acquired later (Finitzo et al,1998). The earlier CWHL start getting access to services, the more likely they are to reach their full potential. The majority of the people in rural areas are neither aware of the importance of EDHL nor the facilities available to them. This chapter attempts to discuss the issues and concerns raised in the research through reviews of literature in three parts. The first section focuses on the significance of EDHL, its impeding factors and the benefits of hearing screening. The second part will highlight the impact of deafness on families using a deaf child in Jharkhand to provide a context for this section, and explores the role of parents and professionals. The emphasis on support services, the lack of its access in Jharkhand, awareness of where to get information, societal attitudes and the use of drama as an influential device is analysed further in the last section of this chapter.

2.1 Significance of the early detection of hearing loss.

The early years of life are a very significant time for a child's physical, emotional, intellectual and social development. The first few years are especially important and critical, this is when normal children rapidly acquire language. Several researchers have also proved that the earlier the hearing loss is identified and they begin early acoustic stimulation of the neural system, the better the language outcomes, academic progress, and occupational performance are (Verhaert et al. 2008; Marchbank,2011;). Their research indicates that the identification before 6 months of age followed by proper intervention results in essentially normal language at age 3, in contrast to late identification at 2 to 4 years of age, which results in delays in language acquisition in children. NDCS (2000) also place emphasis on identification of hearing loss by six months of age, followed by appropriate intervention. This seems to be the most effective strategy for the normal development of language in deaf infants and toddlers. It also lessens the impact of deafness on the child, family and society.

Moreover, the success of the inclusive school depends considerably on early identification, assessment and intervention. Therefore, early detection and intervention are essential to improve progress and shape the PWHL's future development. Recognising a child's difficulty as early as possible, making a prompt intervention to support the child and family is believed to be critical (DfES, 2001), which in turn prevents, reduces or limits the problems. Early intervention in the early years is very much at the forefront of current policy and practice in many countries including England (DfES, 2004, 2006; DfE, 2010; UNESCO, 2010). In

contrast, the hearing loss that remains undetected, even during the first year of life after birth, can have a great impact on language and educational development.

The considerable delay in identification and intervention of hearing loss is a matter of great concern as its consequences are serious. The majority of the CWHL who seem to be a burden to society due to their communication handicap can achieve remarkable outcomes with early identification and early intervention (Ramadevi and Naushad, 2004). Earlier identification of deafness, when combined with effective service provision in the pre-school years, will dramatically improve the chances of successful inclusion of deaf children into mainstream schools and into society (Ohl et al., 2009). In addition, the early identification enables the families to take very early action on behalf of their child and to intervene before language and communication deficit has become established. Thus, early identification and intervention is vital for the effective management of hearing loss in children; as it alleviates the negative impact of hearing loss on speech, language, and auditory development (Rout et al., 2010; Marchbank, 2011). The purpose of an early intervention program is for families and children to receive the necessary instruction for the children to develop appropriate communication and school readiness skills (Marschark, 2002; Webster, 1986).

The government of India has taken certain proactive steps for early identification of hearing loss in children. The enactment of Persons with Disabilities Act is one of these steps (PWD Act, 2004). However, this has failed to be implemented in all the parts of India. Sadly, the identification and aural rehabilitation is mostly initiated by the parents hence it gets significantly delayed (Rout et al., 2010). The JCIH, 2007 recommended that the identification of hearing loss should take place by at least 3 months and intervention should begin by 6 months. The JCIH (2007) criteria for identification should be implemented in all the deprived parts of India. The degree of hearing loss often determines the impact it will have on the child throughout life. However, with early identification and treatment, the impact can be lessened.

2.1.1. Impeding factors of early identification and intervention of HL in rural areas, India.

The National Institute on Deafness and Other Communication Disorders (NIDCD) consider that unlike other disabilities, hearing loss is invisible, the most prevalent, least recognised and least understood sensory deficit. As supported by Rout, the major impeding factors of early identification of hearing loss (EIHL) could be the poor awareness of handicap among the families and the community, poverty, lack of information, scarcity of trained professionals, illiteracy, lack of infrastructure and underutilisation of the media for social issues (2008).

Factors like child nurturing practices, ignorance about the importance of intact hearing sensitivity and critical age for speech development and lack of aural rehabilitation services contribute to the delay in identification of HL (Meyer et al.2012; Vaani, 2012).

In addition, the barriers to timely identification and intervention of hearing impairment could be gender bias, inadequate referrals by professionals, lack of testing facilities and an inability to access services due to the poor socio-economic status of the family. It becomes vital to identify the impeding factors of EIHL specifically in an Indian context for future planning of rehabilitation (Sirur and Rangasayee, 2011; Sukumaran, 2011).

The other important factors that influence the identification, identifying such areas as the attitudes, perceptions and views of local people on disability, its type and definitions, social dynamics, particularly those of gender and age, and the stigma of that disability (Hadjikakou et al.,2010). India being multi-religious and multi-cultural has varied approaches towards the diagnoses of HL. The lack of access to resources or assets like land, wealth, literacy, longevity, voice and credit affect a family's day to day life. In addition, children with poor nutrition, sanitation, and health facilities are very prone to develop infections of the ear (Rama Devi and Naushad,2004). Apart from this, Vaani's research indicates that most of the facilities available are based in urban areas creating a rural/urban imbalance (2012).

Rout (2008) believe that alleviating the above factors will help to reduce delays in identification and enables the access of universal newborn hearing screening programs at a national level throughout the country. Most of the studies in India indicate a higher prevalence and incidence of hearing impairment in the rural population compared to the urban (Ramadevi and Naushad,2004; Sukumaran,2011;Vanni,2012).

In this present time when the West is strongly advocating and following UNHS, a study like this in India will enable evidence based action. The time at which the age of the hearing loss detection takes place in an Indian context needs to be studied in detail.

2.1.2 Benefits of Hearing screening

Realising the importance of early identification of hearing loss, many developed and developing countries have legally regulated Universal Newborn Hearing Screening (UNHS). In recent years, medical literature focuses on the study of the different existing screening

procedures to detect hearing impairment in infants and young children (JCIH, 2007; Ramadevi and Naushad,2004). The UNHS has become standard practice offering paediatric audiology services to meet the individual's needs and provide the best support to all deaf children and their parents . The hearing screening test is offered to babies within the first few weeks of life which enables hearing loss to be identified early. The research by Young and Tattersall (2007) indicates that permanent childhood hearing loss is quite a common disorder with prevalence approximate from one to three in 1000 children. This is a lifelong condition affecting the individual as well as the community. Therefore, many developed and developing countries focus on screening for preventable causes of disability (Young and Tattersall, 2007; JCIH, 2007).

The newborn hearing screening Programme in England is recognised as a world leader in screening, which is involved with the babies and their families from the initial screening through treatment to early intervention and support. It enables the earlier clinical diagnosis of deafness and earlier recommendation for auditory stimulation (Verhaert et al.,2008). It therefore has the potential to significantly reduce the long term costs of providing support services.

Several studies also prove that UNHS lessens the maternal anxiety and negative impact of mother-infant relationships (Herrero and Juan,2006; Verhaert et al.,2008; Ohl et al. 2009). Its ultimate goal is to identify children with hearing loss at the earliest possible age so they can be provided with appropriate early intervention and education. This in turn will allow children to benefit from hearing in their everyday lives. It has been demonstrated that early intervention in hearing-impaired children identified with UNHSs is beneficial in managing verbal or the behavioural skills of CWHL.

There are two different types of screening test used to detect the HL. The auditory brainstem response (ABR) evaluation measures the brainstem's response to sound. It tests the integrity of the hearing system from the ear to the brainstem. The otoacoustic emission (OAE) test is an initial screen of hearing which measures an acoustic response produced by the inner ear (cochlea) (Herrero and Juan,2006; Rama Devi and Naushad,2004)

The NDCS (2001) and JCIH (2007) have recommended that hearing screening programmes should be implemented at the earliest time in all places including rural areas and its support services should be accessible for all deaf babies. However, in the absence of UNHS in rural areas in India, the JCIH (2007) principles for identification within 3 months may seem very difficult to achieve in the near future. The neonatal or postnatal medical care seldom includes

any procedure for the evaluation of hearing abilities. The lack of professionals and equipment only adds to the adversity of the condition (Vaani,2012).

Alleviating the factors will help to reduce the delay to an extent in a developing country like India where universal newborn hearing screening programs are yet to begin at a national level (Rout, 2010). In this regard the identification of at risk factors will enable the early detection.

2.1.3 Identification of risk factors in enabling early hearing detection and intervention (EHDI)

Some of the contributing factors which could help to detect hearing loss early are as follows. Parental diseases, familial hearing disorders, exposure to X-rays during pregnancy, intrauterine infections caused by viruses during the first five months of pregnancy (for example rubella, mumps or cytomegaly), premature delivery, perinatal asphyxia, low birth weight, postnatal jaundice, neonatal seizures and rubella, these were the significant predictors of hearing impairment (JCIH , 2008). These risk factors may help in containing the problems.

Therefore, all the infants with a history of these predictive factors should be periodically screened for hearing impairment. JCIH (2007) also approves that the babies with or without risk factors requiring neonatal intensive care for greater than 5 days will require hearing screening. The goal of EHDI is to maximize linguistic and communicative competence and literacy development for CWHL. Such delays may result in lower educational and employment levels in adulthood.

2.2 A deaf child born in a hearing family

Family is the primary factor and a key socialising agency in the life of an individual. It is said to be the first school, where learning takes place under the care and guidance of parents. Parents are the pillars of this unit. The importance of a family's well-being in the lives and development of young children is widely acknowledged (Spencer et al.,2000;, DfES,2003; Jackson et al.2010). The birth of a child is a momentous and joyful event in the lives of most of families.

However, Hadjikakou et al.,(2003) identified that diagnoses of a deaf child in a hearing family, has a drastic impact on family life. It affects the family system, changes the whole atmosphere of the family in terms of the adjustment with other family members, developing a network and it seems to be a burden in terms of handling the audiological and educational needs of their child with hearing loss. Moreover, Densham, (1995) points out that “parents

go through a process of grieving the loss of the ‘perfect’ child in order to accept a ‘new’ child with a disability...” (p.3). For many parents, the news of a child’s deafness; can be perceived as the end of the world. They are unprepared to face the new responsibilities and their fears of the future become a challenge. Therefore, these families need to be strengthened and empowered.

2.2.1 Impact of deafness on family

The reaction of the family towards the diagnoses of hearing loss will differ from family to family. The responses of the parents to the birth of a deaf child are likely to depend on whether the parents are hearing or deaf. The unexpected presence of a deaf child has a drastic impact on a hearing family as it becomes a family with a disabled child (Gregory et al.,1998; Densham 1995). It affects the family system and the dynamics with other family members, developing a network of family relationships, and therefore the family's well-being is vital because the family's influence is important in the lives and development of young children. As Katherine et al., state that since the deaf child is a component of the family system, the deafness belongs not just to the child but to the entire family (2011).

Helen Keller, the most famous deaf-blind, said in her autobiography, ‘Blindness cuts people off from things, deafness cuts people off from other people’ (Gregory, 1995a:20). Consequently, deafness separates the deaf person from the hearing world and so the communication barrier leads to segregation and loneliness. According to Spencer et al.(2000) the deafness affects the development of reciprocal interactions between hearing mothers and their deaf infant from the early stage(2000). The deaf child is at increased risk of developing insecure attachments due to the mother’s negative reactions to the diagnoses of deafness and subsequent poor communication. At this point of emotional stress and trauma the role of the professional is very significant and this will be discussed in the coming paragraph.

2.2.2 Role of parents

Parents and family have certain responsibilities such as to generate income, protect, nurture, love, educate and maintain its members and home. Ingber et al.(2009), state that when a child is disabled, these responsibilities become more crucial in regard to the expense, the time, the energy needed for care, safety and the wellbeing. Thus, every ordinary task becomes more difficult and more stressful. As mentioned earlier HL affects not only the child but all those connected with them. However NIDCD (2002) suggests ways to make life easier for everyone. Parents need to understand the full nature and extent of a child’s hearing loss and

lovingly accept the child with it. Warm and authoritative parenting is critical to children's social, emotional and intellectual development. Creating a stimulating learning environment at home, such as interacting with the child by holding, facing, smiling at it and responding to its needs. Parents are a child's first and natural teachers and all children almost always learn language from their parents. Goss, 2010 states that parent's strategies for coping with CWHL can greatly influence their overall development. It is also suggested that parents should not compare the performance of their disabled child with other siblings.

The Department of education specify that parents are the service provider and active supporters in implementing professional advice and carrying out the same at home (DfE, 2003). Today's therapists and educators have accepted the potential of parents. Each child is unique with different abilities, strengths and skills which are to be recognised and strengthened. Moreover parents are the most important part in raising their child. Raymond and Karen (1984) point out that parents and professionals are the most influential in relation to the emotional, educational and personal development of children. It has been recognised that family has a value in developing and implementing programs for the disabled member (Margaret, 2011). They have much to offer the professionals by documenting their day-to-day experiences living with the family member with the disability. The following paragraph discusses the role of professionals.

2.2.3 Role of Professionals

The professionals have a great responsibility to alleviate the pain, anxiety, depression and grief, which affects both the deaf and their family. Densham (1995) claims a sense of vulnerability and hopelessness is felt by parents, which could be well handled by professionals. The approaches and attitudes of professionals could have a great influence on parents, who in turn influence their child, and in turn those children become adults, influencing their generation. So it is a dynamic process initiated by the professional. As pointed out by Hadjidakou et al.(2010) the intuitive, thoughtful and caring professionals can have a profound and positive effect on this whole process. Certainly, they are a channel of grace in promoting positive feelings and creating a pleasant environment to cope with the consequences of deafness.

The professionals need to provide guidance, advice and relevant information regarding medical and technical aspects of the HL, different options for communication and education of CWHL (Eleweke et al.,2008; Margaret, 2011). These should be carried out diligently reducing the parents' distress. The majority of people from rural areas and those without

experience of HL might be ignorant about the available information. Professionals could help them by providing information such as literature, videos and relevant websites, erasing their doubts. Eleweke et al. (2008) recommend the professionals to respond in an unbiased manner.

2.3 Government support services for PWD in India

The vast majority of people in India suffer from poverty, disabilities, illiteracy, exploitation, poor health and sanitation. There are many schemes at national, state, and district level for the welfare of the community and the rehabilitation of PWD. The government of India has been advocating and promoting rehabilitation services in disadvantaged communities both among the urban poor populations as well as in rural areas (Sirura and Rangasayeeb, 2011; Singal, 2010). The inclusive education in regular schools is being promoted by policy which is taken care of by Sarva Shiksha Abhiyan (SSA). Community based multi-purpose workers are trained to identify children with special needs, refer them to SSA schools and to work with their families. NGOs have been recognised by the government as key partners in implementing this programme.

The constitution of India ensures equality, freedom, justice and dignity of for all individuals and implicitly mandates an inclusive society for all including persons with disabilities. The policies of the Government of India towards the welfare of persons with disabilities have been reflected in the enactments, schemes and through institutions established for various relevant activities

2.3.1 National policy frameworks

The Indian government has introduced various Acts in support of children and adults with disabilities. These include, Persons with Disabilities (PWD) for equal opportunities, protection and full participation (Act, 1995), National Trust Act of 1999, and more recently, the Right to Free and Compulsory Education Act, 2009 aims at ensuring that every child in India in the age group of 6-14 has the right to go to school, in fact must go to school, regardless of gender, caste, religion or ability.

Moreover, the UN convention on the Rights of the Persons with Disabilities (UNCRPD,2006) exhorts that deaf children have the same human rights as all other children. India being as its signatory is obliged to protect the rights of children with disabilities to develop their full capabilities. But, in practice those rights are violated or neglected in almost all areas of their lives, particularly the PWD in remote places. The recent research of Vaani,2011 in the eastern part of India , confirms my experience that PWDs living in remote and rural areas experience

double disadvantage in regard to receipt of services as compared with their urban counterparts. They lack adequate diagnosis, identification and treatment services, education, vocational training and employment opportunities.

According to research by Singal,(2006b) the PWD especially those who are poor, suffer from profound social exclusion, their rights are denied which in turn affects their participation in social, educational, cultural, and political areas of life. They rarely get opportunities to share their perspectives with the community, remaining hidden and excluded from the mainstream activities of society. There is very little understanding of their abilities, skills, and potentials.

2.3.2 Lack of implementation of provision in Jharkhand in the field of deafness

The problems of a developing country differ from those of a developed one. Jharkhand as mentioned earlier is the least developed state of a developing country and the majority of the disabled reside in rural areas. The funding for prevention, early detection, and rehabilitative programs is severely limited. The accessibility, availability, and utilisation of rehabilitation services and its cost-effectiveness are the major issues to be considered. The delays in diagnosis are common, and social attitudes, local customs, and cultural bias are contributing factors (Rout, 2008; Kumar and Mohapatra, 2010).

The recent research in the eastern part of India indicates that the state of Jharkhand is faced with limited medical services, illiteracy, poverty, old customs and beliefs, and poor finances. The prevention and the intervention of deafness are being neglected and insufficient numbers of professionals and training institutions offering related courses add to it (Vaani,2011). According to NDCS,2006, in India, newborn screening is yet to catch the attention of the Health Ministry.

2.2.3 Information about support services

The literature indicates that parents require very timely, clear and unbiased information to cope positively and face the challenges of raising their young children with hearing loss. (Eleweke et al.,2008) It is necessary for parents to know about hearing loss, its consequences, specialised support, and all the things their children will require. The literature suggests that families who receive information about emotional and other support services, are best able to deal with the children (Marschark et al, 2011; Eleweke et al.,2008) However, it is essential to make sure that this information reaches every family, especially in rural areas who are deprived of it.

In the Family Pack, (DfES,2004) it gives details and necessary information regarding deafness, support, and the services that are available for parents and their child, and where and how to get them, the people who will come in to contact with the family, and practical tips to help their child. This information is always relevant detailing health, education and social services for the family. However its implementation in villages with illiterate parents especially in rural areas could be problematic, as they may not be able to understand it. It could be suggested that along with the text, pictures and video could be included.

2.2.4 Females with disabilities in India

It has been observed that women and girls with disabilities in general face significantly more difficulties in both public and private spheres such as health, education, vocational training, employment and housing. They experience double discrimination which places them at higher risk of gender-based violence, sexual abuse, neglect, maltreatment and exploitation. They experience inequality and tend to receive less care than disabled boys. Some are unwanted, abandoned, rejected, and are left on the streets to be sheltered in the orphanages. The majority of the inhabitants at the orphanages are females with disabilities. Some are even more likely to die or be killed (Singal,2006a).

There is a lot of gender disparity, many of them are deprived of education and are kept in isolation. Disabled women are less likely to marry than disabled men, and women who become disabled are often divorced or left by their husbands. They are seen as being incapable of bearing children or of looking after them, so their children are often put into the care of grandparents. The same study found that six per cent of physically disabled women and eight per cent of mentally challenged women had been forcibly sterilised (Rout et al,2008) and are also particularly vulnerable to abuse and exploitation. A study in Orissa found that 100 per cent of the disabled women surveyed were beaten at home, and 25 per cent of mentally challenged women had been raped (Olusanya,2011)

The ill-treatment, devaluing, exploitation, degradation and humiliation of females with a disability were my major concern. This motivated me to write a drama and present it to highlight these issues in the community of Hazaribag. The current study supports the existing studies regarding the existing barriers towards early identification and intervention. The study is also proceeds further towards improvement tough community involvement. The next chapter brings in light the methods involved for the awareness strategy and the overall impact.

Chapter- 3 Methodology

Introduction:

This study attempts to investigate the views, perceptions, knowledge and attitudes of the people from the rural areas of the Hazaribag district in Jharkhand, India, with regard to disability, particularly deafness. The research involves multiple methods in order to answer the research questions. This research was carried out through a questionnaire-based survey and a drama performance (Peter,2009). In setting up a research itinerary on ‘Exploring ways to encourage earlier detection of hearing loss in the families of rural areas in Jharkhand’,an

expert consultation approach is used through members of a multidisciplinary team (Narayanaswamy, 2009). The research methods used for this study in this chapter includes research design, context of research procedure, survey, sample design and instruments. As noted by Cohen et al. (2007), the term 'research method' refers to the range of approaches that have been employed for gathering data.

3.1 Research design

The research was carried out by a multidisciplinary team on my behalf through questionnaires, the use of drama, Skype interviews and email responses. The fact that I was not able to go back to my country to do this research directly was due to expense, time and accessibility. Moreover, as head of the School for deaf school in Hazaribag, I have a good rapport with the influential and powerful heads from different organisations, institutions, schools, and other areas in the health and social field. I was sure they would complete this project responsibly for my sake as well as for the development of the rural areas. In addition, being effective leaders of those areas, their involvement will have greater impact on the society at large. Thus, it was arranged in such a way that the aims of research were to be fulfilled, ensuring reliability.

The drama was enacted in Hazaribag to encourage earlier identification of hearing loss and entry into the school. Further assessment was done to find out its impact on local audiences through Skype interviews, emails and telephone responses.

3.2 Research procedure

According to Robson, the nature of any research determines the methodology (2011). So in this research, the expert consultation approach was followed in which four multidisciplinary team members (two special educators, a social worker and a health worker) were selected to carry out this research on my behalf. Their selection was on the basis of their experiences, vast knowledge in the specialised field, accessibility, influence and their willingness to take part in this research. In order to ensure the reliability I have purposely chosen this particular team. They were informed about the study through emails and phone calls and had responded positively. Each one was entrusted with a particular task such as; the social worker was the co-ordinator who would facilitate the overall research project as directed by me. The details

of the research plan were sent to him by email asking him to conduct a short meeting with the other three co-members to discuss the whole process. The research outline plan contained a tentative timetable with each one's task, for example who, what, when and how will this research be carried out (see appendix- 1).

The health worker and the social worker were responsible for the survey in Ramagdh District within 40 days. The assistant headteacher of St. Michael's deaf school and one of her staff were responsible for the drama presentation. The communication was in their local language and within their own context. I was in contact with them throughout, explaining and discussing the demands of the research and to ensure that the process was followed. Reminders were also sent to them through emails, Skype and phone calls. The four heads of mainstream high schools, a health administrator and an assistant headteacher of a deaf school were involved in this research study for the questionnaire-based survey. The manual survey was paper-based and was distributed to above selected persons. This was to be conducted in the five villages of Hazaribag, Ramghad, and Koderma Districts.

3. 3. Instruments

3.3.1 Questionnaire-based survey

The purpose of choosing the questionnaire-based survey was that it provided a simple, straightforward approach to the findings and gave general information (Robson,2011) which will fulfil the aims of my research. Though it has certain limitations such as, data could be affected due to the respondent's knowledge, experience, motivation or they may not consider its importance as many of them would be uneducated. Since it is done through the core team who have a respected place in those areas, I am sure this research must have been taken more earnestly, with the members enthusing about the motivations and helping them in reading and writing the questions sincerely.

Hall and Hall (1996) state that the questionnaire is a tried and tested method of generating information that is widely recognised as a standard method of collecting information. It helps the researcher to differentiate between the opinions of participants from different backgrounds, genders or experience (Cohen and Manion,1994). Therefore, a questionnaire-based survey was found appropriate which facilitated greater participation of the respondents.

3.3.2 Sample population

Five villages from three districts (Kodrema, Ramgadh, and Hazaribag) were investigated. Thomas, states that the quality of a piece of research mainly depends on the appropriateness of methodology and instrumentation (2009). The total sample size was 70 people. This was open to all with particular focus on the age group of 19 - 16 and above. The team members were clearly informed about the plan regarding choosing the sample by mail. Participants were recruited from the above mentioned districts and their selection was based on different background, gender and age groups (See appendix –2).

The survey had twenty questions divided into two sections. The first section was the profile (factual information), containing socio-demographic characteristics of the respondents such as age, gender, occupation, economic status, village, education, marital status, language and religion. The second section consists of opinion or judgement to gather information on the perceptions, knowledge, attitudes, identification and intervention on disability in general, and then specifically on deafness. The questionnaire was initially prepared in English which was then translated in Hindi, the common language of the area (Appendix- 3). The native Hindi speaker was asked for its translation into Hindi in order to ensure the validity of both versions. Since, most of the people in these areas have low levels of literacy and are not familiar with this type of survey, it was necessary to begin with close-ended questions as recommended by Cohen et al.(2007) as they are fast and easy to complete. These were followed by two open-ended questions where they were asked to express their views on how the PWHL could be more equal to their hearing peers or if they have any suggestions.

The set of both English and Hindi questions were sent to the team members by email for piloting. The co-coordinator was requested to do the piloting with anyone of that area in order to ensure its validity, clarity, reliability and practicability (Robson,2011). In addition, the aim of piloting was to check the items, instruction and layout of the questions and to gain feedback on the type of questions and its format.

The completed pilot questionnaire was returned through scanned email which was found to be the most appropriate way to share this information. As the research was to be carried out in five villages of three districts of Jharkhand, the schools were found to be the most effective and practical way of getting data from a good cross-section of the populations such as parents, staff, co-workers and students. In order to get a generalised outcome of results, the heads of four mainstream high schools and a special school in Hazaribag District were requested to collaborate in this survey and they responded positively. The assistant head-teacher of St. Michael's deaf School was asked to make photocopies of seventy sets of Hindi questionnaire

forms and to purchase a small gift for each respondent. These were to be distributed to the heads of the four mainstream schools, health administrator and the other three team members. The email request was sent to each of them, asking to collaborate in this research and the detail information and explanation was given in it (See appendix- 2).

The coordinator was asked to examine whether my instructions were followed and made sure that each respondent was given a small gift as a token of gratitude for their participation in this study. Being aware of the heavy schedules of the above appointed heads, they were given the choice to entrust the completion of the survey to any one of their responsible staff. Within the 40 days, the coordinator was asked to collect all the completed questionnaires from schools and villages which were sent to me within an allotted time by post. They also made sure that they kept a photocopy of filled in forms, in case of any problems with the post.

3.4 Drama Presentation

Another effective device used for this research was drama (Peter, 2009). Most of the people from the rural areas rarely have the chance of coming together for learning, fun, meetings or social gatherings. Taking this into consideration, the use of drama could become a powerful means of creating an awareness of topics, gaining knowledge and adding interest and enthusiasm for the people in the villages. The techniques of drama involve a wide range of activities which make the audience active and passionate. The thoughts, emotions, words and expressions help to communicate intended messages, meanings and are able to present a form of reality (Cattanach, 1992) together with an element of fun and relaxation. It is an effective and efficient way of bringing delicate issues to the surface.

This study aims to use drama to develop a positive imagination, perception, attitudes and views regarding deafness, helping to promote its earlier detection and sensitising the rights of the deaf girls to an education. In addition, ‘The power of drama is its double edge’ - doing and watching at the same time (Peter, 2009.p.6). Thus, it builds confidence in the actors and allows them to make it their own experience. So the overall objectives of drama were to gather the community, sensitise the social issues on deafness, exchange experiences, and to identify potentialities, constraints and new skills towards development.

3.4.1 Procedures of drama:

Drama has four steps consisting of working on a drama script, drama rehearsal, drama presentation, and its evaluation by skype interview. Firstly, the drama was written in Hindi the local language of the people which was later translated into English. (See appendix- 5) The

piece ultimately gave the message about the importance of early detection of hearing loss and awareness of the rights of a deaf girl. The drama script was sent to those in charges of drama presentation (special school teachers) who were asked to select appropriate candidates for its performance and involve some of the villagers. All the relevant instructions and directions were communicated to them orally and in writing (phone, skype and email). A short meeting was conducted by the assistant head-teacher regarding the organisation of the drama, in which they selected actors for the performance. I was told that almost all of them (except one) were inexperienced actors and needed lots of practice to get into the accents, emotions, and rhythm/intonations of the piece. Information about the performance was published in different places within the villages on posters fifteen days before the production. It was also announced in the local church and notices were given to the parents of deaf children at the school.

3.4.2 *Sample and drama presentation:*

As reported, seven pre-school deaf pupils, three teachers from the school for the deaf and four villagers were the actors in the drama. The drama practice was held in the school for a week, an hour before the school closes. I was continuously coordinating the team through internet and skype meetings. Around 65 people from nearby villages, a few parents of deaf children and the staff of that school watched the play, and a total of fourteen people took part in the drama. The drama was performed in the special school hall and lasted for 50 minutes. The characters of the drama were a deaf girl aged 5, her parents, a doctor (ENT), the headteacher, a teacher and some deaf children in a classroom set up. The video of the drama was recorded by one of the deaf pupils of the school.

3.4.3 *Summary of the drama:*

A title of drama- A conversion (in Hindi ‘ Parivartan’)

The theme - ‘A right to dignity, value and self-esteem’

Sub-themes - Gender issues in disability, undervaluing a girl with hearing loss and access of her rights to education.

The voice of the deaf girl- Look at my abilities, not my disability

This drama is about a deaf girl who is hated, ill-treated, exploited and abandoned by her father because she is deaf. He considers her useless, a burden and a shame to the family. She does not have her rights- to education, to live and function happily in the world around her and she is being segregated. Conversely her mother accepts her and her disability, making efforts for

identification and intervention. The girl gradually progresses and develops her talents and abilities in sports and playing musical instruments. Her excellent achievements make her family popular in the whole village. This in turn converts her father and his attitudes towards her changes. He gladly accepts her and begs pardon for his mistreatment. She transforms him and finally he is a changed person. In fact this is not a drama, but an actual situation, it is a reality visible in many parts of India, where the children with special educational needs are unwanted, unloved, neglected, undervalued, and only used for begging.

3.5 Interview (Voice over internet)

For the purpose of this study an interview based method was considered to be the most appropriate and powerful way of understanding parental views of deaf children, their comments and reactions to the drama.

3.5.1 *Purpose of interview*

The Skype interview aimed at gaining an insight into the impact it had on them. As Robson (1999) states, the interview is one of the main data collection tools in qualitative research. It is a very good way of accessing people's perceptions and constructions of reality. Therefore I chose the Skype interview method, even though the participants do not have access to computers and the internet. Its main purpose was to have face to face interviews on Skype which might enable the respondent to be more enthusiastic, spontaneous and allow them to speak more as this might attract them or fascinate them. The use of multisensory channels such as verbal, non-verbal, and aural (Cohen et al., 2007), the tone, the facial expression, or hesitation in responding to a question during interview can provide interesting information (Thomas, 2009).

Secondly it was more convenient for recording as well as it didn't cost anything. Moreover, the participants would have the opportunity of using new media which was a new experience for them. As Robson (2007) stated the online interviews can provide great flexibility for the interviewer and participants. The email interviews allow the participants to respond at a time convenient to them negating the need to arrange specific interview times and dates.

However, it is possible that not everyone has used or has access to the internet. Also online interviews might be distracting or any connection problems with the internet may cause the respondents to not be fully engaged with the interviewer.

3.5.2 *Interview arrangement*

The aspects of informed consent, confidentiality and the consequences of interviews as stated by Cohen et al. (2007) were taken into consideration. Four females and two males from different age groups and backgrounds were selected. Among them, two were the parents of deaf children, three had also participated in the questionnaire, and one was the coordinator of the drama. First, I briefed them on the nature and purpose of the interview and arranged the appropriate date, time and venue for the interviews convenient for them. St. Michael's school was felt to be a suitable venue where the internet was accessible. The interviewees were new to Skype as well as the interviewer, who was the head of the school, which might have created a little discomfort for the participants. In Indian culture, there is a huge gap between parents and the professional, which might affect their responses. Being aware of this, they were initially made comfortable with friendly chat, and then gradually introduced to the main topic. I had to be more dynamic and vibrant in encouraging them to speak.

3.5.3 *Topics of interview*

The interviews were semi-structured with a prepared set of questions that were modified appropriately depending on the answers they gave (Robson, 2002; Thomas, 2009). This style of interview was used because it would give more flexibility for the interviewee to expand on their answers which would help in producing richer data. As suggested by Silverman (2001) and Cohen et al (2011) open-ended questions allow the opinions and beliefs to be exposed freely and are often the most effective route towards understanding people's experiences in an authentic way. The questions were asked mainly about the performance of the drama, its significance and its overall impact on them. The interview was in Hindi and they consented to the interview being recorded. The main themes and summary were then transcribed in English to produce data with high reliability (Silverman, 2001).

3.6 Method of data analysis:

As mentioned earlier, this research was of a flexible design with a multi-method approach, where data was collected using two instruments. The questionnaire-based survey and the semi-structured interviews on feedback responses of drama presentation were administrated on Skype and emails.

The information received from different research methods are analysed separately and the discussion chapter combines the results. After gathering all the completed questionnaires from the respondents, the total responses for each item were obtained and tabulated. The data came in all different modes such as responses to questionnaires (words and numbers), audio-video

tapes and emails (words). Therefore this research has a mixture of qualitative analysis for words and quantitative analysis for numbers interpretation. Robson states that ‘analysis is [the] breaking up of something complex into smaller parts and explaining the whole in terms of the properties of and relations between, these parts’ (p. 412, 2011). Preferably, data is summarised and displayed so that the findings can be identified and conclusions drawn.

3.6.1 *Analysis of Survey:*

The manual surveys were coded and entered in Statistical Packages for the Social Sciences (SPSS 19). Each variable item of the question was coded and the values were assigned which gives clear, precise and informative analysis of it. Open-ended responses and feedback were imported on Microsoft Office Word and transcribed in English. The open responses are mainly in the form of feedback and experience (See Appendix-3). The coding of these open responses emerged in 5 categories which are discussed in the following chapter (4). The data analysis was to calculate the frequency and percentage in each category of variables in a descriptive way and then they were cross tabulated.

3.6.2 *Analysis of interview (VOI)*

According to Thoma (2009), an interview method is suitable where a researcher wants to explore the feelings, attitudes, and values of a research participant. Women are more responsive to experts of the same sex, therefore I purposely selected four female and two male interviewers. This way all participants will feel comfortable to disclose their feelings.

The transcription of the recorded interview is summarised in English and only the relevant extract will be transcribed. The analysis will be done on themes emerging from the interviews and the categories of the themes will be discussed. The discussion of the theme will include the results of the survey as well.

3.6.3 *Analysis of the email respondents:*

Some feedback and opinions were communicated by email. These are analysed according to prominent themes such as participant’s willingness for better outcomes, awareness of PWD in these areas, information on support services, and realisation of responsibility towards PWD.

3.7.1 *Ethical issues*

Ethical issues were considered throughout this research project. The participation of the respondents was voluntary. The right to withdraw from research and additional information

were explained in the initial invitation letter and call. The front sheet of the manual survey was an information sheet with a brief request to complete the survey if willing to participate in the study. The survey was completely anonymous and the respondents were just required to complete the forms. The consent to record the interview for transcription was also discussed.

The consent of drama actors were ensured in the initial phase of practicing. No member was forced to become a part of this team and it was ensured that they participate with their own willingness. It was taken in consideration that the PWHL participants were given clear demonstration of the purpose of drama and their involvement in it. A prior consent was also taken from their parents. Throughout the process the coordinating members ensured the safety and emotional well-being of all those participating in the drama.

The interviewers were invited for the talk on skype. Their consent and willingness to participant was well ensured. The confidentiality of the information they provided was also ensured by the researcher. They had all freedom to withdraw at any stage of the interview. The names used in this report cannot identify the real participants.

3.7.2 *Reliability and validity*

The reliability of the questionnaire was ensured by conducting in depth interviews of the drama participants and I found that their responses were similar to the questionnaire results. The data was collected from the respondents who were from diverse socio-economic backgrounds, religions, different languages, gender, age groups, and marital statuses. The respondents were taken from a vast area to encourage reliable research. Further performances of the drama were not possible due to lack of time. I have ensured the validity of the results by using mixed methods such as a questionnaire –based survey and interviews.

3.7.3. *Limitation.*

This research was carried out by the team members under my direction. Its procedures and plan were clearly informed and regularly kept in contact orally and writing (emails, phone and Skype). Even then, my direct involvement was missed with the fifty-eight respondents of the survey and the audience of the drama. The six person's skype interviews and three email respondents were asked the overall reactions and feedback on drama and survey. My own participation and personal observation could have generated more turn out rate of the survey and audience of the drama. However, the overall participation of the team is much appreciated.

Secondly, even though the drama and questionnaire were in line with the topic of research, I was not well equipped with the literature at the time the questionnaire was prepared. It was felt that some very important questions were missed out in the survey such as: the causes and barriers towards identification, availability of screening tests when child was born, place of child's birth (for example hospital, home, nursing home). If this information was procured by the large survey sample then more results could have been confirmed.

Chapter 4

Data presentation and analysis of the research

In this chapter the results are analysed in two main sections. The first section deals with the findings from the questionnaire-based survey. The second looks at the feedback to the drama, synthesising the Skype interviews and emails. These were analysed using both quantitative and qualitative approaches.

4.1 Questionnaire based survey

The research questionnaire discussed in chapter 3 (research methodology and appendix - 2) was distributed to four head teachers of the school, two social workers and a health administrator of Hazaribagh. Fifty-eight replies to the questionnaire were received (83% response) by post within the allotted time.

4.1.1 Demographic

The first part of the questionnaire described socio-demographic characteristics (age, gender, marital status, occupation, education, income and religion) within 10 questions.

Table 4. 1 Cross tabulation – Gender and Marital Status

Gender	Percentage	Marital Status	
		Single	Married
Male	62	52	70
Female	38	47	30
Total No.		58	

The lower participation of female respondents indicates their lack of exposure in the community, which is still true in Indian culture. However, for the voice over the internet (VOI), more women were chosen. The adult age was requested in order to get relevant, accurate and informative data. As seen in Table 2 the majority of the participants were aged between 20-59, which was also the preferred age range for this study. The respondents were from five different villages of Hazaribag, Koderma and Ramgadh as seen in the map (Chapter 1). Geographically a wide area is covered due to the involvement of heads of different schools and the multidisciplinary team. Interestingly, the highest number of respondents were from Hazaribag and Bhurkunda villages each 24%, whereas Bartuwa and Patra were equal with 19%.

Table 4. 2 Cross tabulation age and villages in percentage

Age	%	Bartuw a	Bhurkund a	Hazariba g	Kodarm a	Patr a
Under 19	10	0	7	14	20	17
20 - 29	25	22	21	29	14	8
30 – 39	26	22	50	14	0	17
40 - 49	19	56	7	21	0	17
50 - 59	15	0	14	21	20	25
60 +	5	0	0	0	20	17
Total No.		58				

The employment status in table 4.3 illustrates the highest number of respondents earn a monthly income less than Rs1500-3000. As can be seen only 7% of respondents' monthly income is more than Rs 8000. This illustrates that the majority of the participants were from poor economic backgrounds.

Table 4. 3 Cross tabulation of occupational status and family income in percentage

Current occupation	percent age	Less than Rs. 1500	1500-3000	3000-5000	5000-8000	More than 8000
Farmer	23	20	17	36	0	25
Shopkeeper	4	0	6	0	25	0
Teacher	19	7	17	18	0	75
Student	16	7	22	18	0	0
Tailor	4	0	11	0	0	0
Daily wager	24	47	17	27	25	0
Technical	3	7	0	0	25	0
Total No.	58					

As Singal (2011) states that the low and middle income could be one of the major causes of disabled people having less access to medical treatment and education, and they are in turn socially excluded. In terms of educational qualifications, the majority of them are - educated up to middle school or less than primary, 14% had no educational background and only 10% had graduated. Most of these respondents with a low level of literacy required assistance in filling in the questionnaire. Perhaps, poverty and a low level of literacy could be major reasons for the lack of knowledge and awareness of provisions and support services from the government.

Table 4. 5 Percentage of religious groups

Religion	Percentage
Hindu	48
Sarena	7
Muslim	14
Christian	31
Total No.	58

As could be seen in table-5, nearly half the respondents are from a Hindu background, a good number are Christians with Sarena's being the lowest. As Hindi is a regional and national

language, certainly the majority of them (59%) were Hindi speakers however the rest of the smaller groups (Uraw, Sadhari and Sandhli 24% /10% / 5%) are bilingual in Hindi. Therefore the drama was also conducted in Hindi which could be understood by all.

4.1.2 Nature of disability and its process of identification

The second section of the questionnaire had 13 questions on disability particularly hearing loss. As investigated, nineteen participants have a disabled person in their family, thirty-three have come across a person with a disability (PWD) and two were not sure. Respondents noted that the majority (52%) were disabled males, 28% female and 17% unknown. This could be interpreted that female PWDs are not exposed to society so are not known to many people. According to the sixteen respondents, the age group of PWD is between 11-20 years and approximately half are missing values. There were no respondents below 5 or above 40 years of age (Chart-4.1).

The majority of PWD were PWHL and a physical disability (35% / 28%). Blindness was less common with 3% (Chart-2). With regard to respondents' relations to PWD, 22% of them were the neighbours, 12% for both sons and brothers and 10% was a missing value.

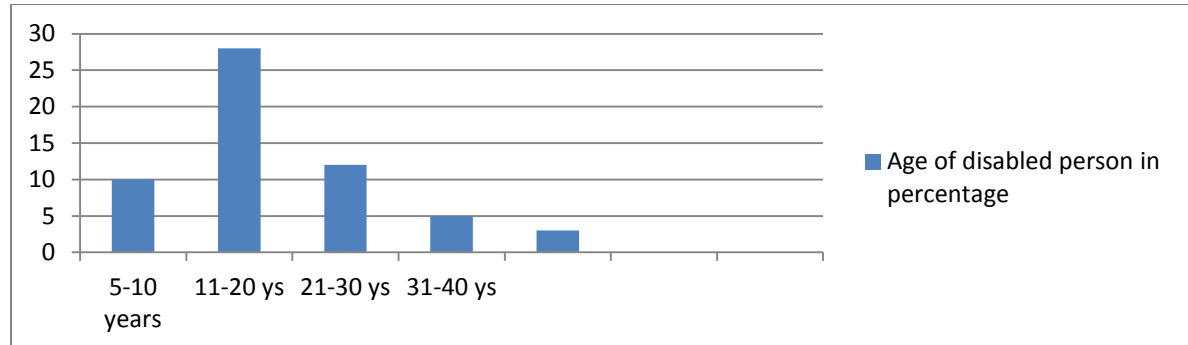
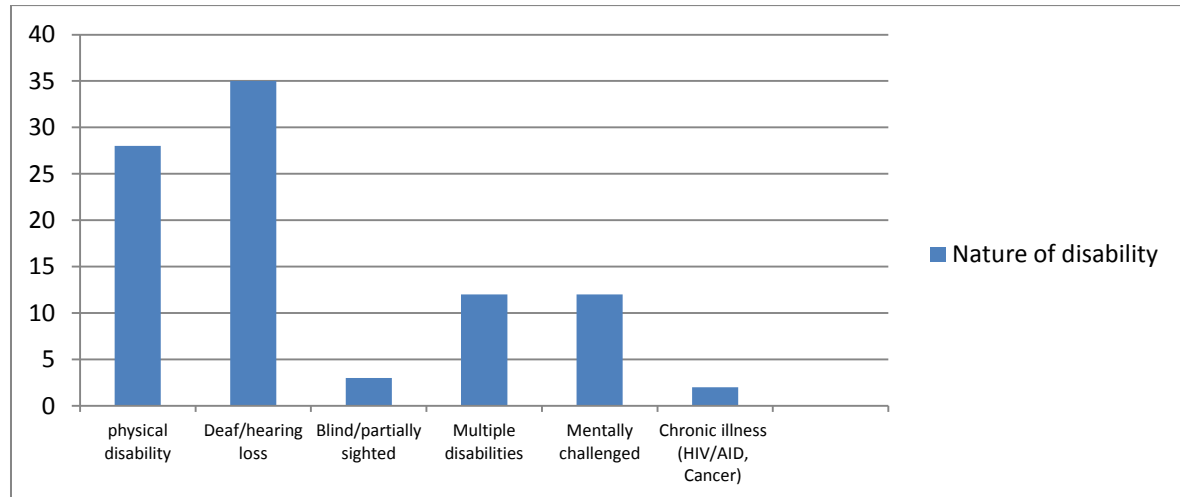


Chart 4.1: Age of PWD

The most popular age-range where the disability was identified was between 3-4 years (23%). This could also be true of people with hearing loss (PWHL) as they were the highest group known to the respondents and the delay in diagnosis is already known. Most probably the screening test is not done in these areas. Those identified with hearing loss between the ages of seven months to one year (21%) could also possibly have a physical disability (which is the second highest group), whose disability is much more visible. Only 6% were found to be identified at the 0-6 month age group. Certainly, this group must have had a very prominent visible disability like blindness or multiple disabilities, which could be identified at an early stage and known to the people in the villages. The disability was identified mostly by family

members (59%) and 21% by doctors which illustrates the poor implementation of screening tests and assessment by the government (See chart 4.2).

Chart 4.2 Nature of disability in percentage



Surprisingly, almost half of the respondents (49%) did not know and 13% were not sure, about access to the government-provided support services for PWD, only 38% were aware of it. This evidence clearly shows that many parents of children with hearing loss do not receive adequate information. Eleweke et al (2008, p.201) state that ‘the failure to provide information about support services to families has adverse consequences’. Therefore, 31% of respondents were dissatisfied and 14% very dissatisfied with the support services being offered to PWD. Only 2% were very satisfied and 35% little satisfied.

The following section was specifically related to hearing loss. The participants who had not come across a person with hearing loss (PWHL) were asked not to answer the next section of questions. Therefore 51 responded to the rest of the questions. The contribution and the involvement of PWHL to both family and society as indicated in chart 4.3. is strongly disagree(31%) and 38% disagreed. This indicates that ordinary people do not acknowledge the role of PWHL, they still consider them submissive or useless and are underestimated. Only 3% of respondents recognised the PWHLs contribution to family life expressing strong agreement and 10% agreed with their contribution to the family (see chart 4.3).

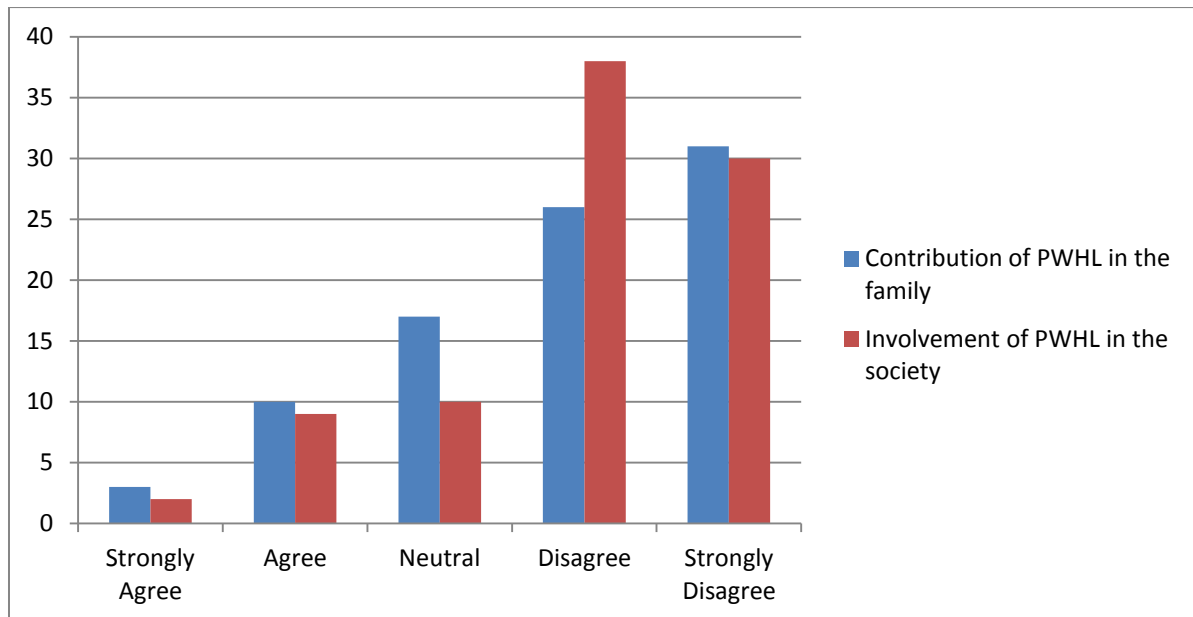


Chart 4.3. Contribution and involvement of PWHL

In India, disabled people are seen as passive victims requiring charitable help (Thomas P.2005). This is clearly seen here; they are considered dependent and their contribution is not given worth.

In terms of their mode of communication, 54% disagreed and 16% strongly disagreed that they do not understand PWHL way of interacting. Just 3% of respondents are able to understand them which show a huge gap between hearing and non-hearing people. Similarly, in regards to PWHL's rapport with peers and fellow villagers, these interactions were also found less than satisfactory. The lack of communication might be leading to misunderstandings between each other.

4.1.3 Information on support services offered by the Government for PWHL

Further information was gathered on specific support services offered to PWHL by governments. For instance, free diagnostic test, hearing aids, disabled scholarship, Swami Vivekananda pension scheme, free vocational training, travel concession and job placement in local industries and trades. In all these, most of the respondents (30%) had mixed opinions (23% positive and 19% not sure) and very few were satisfied with the support services. (See chart 4.4).

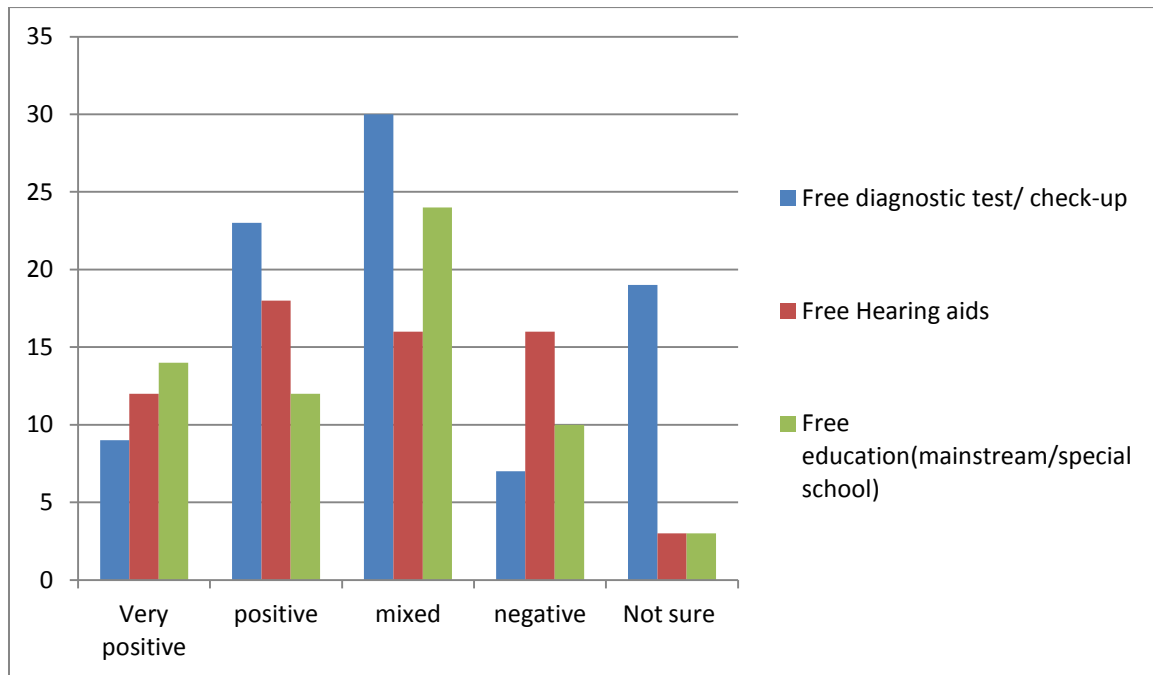
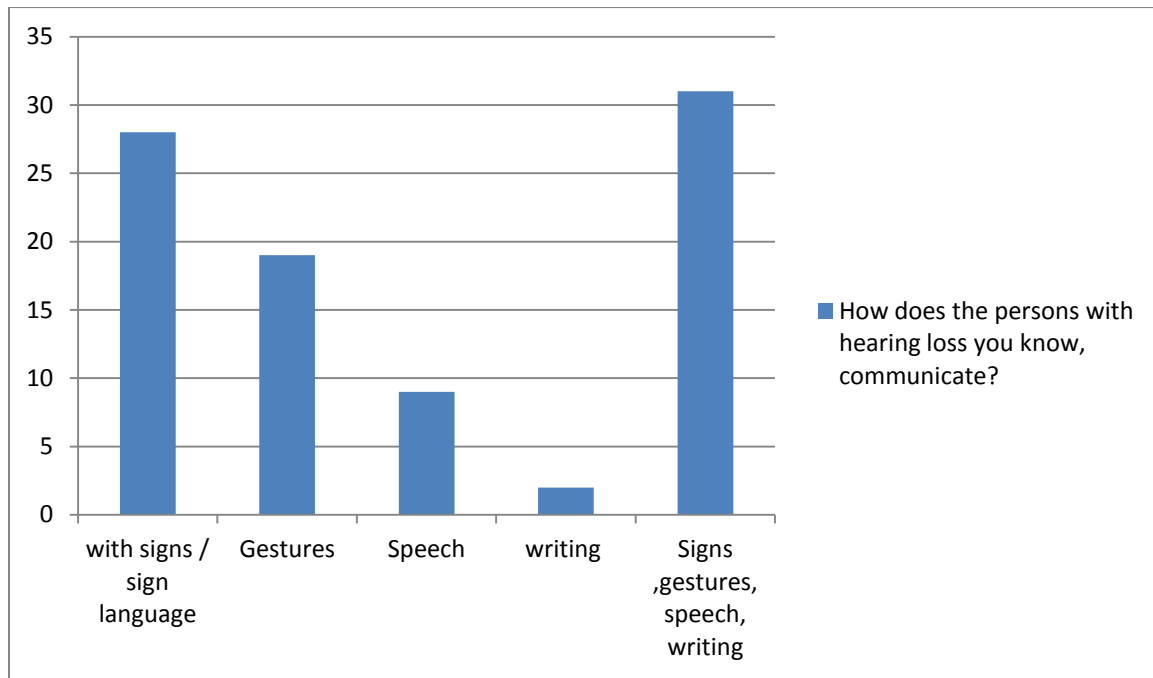


Chart 4.4 free diagnostic test, hearing aid and education.

This indicates that in some places free diagnostic tests and free hearing aids are either not properly offered or implemented, or many of them may not be aware of accessibility and provision.

The respondents had differing views regarding free education for PWHL in mainstream or special schools, nearly 48% either have a mixed opinion or are not sure, and only 14% have positive views about it. This again shows that many of them may not have knowledge or information about this area. Similarly, in regard to the provision for PWHL, parallel views are found. Nearly 28% are not sure, 20% have mixed opinions, 15% negative, and only 5-10% have positive attitudes towards them. Thus, it could be interpreted that there is a greater need to improve awareness and the information available in these villages (See chart 4.5)



Further views were sought regarding PWHL's modes of communication of which 31% responded on total communication that is the use of signs, gestures, speech and writing, and twenty-eight per cent said only signs and sign language. The last closed ended question was asked about the education of PWHL. The majority of respondents (36%) are of the view that their education is only up to primary level or less, 21% said up to matriculation, 10% replied with no education and sadly none had mentioned higher education. Thus, it can be inferred that PWHL have a lower education attainment.

4.2. Analysis of Open-ended questions (Qualitative data)

In the open-ended questions the respondents were asked how could the PWHL be more equal to their hearing peers and they could give any suggestions they may have. The principal themes that emerged from these were : use of hearing aids, support from family, teachers and peers, recognising their abilities, encouragement from society, inclusion, support services to be provided by government to deaf children and their families and they need to be goal oriented. Comments on these are exemplified in five major themes in the following paragraph.

4.2.1 Emerging themes from open ended questions

4.2.1.1. Use of technology in developing speech and language

Six people indicated that the technology especially the use of hearing aids could be a great help to develop speech and language, which will eventually have an impact on their academic performance. Mr. Alok said,

“Since they cannot hear, by using hearing aids deaf children are able to hear and can speak like other normal children”.

The appropriate hearing aids and their maintenance will enable deaf children to listen to speech. The free pocket hearing aids are provided by the government for low income families. However these are distributed without a diagnostic test to any deaf child who has a disability certificate. According to my experience, these are rarely beneficial as their maintenance is very poor. The ear moulds for hearing aids are not provided; just the ear tips are given, which don't fit a lot of the children very well. The poor families are neither able to afford ear moulds or buy new batteries. Most of the people think that once they are fitted with hearing aids, they will spontaneously speak. They are not aware that deaf children need to be fed the language, which hearing children learn naturally.

“My family was very happy to get the free pocket hearing aids for my brother. But for this we had to travel two hours by bus and to stand four hours in the queue and now it is lying in a corner” [Mr. Rajiv, brother of a deaf boy].

Surprisingly, none of them have mentioned about the other resources like, digital hearing aids, cochlear implants, new-born hearing screening, early intervention with quality education or speech therapy. All these latest technologies have transformed the opportunities for deaf children, which can help them to be more equal to their hearing peers. This indicates their limited knowledge and awareness regarding this issue. As the use of technology is felt to be a great aid for the achievement of deaf children, the state government should channel the provision well.

4.2.1.2 Equality and inclusion

Some have expressed that PWHL need to be treated equally, to be considerate to them and give them their due respect and rights. It is observed that parents neglect and ignore their disabled children whereas their other normal children are cared for, loved, and money and time is spent on their overall development.

The deaf children are not included in many celebrations, festivals or social gatherings. Parents are uncomfortable and feel embarrassed by their presence in the group. Their signs and gestures seem to be awful to the rest of the society. Therefore, sensitising the societal attitudes is essential for the inclusion as equality of the PWD.

Ms. Leela expressed, “my neighbour, a deaf girl, wanted to join us for the festival of Diwali with her siblings, but her father did not allow her”. So they are segregated in the family as well as in the society.

4.2.1.3. Support and encouragement from parents, teachers and peers.

The PWHL require support from parents, peers, teachers and society according to the responses of ten of the respondents. Their abilities have to be recognised and developed.

“Schools should encourage them and give them chances to be equal with their hearing peers. Other students should be sensitive to their needs for example, being friendly, understand their signs, speech and gestures and support them” was the response from Mr Arun.

Parents and family need timely unbiased information and guidance that will enable them to respond appropriately to the educational programs for their CWHL (Eleweke et al, 2008). In-service training is essential for teachers in order to understand and help these children.

4.2.1.4 Criticism of government policies and provisions

It should be mandatory for the Government support services to be implemented everywhere. In 1996 the government of India enacted the Persons with Disabilities (PWD) Act which ensures free and appropriate education until the age of 18, equal opportunities, protection of rights and full participation (Ministry of Law Justice and Company affairs, 1996). It covers education, employment, non-discrimination, prevention and early detection and social security which include both preventive and promotional aspects of rehabilitation.

Mr. Ram said, “Much is on paper, but nothing is being applied in our areas for handicapped children”. This observation specifies their dissatisfaction regarding the implementation of the support services in their neighbourhoods.

4.2.1.5 PWHL need to be goal oriented

Three participants responded that together with all of the above supports and consideration, PWHL should also have aims and goals in life. Kavita expressed, “They need to work hard, strive for success and have a goal in life. Furthermore, they need to be motivated and guided in the right direction by professionals”. This is expected of professionals and special educators who need to be the torch bearers.

4.3 Drama based interventions

The second section of data analysis is on the interviews (voice over internet) and the feedback on the impact of the drama on the audience. According to Cattanaach (1992) drama is an invaluable tool that supports every aspect of learning development. Some evidence suggests that it is a vehicle to raise the voice of simple ordinary people. Drama is defined as the participation in a simulated social situation that is intended to highlight the role of the person in the simulated context, governing real life social episodes (Peter, 1995). The focus of the interview was on the overall reaction of the audience, the impact it had on them, any suggestions and its educational value.

4.3.1 *Voice over internet (Skype interview)*

Six among the sixty-five who watched the drama, including the appointed coordinator of the drama were interviewed on Skype. Informed consent was obtained from each of them by email through the coordinator. The schedule and venue of the interviews was decided with her over the phone as suggested by the interviewees. The interview conversation was in Hindi which could be followed by all. Only the relevant extract from the recorded conversation was transcribed in English (see appendix-5).

4.3.2. Themes developed from interviews

The main themes of drama were gender discrimination in disability, the undervaluing of a deaf girl and access of her rights to education. The major themes that emerged from the interview data were: the audiences reaction to the overall performance, gender discrimination, societal attitudes towards disabled people, disability provisions, shared responsibility among parents, recognising and enhancing the abilities of deaf children, the role of professionals, difficulties experienced by families of PWDs and the demand to perform this drama in various other places. These themes are combined and described in four major headings in the following paragraphs.

4.3.2.1. The reactions of the audiences on the presentation of the drama

All six of the interviewers expressed that this kind of role play was the first they had attended. It reflected the hidden reality of how the deaf girls are being treated in the family and the community. It had been found that these families are being looked down on by society which in turn leads them to maltreat their disabled children. The conversation with Mrs. Bharti, a mother of two deaf girls whose youngest daughter acted as a deaf daughter in the drama shared her thoughts,

“This drama has opened my eyes. I realised my lack of responsibility towards my two deaf daughters. I used to think; anyhow they are deaf, what good can be expected from them, which made me give more attention to the other two hearing children. But now, I am challenged and empowered to educate them. I was happy to see my daughter acting in the drama”.

As conveyed, the overall presentation of the drama had a great impact on the audience; many parents of disabled children were moved with passion as well as being confronted on their own behaviour. They were inspired by the mother in the drama to make efforts to invest in the future of their children.

“The roles in the play were very clear and impressive; we have come to know the importance of the identification of deafness and can give suggestions, encourage and direct the parents of deaf children for education.” [Mr. Promod, in the interview]

The other comments below express the quick actions taken by the three parents of hearing children,

“The drama was a great revelation in understanding the parents of PWHL, their pain and struggles. Soon after the drama I and two more ladies talked with a mother of three deaf children (two daughters and a son). We appreciated her efforts and encouraged her to educate all her five children”. [Mrs. Sheela, one of the interviewees]

I believe this must have been a very effective encounter between parents of hearing and non-hearing children. Certainly, the mother of PWHL must have been empowered. This small act of kindness has begun to fulfil my research aim and I intend to follow this up on a larger scale, after I return back to India.

For some, the scene of the school where deaf kids were being taught was a very touching experience, as it was the first time they had seen it. The experience of the drama was also shared with the other members in the family who could not be present. The villagers felt strongly that the drama should be performed for other villages, which is something I will consider perhaps with some revisions to the piece.

4.3.2.2 Gender discrimination

In general, gender inequality reflects the highly gendered nature of Indian society and even more so with disability. As a whole, females are less likely to be educated and valued, and of course if the female is disabled, access to education is even more difficult. Several researchers

in India have identified that disabled girls tend to receive less care than disabled boys, and are more likely to die or be killed (Thomas, 2005, cited in Erb and Harris-White 2002; Mohapatra and Mohanty, 2004). Similar opinions were expressed by two ladies and I have also come across such opinions in my own experience. Some disabled girls are abandoned, deserted and survive on begging and some manage to find shelter in orphanages. The school under my leadership also has two disabled girls who were deserted by their family; they are being looked after by our institute. Even today we do not know who and where their parents are.

This issue was emphasised in the drama enacted where the deaf girl is ill-treated, degraded, unwanted and not given her right to education by her father. When asked, what could be the reasons for it, Mrs. Maggi replied that the dowry system could be one of the major reasons for it, which she indicated with a vivid example of a deaf girl from her village. As she informed in the interview:

“A deaf girl with a primary education was married to a normal boy for the dowry sake. He divorced her after a year leaving her with a beautiful, six month old normal girl. This was because the girl’s family were unable to fulfil his demands for more dowries”.

There are hundreds and thousands like her who are devalued and ill-treated in the name of disability. Previous research has pointed to significant challenges for people with disabilities in getting married and having families. Even where marriage can be arranged, disabled women in particular are frequently married with much older men or unsuitable partners, and rates of divorce and abandonment have been found to be high, as the National Sample Survey data on widowhood among disability would seem to support (NSS 2002). It highlights the realities faced by families of PWD.

4.3.2.3.. Provision to the PWD

This interview was an opportunity particularly for three women, where they could ~~to~~ express their views openly and freely and their voice was heard. Overall, their dissatisfaction regarding the implementation of support services for PWD in their areas was conveyed. This issue also had emerged in the open-ended questions part of the survey which indicates a serious concern. Mrs. Rose replied,

“We hear that there are lot of facilities being offered by the government for the welfare of handicapped people. But unfortunately in my village many of them are deprived of it, due to a lack of information. Moreover some of those who claim for their rights are ignored, neglected or the dates of services are being postponed”.

The people from remote villages have to walk 2-3 hours to reach the governments' offices, forfeiting a day's wages. This makes them disappointed and disinterested in being persuaded in the benefits of support services. I have had a similar kind of experience in getting Disability Certificates for the three orphan children mentioned earlier who are under our Institute's care. Several times we had to run behind in getting this work done. There is a greater need to launch a disability line for enabling the public to have easy access to information regarding disabilities and to avail the services.

4.3.2.4 Societal attitudes towards disability and disabled people

I believe the attitudes mainly depend on a person's beliefs, cultural and religious values, and on the norms of the society. As reported, the attitude towards and perceptions of disabled people is complex and varied in types of impairment, different social, community and family dynamics. Two interviewees expressed that many people in our villages try to hide the disability because of social stigma. Due to their beliefs and superstitions, they consider disability as misfortune or a curse from God. The disabled are seen to be a burden who would not be able to work or marry, and are rejected by the society. Their families are being looked down on and general apathy and disregard shown to their handicapped children. This leads to low self-esteem and self-confidence for both PWD and their parents.

The attitudes of society, families and PWD themselves can contribute to how that person experiences life with their disability. The studies have shown that the factors associated with negative attitudes include parental distress, conflict between siblings, and interaction and communication (Olusanya, 2011). However, the positive attitudes need to be fostered and the worth is to be acknowledged.

4.4 The feedback responses from the team members on the overall research project (Survey and drama) by email

I highly appreciated the great support and participation of the team members of this research project. Through emails and calls, I expressed my heartfelt gratitude for their willingness and generosity for conducting this project successfully on my behalf and direction. Since this was done through an expert consultation approach, I was keen to know the overall views, thoughts, problems and difficulties that they faced during the whole process of surveying and

the presentation of the drama. Thus, an email request was sent to all the eight team members involved in this research. Five of them replied to my email and expressed their comments (see appendix- 7). The following are extracts from their emails.

4.4.1 The extracts from the email responses

The two respondents reported that a good rapport with participants and explanation of the purpose of the survey was required initially. The survey made them aware of each person's role in supporting people who are disabled. He also said, "It boosted and encouraged those who have a special appetite to respond to the needs of such people". [The Headmaster from Bhurkunda School]

The social worker who was the coordinator of this research on my behalf said, "The survey helped them to realise that there are people genuinely interested in knowing the handicapped people and lending a helping hand to them". The drama was felt to be influential, where many people expressed their support for the families of PWD. [A male social worker from Hazaribag]. The assistant headmistress of a school for the deaf, also commented in this survey, "I came to know that there are so many handicapped children in our society. A small gift given to each participant added to their joy and enthusiasm. The open ended questions were difficult to answer, as many were not used to it. The role players in the drama were very enthusiastic and gave enough time for practice as required". [The assistant headmistress of a school for the deaf, Hazaribag]

The young boy who acted in the drama, as a father of a deaf girl child said that his attitude towards deaf children has been changed, "I never thought deaf children could perform so well, now my love and interest in deaf children has increased. It was my first experience in acting in a drama which I was initially hesitant about, but this has boosted my confidence and endowed me to be an ideal father in the future". [A father of a deaf girl in the drama]

The analyses of the data from different resources have highlighted multi-various issues. The information is significant in terms of discussing the importance of awareness in a community based situation. The data confirms the studies on poverty and gender inequalities of PWD, however, the new facet achieved in this research is the element of drama and the response of community.

Chapter 5

Discussion

This study has investigated the perceptions, views, attitudes towards CWHL, the services being offered to them, and the barriers to early detection of HL. This was achieved through a questionnaire-based survey, a drama performance, and interviews. It has enhanced and empowered participants CWHL and their families in three districts of the state of Jharkhand, India. The respondents were from a variety of backgrounds supporting a reliable sample for

the research. As earlier mentioned in the chapter on methodology, this was possible due the collaboration of the multidisciplinary team.

5.1 Strengths and weakness from the main findings

The analyses of this study indicate that overall India has one of the more developed national policy frameworks for disability in developing countries. Yet this has to work well for its implementation particularly in rural areas. On one hand, the legislations have helped to shift public attention from giving charity to disabled people to protecting their rights and treating them with respect. However, it was found that most children with disabilities in India are deprived of opportunities to develop to their full potential and to participate in society. Their access to education is denied and their voice unheard. Over the years efforts have been made at State and Central level in acknowledging their rights and promoting inclusion through various schemes. Based on the analyses, it is clear that most services for children with disabilities are concentrated in developed urban areas or close to the district headquarters. The vast majority of children with disabilities who live in rural areas are deprived of these services.

The overall findings of this study support the previous reported results and my own assumptions. The key factors that are found from both surveys and interviews are the lack of awareness among people about HL, the lack of trained professionals, an inadequate infrastructure, illiteracy, poverty, and social and cultural beliefs (Rout,2010, Vaani,2011). These features affect the early identification of hearing loss in these areas. Although in recent years, the disability rights movement seems to be active in India it fails to implement its actual aim. In many ways, the people from rural areas are deprived of many things such as education, medical treatment, support services for PWD and employment. If nothing could be done to provide provision, at least the government can initiate a campaign of awareness for identification by involving means of media.

The findings confirmed that the PWHL were found to be the highest group by the respondents and their age of the identification is 3- 4 and aural habilitation takes place by age of 7. It is worth noting that their education is at a lower level, the gestural communication used and their speech and writing seem to be poor. Most of the respondents indicated that there was a clear need for auditory

5.2 *Drama: a device to encourage earlier detection and access the rights of the deaf girl*

The drama had a great impact on the audience. It revealed to them general views and attitudes towards families of PWD and some were confronted by their prejudicial treatment of the deaf girl. Drama was a live-show and participants seemed to have felt real in that act of performance. They could relate to the characters and were inspired to make efforts to enhance the future of their children. Some felt challenged as well as empowered to educate their children and realised their lack of empathy for the deaf girl. The actors in the play gained a lot of confidence performing it to the larger community.

There is a general preference for male children in India, which promotes female foeticide and infanticide. The son preference is rooted in a patriarchal society and the prevalence of dowries could be a major cause, even more so for the females with disabilities. This drama recreated this, where the deaf girl is being ill-treated, and is not given her right to education by her father. The audience were moved with passion and wanted to stop this inequality and injustice done to the innocent deaf children.

The drama was also a means of entertainment imparting a lot of information to reach the audience. Not only that, the print media coverage opened the channels for discussion and networking. The local newspaper clips on the drama presentation was also published on Facebook (See appendix- 6). This too aided the spread of information to which many commented. Most of the participants suggested that this type of drama should be performed in many places.

5.3 The societal Attitudes towards PWHL

Disability in general is perceived either as punishment for misdeeds in a past life or a curse on the families. It has been considered a 'special' issue, isolated from mainstream development. The analysis on PWHL's contribution to the family and society has also shown mostly negative responses. This discouraging attitude is one of the main causes that PWHL remain a victim of societal stigma. People with hearing loss are mobile, physically active and independent to survive only if certain amount of support and opportunities are made available to them. This disability of HL is mocked at social level like many other disabilities however PWHL could participate in various walks of life.

Chapter 6

Conclusions and recommendations

This study demonstrated the concerns of PWHL living in remote and rural areas, experience double disadvantaged in regard to receipt of services. The delay in detection of their hearing loss affects their quality education. This in turn affects their bright future and makes them vulnerable to be exploited and stigmatised.

To sum up the findings of this report it is highly important to mention the role of family and local community in supporting the PWHL. Nursing homes, school and worshipping places are the sites of dispersing information and helping people to transform their attitude towards disability of any sort. In this study the community members networked with each other for the first time in their life. This opportunity of making community groups and networking between local members was proven to be very supportive towards the family of disabled person.

The identification and screening provisions depend on awareness of parents and the family members. Professionals are the second tier that can help the process of screening and identification. The study confirms that early age identification has not been followed in these communities and largely it is because of lack of awareness regarding hearing loss and its screening methods.

Recommendation

Taking into consideration the above challenges faced by PWHL and their families, I believe the reformation must take place both in implementation of policy and the institution of healthcare, education, assistive devices and rehabilitation, vocational training. There should be linkage between

- The Professionals (audiologist, speech therapist, special educators and psychologist) need to work together and involve parents of CWHL in the production, evaluation, and delivery of the range of information on the development and care of their children. The information provided should be clear, unbiased and adequate that helps in supporting the families of young CWHL.
- In Jharkhand early interventions Centres are almost non-existent in the State. Efforts should be made to establish early identification and intervention centres with complete services.

- Awareness programme should be initiated for the public at large. This could be done by organising medical camps, village awareness camps, and orientation of village school teachers, in-service-training of teachers, counselling parents and the performance of drama as it had great impact on people. Newspapers, radio and television are increasingly becoming popular in Jharkand and many other state of low development index. It seems that these channels could play a significant role for the awareness of screening methods and provisions available.
- There is greater need of deaf association and parents of CWHL association in Jharkhand and Hazaribgah which I intend to start. The aims would be to make the community aware of the issues of disability and play active role in participation and support campaigns for people in need.

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Appendix 1: Research outline plan

Plan for data collection

In setting up research itinerary on 'Exploring ways to encourage earlier detection of hearing loss in the families of rural areas of Jharkhand, India, 'an expert consultation approach' will be used by the members of multidisciplinary team.

1. The team members are selected mainly from the fields of education, health and social work, who will carry out research on my behalf. They are being selected on the basis of their experience and vast knowledge in the specialized field, have great influence on people in the villages as well as their availability and willingness to part take in this research study for the welfare of people. They are already given information about this through email and have responded their readiness to participate. Following are team members .

The facilitator - Mr. M.K. Jose - Social worker and researcher

Team members - Ms. Sunila & Mr. Christopher (Social worker)

Ms. Ranjita & Ms. Angle (Health worker)

Sr. Roshni & Veronica (Special educators)

Ms. Esther & Kumudahni (Hindi translators)

2. Mr. Jose will be asked to conduct a short meeting with the above members to explain their roles in the participation before 20th March. Sunita, & Ranjita will be responsible for survey in Patra & Bartua villages. Approximately 70 people of will be the target samples from the above villages to be surveyed. The selection for samples will be based on different categories & age group such as, unmarried/engaged between age 20-30, some parents 30- 55 ys.,health workers, aganvadi workers, persons with disabilities, few teachers from villages.

3. Roshni, Veronica & Esther will translate the draft questionnaire and drama. By 12th of March the first questionnaire for piloting will be send to Jose by email, who will after completing, send them back to me. By 31st of March the team will conduct a survey in the above mention villages. They will explain the questions and also give personal assistance to all those who do not know to read and write.

4. The team will give information to the leaders of the village, self-help group, church leaders, school head-teacher , health workers and agnavadi workers about the presentation of the drama which will be organized in the Patra village. Sunila, Christiopher & Ranjita will arrange short meeting in the villages regarding presentation of drama by 3rd of April.

5. Roshni and veronica will be given incharge of organizing drama. The role players for drama will be the members of the focus group (chosen by Sunila & Ranjita) 3 teachers from their School, 3 deaf pupils, 4 parents , few little children & parents (from the same village, where the drama will performed) and any other members could be chosen as required. They will have to do some practice & rehearsal of drama before they perform to the large group of the audience expected to be around 200 people. The team together with the focus group will arrange for drama , which is likely to take place by 30th

April. The video recording and photos will be asked to take. The interviews of few audience to get the feed-back after drama presentation.

6. I will have regular contact with team members by emails, skype & phone to ensure what is expected is happening. Being in touch with them, I will collect required information. I have a great hope & confidence in team members. As I foresee, this research will have positive impact on the villagers. It is going to be an eye-opener for them. The guidance, suggestions and support of my supervisor, Dr. Linda is going to be a great help to make this research more relevant, successful & effective. When I go back after completion of my Masters definitely I will do its follow up.

Appendix 2 Questionnaire in English and Hindi



Questionnaire

I am a master's student at the University of the Birmingham, U.K. This questionnaire is a part of my master's course in 'Inclusion and special educational needs'.

Its purpose is to know the background of your area, understand your views and opinion regarding disability, particularly hearing loss.

All information given in these questions will remain confidential. I ensure, in writing up my final report the identity of individuals will be protected.

I will be happy to talk to you, or contact you, If you have any queries, please feel free to contact. Email: christinadmello13@gmail.com

Mob. No. 07407106163

Thanking you,

With regards,

Sr. Christina Dmello

University of Birmingham.

United Kingdom.

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

The purpose of this questionnaire is to obtain your views and opinions regarding the identification of disability in your area, particularly of hearing loss. Please tick (✓) in the box that best describes your current status.

Section I : Personal Information.

1	Gender	Tick one option
A	Male	
B	Female	

2	Age group	Tick one option
A	Under 19	
B	20 - 29	
C	30 – 39	
D	40 - 49	
E	50 - 59	
F	60 +	
3	Marital Status	Tick one option
A	Single	
B	Married	
C	Widow	
D	Divorced	
E	Any other please specify	

4	Children	How many	School going children	Married Children
A	Boys			
B	Girls			
C	None(please tick)			
5	Current occupation			Tick one option
A	Farmer			
B	Shopkeeper			
C	Teacher			
D	Student			
E	Tailor			
F	Daily wager			
G	Technical expert			
H	House wife/husband			
I	Any other, please specify			
6	Name of village			
7	Monthly family income			Tick one option
A	Less than Rs. 1500			
B	1500-3000			
C	3000-5000			
D	5000-8000			
E	More than 8000			

F	Do not know	
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8	Education or qualification	Tick one option
A	Primary school / less than	
B	Middle school	
C	Matriculation	
D	Intermediate / Teacher Training	
F	Graduation and above	
G	None	

9	Religion	Tick one option
A	Hindu	
B	Sarena	
C	Muslim	
D	Christian	
E	Any other please specify :	
10	Spoken Language	Tick any
A	Mundhari	
B	Sadhari	
C	Uraw	
D	Sandhali	
E	Hindi	
F	Any other please specify :	

Section – 2 : Disability

1	Has any member in your family with disability?	Tick one option
A	Yes	
B	No	
C	Do not know	

If yes, please go to question 3, if not, please go to question 2

2	Have you come across a person with a disability?	Tick one option
A	Yes	
B	No	
C	Not sure	
3	Gender	Tick one option
A	Male	
B	Female	
4	Age	
5	Nature of disability	Tick one option
A	Mobility (physical disability)	
B	Deaf/hearing loss	
C	Blind/partially sighted	
D	Multiple disabilities	
E	Mentally challenged	

F	Chronic illness (HIV/AID, Cancer)	
G	Any other please specify :	
6	What is your relation with person with disability?	Tick any
A	Son	
B	Daughter	
C	Mother	
D	Father	
F	Brother	
E	Sister	
F	Cousin	
G	Grandson / granddaughter	
H	Any other please specify :	
7	At what was age the disability identified?	Tick one option
A	0 - 6 months	
B	7 Month- 1year	
C	1-2ys	
D	3-4ys	
E	4-6Ys	
F	7ys. and above	
G	Do not know	
8	Who identified it first?	Tick one option
A	Doctor	
B	Teacher	
C	Family member	
D	Neighbour	
E	Peers	
G	Any other please specify :	
9	Do you know about the support services (facilities) access for a person with disability offered by the government?	Tick one option
a	Yes	
b	No	
C	Not sure	

10	How far are you satisfied with the support services being offered to a person with disability from the government in your areas?	Tick one option
a	Very satisfied	
b	Little satisfied	
c	Neither satisfied / nor dissatisfied	
d	Dissatisfied	
e	Very dissatisfied	

Thank you very much for your participation.

You have mentioned a person with hearing impaired, so please answer a few more questions.

Q. 11. Please ring the response that you think is most appropriate to each statement on the persons with hearing loss(H.L). If you wish to make any comments in addition to these ratings please do so on the back page.

Strongly Agree 5	Agree 4	Neutral 3	Disagree 2	Strongly Disagree 1	
1. The person with H.L.makes a big contribution to the family	5	4	3	2	1
2.She/he is involved in a society	5	4	3	2	1
3. I understand his/her way of communication	5	4	3	2	1
4. He/she has good rapport with peers/ villagers	5	4	3	2	1

Q. 12 How would you feel about the support services that are being offered to people with H.L. in your area? (Please ring on one option)

	Very positive 5	positive 4	mixed 3	negative 2	very negative 1	Not sure 0			
a.	Free diagnostic test/ check-up			5	4	3	2	1	0
b	Free Hearing aids			5	4	3	2	1	0
c	Free education(mainstream/special school)			5	4	3	2	1	0
d	Student Scholarship			5	4	3	2	1	0
e	Swami Vivekananda Pension scheme			5	4	3	2	1	0
F	Provision of free vocational training			5	4	3	2	1	0
g	Travel concession			5	4	3	2	1	0
h	Job placement in local industries and trades.			5	4	3	2	1	0

13	How does the persons with hearing loss you know, communicate?	Tick any option
a	with signs / sign language	
b	Gestures	
c	Speech	
d	Writing	
e	signs, gestures, speech and writing	
f	Any other please specify	

14	What is the level of education or qualification of the persons with hearing	Tick one option
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	loss ?	
a	Primary/ less than	
b	Middle school	
c	Matriculation	
d	Higher secondary/ vocation training	
e	Graduation	
f	None	

Suggestive questions:

1. How could the persons with hearing loss be more equal to his/her hearing peers?

2. Are there any other comments you want to make?

Thank you very much for your participation.

Chiristina Dmello

University of Birmingham.

United Kingdom.

Appendix- 3 Data Analysis

Q.2	Age	Frequency	percentage
	Under 19	6	10
	20 - 29	14	25
	30 – 39	15	26
	40 - 49	11	19
	50 - 59	9	15
	60 +	3	5
	Total	58	

Q.3	Marital Status	Frequency	percentage
	Single	27	47
	Married	30	52
	Widow		
	Divorced		
	missing	1	
	Total	57	

4. A	Children	Frequency	percentage
1	Boys	14	24
2	Girls	11	19
3	none	3	5
	Missing value	30	
4. B	School going children		
	single	2	3
	Two children	9	16
	Three	7	12
	Four	2	3
	Missing	32	66
4. C	Married Children		
	One married	2	33
	three married children	2	33
	four married children	2	33
	None		
	Total		

5	Current occupation	Frequency	percentage
	Farmer	13	23
	Shopkeeper	2	4
	Teacher	11	19
	Student	9	16
	Tailor	2	4

	Daily wager	14	24
	Technical expert	2	3
	House wife/husband	3	5
	Health worker	1	2
	Any other	1	2
	Total		

6	village	Frequency	percentage
	Bartuwa	11	19
	Bhurkunda	14	24
	Hazaribag	14	24
	Kodarma	4	7
	Patra	11	19
	missing	4	7

7	Monthly family income	Frequency	percentage
	Less than Rs. 1500	15	26
	1500-3000	18	31
	3000-5000	11	19
	5000-8000	4	7
	More than 8000	4	7
	Do not know	4	7
	Missing value	2	3
	Total	58	

8	Education or qualification	Frequency	percentage
	Primary school / less than	13	22
	Middle school	14	24
	Matriculation	7	24
	Intermediate / Teacher Training	10	17
	Graduation and above	6	10
	None	8	14
	Total	58	
9	Religion	Frequency	percentage
	Hindu	28	48
	Sarena	4	7
	Muslim	8	14
	Christian	3	5
	Any other	18	31

10	Spoken Language	Frequency	percentage
	Mundhari	-	-
	Sadhari	6	10
	Uraw	14	24
	Sandhali	3	5
	Hindi	34	59
	Any other	1	2

	Total		
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Section II

II .1	Has any member in your family with disability?	Frequency	percentage
	Yes	19	33
	No	36	62
	Do not know/missing value	3	5
	Total	58	

II.2	Have you come across a person with a disability?	Frequency	percentage
	Yes	33	60
	No	7	12
	Not sure	2	3
	Missing value	16	28
	Total	58	

II.3	Gender of disable person	Frequency	percentage
	Male	30	52
	Female	16	28
	Both	2	3
	missing	10	17
	Total	58	100

II.4	Age of Disable person	Frequency	percentage
	5-10 years	6	10
	11-20 ys	16	28
	21-30 ys	7	12
	31-40 ys	3	5
	41 -60 ys	2	3
	Missing value	26	45

II.5	Nature of disability	Frequency	percentage
	physical disability	16	28
	Deaf/hearing loss	20	35
	Blind/partially sighted	2	3
	Multiple disabilities	7	12
	Mentally challenged	7	12
	Chronic illness (HIV/AIDS, Cancer)	1	2
	Missing	5	9

II.6	What is your relation with person with disability?	Frequency	percentage
	Son	7	12

	Daughter	2	3
	Mother	1	2
	Father	1	2
	Brother	7	12
	Sister	2	3
	Cousin	3	5
	Family friend	2	3
	student	5	9
	neighbour	13	22
	villagers	4	7
	relatives	4	7
	missing	6	10

II.7	At what was age the disability identified?	Frequency	percentage
	0 - 6 months	4	7
	7 Month- 1year	12	21
	1-2ys	11	19
	3-4ys	13	23
	4-6Ys	4	7
	7ys. and above	1	2
	Do not know	6	10

II.8	Who identified it first?	Frequency	percentage
	Doctor	12	21
	Teacher	3	5
	Family member	34	59
	Neighbour	3	5
	Peers	2	4

II.9	Do you know about the support services access for a person with disability offered by the government?	Frequency	percentage
	Yes	22	38
	No	26	49
	Not sure	7	12

II.10	Satisfaction with the support services being offered to a person with disability from the government in your areas?	Frequency	percentage
	Very satisfied	1	2
	Little satisfied	20	35
	Neither satisfied / nor dissatisfied	7	12
	Dissatisfied	18	31
	Very dissatisfied	8	14
	Missing	4	7

Q. 11. Please ring the response that you think is most appropriate to each statement on the persons with hearing loss(H.L).

11. a	The person with H.L. makes a big contribution to the family	Frequency	percentage
	Strongly Agree	2	3
	Agree	6	10
	Neutral	10	17
	Disagree	15	26
	Strongly Disagree	18	31
	Missing	7	12
11.b	She/he is involved in a society	Frequency	percentage
	Strongly Agree	1	2
	Agree	5	9
	Neutral	6	10
	Disagree	22	38
	Strongly Disagree	17	30
	Missing value	7	12
	Total		

11.c	Understand his/her way of communication	Frequency	percentage
	Strongly Agree	-	-
	Agree	2	3
	Neutral	9	16
	Disagree	31	54
	Strongly Disagree	9	16
	Missing	7	12
	Total		

11.d	He/she has good rapport with peers/ villagers	Frequency	percentage
	Strongly Agree	12	21
	Agree	5	9
	Neutral	12	21
	Disagree	22	38
	Strongly Disagree	-	-
	Missing	7	12

Q. 12 How would you feel about the support services that are being offered to people with H.L. in your area? (Please ring on one option)

Q.12.a	Free diagnostic test/ check-up	Frequency	percentage
	Very positive	5	9
	positive	13	23
	mixed	17	30
	negative	4	7
	very negative	1	2
	Not sure	11	19
	missing	7	11

12.b	Free Hearing aids	Frequency	percentage
	Very positive	7	12
	positive	9	18
	mixed	9	16
	negative	9	16
	very negative	2	3
	Not sure	15	26
	missing	7	12
12.c	Free education(mainstream/special school)	Frequency	percentage
	Very positive	8	14
	positive	7	12
	mixed	14	24
	negative	6	10
	very negative	2	3
	Not sure	14	24
	missing	7	12

12.d	Student Scholarship	Frequency	percentage
	Very positive	5	9
	positive	6	10
	mixed	11	19
	negative	9	16
	very negative	5	9
	Not sure	15	26
	missing	7	12
12.e	Swami Vivekananda Pension scheme	Frequency	percentage
	Very positive	4	7
	positive	3	6
	mixed	7	12
	very negative	10	17
	negative	8	14
	Not sure	19	33
	Missing	7	12

12.f	Provision of free vocational training	Frequency	percentage
	Very positive	3	5
	positive	5	10
	mixed	13	22
	very negative	8	14
	negative	7	12
	Not sure	15	26
	Missing	7	12

12.g	Travel concession	Frequency	percentage
	Very positive	3	5
	positive	3	5

	mixed	12	21
	very negative	7	12
	negative	9	16
	Not sure	17	29
	Missing	7	12

12.h	Job placement in local industries and trades	Frequency	percentage
	Very positive	2	3
	positive	6	10
	mixed	10	17
	very negative	10	17
	negative	7	12
	Not sure	16	28
	Missing	7	12

Q.13.	How does the persons with hearing loss you know, communicate?	Frequency	percentage
a	with signs / sign language	16	28
b	Gestures	11	19
c	Speech	5	9
d	writing	1	2
e	Signs ,gestures, speech, writing	18	31
	Missing System	7	12

Q.14	Education or qualification of the persons with hearing loss ?	Frequency	percentage
	Primary/ less than	21	36
	Middle school	12	21
	Matriculation	8	14
	Higher secondary/ vocation training	4	7
	Graduation	-	-
	None	6	10
	Missing	7	12

Appendix- 4: Details of Sample selection



UNIVERSITY OF
BIRMINGHAM

Dear Head-teachers, Health-administrators and social workers,

Regards from Christina!

I hope and pray that all is fine with you and must be engaged in doing great work. As you know that I am a master's student at the University of the Birmingham, U.K. The Dissertation is a one of the major part of my study for which I need to do some investigation in our areas. According to my research topic, I am supposed to do the field work and collect the data, but unfortunately it's not possible for me to come & do it by myself. Therefore, I have arranged an expert team from different fields (social worker, health worker and special educators) I am glad to have M.K.Jose as facilitator to do this research on my behalf.

Dear all, in addition to it I need your cooperation for surveying few of your either parents, clients, student or staff from rural areas. Therefore, May I request for your collaboration for the data collection? I am sure to get positive reply from you as it is going to be for the benefit of our people as well as for my study. Assuming that you will participate in the first part of my research, I would like give few instructions regarding the sample. However the team members will give detail information about it. The sample selection will be based on different categories & age groups. The total no. in the sample is nearly 70 people. The following are the target audience and its criteria.

My focus is on rural area, as the topic is 'Exploring ways to encourage earlier detection of hearing loss in rural area, Hazaribah, Jharkhand, India'. So please select the participant from rural area and as much as possible according to the following categories.

1. Some of them could be Young parents of age group between 25-45 from different families. Few of them could be from the same family (e.g. husband & wife). **2.** Few, unmarried/engaged between age 20-30. Few teachers, health workers also will be included in them. **3.** Some parents of age groups between 46-60 from different families (includes village leaders, aganvadi workers) **4.** Some persons with disabilities or any member of his/her families.(above 16ys.) Kindly assist them in understanding the questions, to read & write for them, if they do not know. You can also delegate this task to any one of your staff, as I am aware, that you have many other responsibilities.

Roshni will give questions forms which are translated in Hindi. Yet, please follow English version for more clarification. I wish to give a small gift to each participant as token of my gratitude for sharing their views and opinions. So please get it from Sr. Roshni. And for your noble work, certainly God will reward you.

Thanking you and looking forward for your support,

Best wishes,

Christina Dmello

University of Birmingham,U.K.

Appendix- 5 Drama transcript

Title of drama : A conversion (“Parivartan” in Hindi)

Theme of the drama: “A right to dignity, value and self-esteem” and its sub-themes were gender issues in disability, undervaluing a girl with hearing loss and denying her access to education. To live with dignity, value and self-esteem is the right of every person including those with disabilities.

Summary of the drama: ‘ Look at my abilities, not my disability’

This drama is about a deaf girl who is being hated, ill-treated, exploited and abandoned by her father, because she is a deaf. He considers her as useless, a burden and a shame to the family. She does not have her rights- to education, to live and function happily with world around, she is segregated. But her mother accepts lovingly with her disability and makes an efforts for her diagnostic test and its further intervention. She admits her in the school where the girl gradually progresses and develops her talents and abilities in Sports and musical instruments. She receives an excellent award in these areas which is published in all the local news. The villagers highly appreciate her father for his daughter’s great achievements. As her speech and language is developed , she calls her father ‘Papa..,papa..’ The father is then moved and embraces her lovingly. He asks pardon for his mistreatment. His heart is converted, She transforms him and finally he is changed person).

Characters :

Father - Prakash , Mother- Jyoti- deaf girl – Anjali , doctor –Promod,

Headteacher- Deepa, Teacher- Miss Sarita and six deaf children.

Introduction (The announcer Roshni, welcomes the audience and gives brief sketch of the drama).

Prakash: hi, Jyoti, where’s my shirt, bring it soon!

Jyoti: Here it is!

Prakash: Ohh, how many times I have told you to keep the things on its proper place, but you You are always pre-occupy and taken up with this useless deaf girl, and don't care for other things of the house.

Jyoti: Hey, why do you always poke and become frustrated with this child. Whatever it maybe, she is our child. We should accept her, care for her and give her the dignity. We have to bring her up with love.

Prakash: Love.. and to this deaf child! Oh, Never.. she is a shame, disgusting , a burden for us. And because of her, I cannot show my face to anyone in our society. You don't know, how people talk about me ... a father of a deaf child and our relatives always irritate me and so I feel like killing her, to press her neck & kill her.

Jyoti: What ! you are a father... and speak such a nonsense about our child. Hi, Keep in mind! We don't have to bother the world, people may speak anything rubbish , we need to look after our family, she is our child, , we have to cheer her and make her life fruitful.....

Prakash: After all , what will you do with this 'deaf & dumb' ! she is a burden, a shame to our family. Hi, listen carefully, I won't spend any single pence for her ...

Jyoti: I promise.. you see.. I will educate her, access her rights and make her future bright!(Jyoti takes her daughter to ENT doctor for diagnostic test)

Jyoti: Hello doctor, Can I come in?

Doctor: Yes!

Jyoti: Doctor, see, my child does not talk!

Doctor: Since when does she not talk?

Jyoti: Huumm, I don't know as such, but I think... she does not hear too.

Doctor: Is she deaf by birth?

Jyoti: That I don't know..., but she can't hear anything..

Doctor: Ok, don't worry, I will check it.

(Doctor makes her sit and give the instructions regarding the diagnoses process (with signs) the deaf child gives response)

Doctor: see, the nerves in the her ears are damage therefore she is not able to hear, so she cannot talk. I will give her a hearing aid, which will help her to listen .

Jyoti: (astonish) ohh, that means she can hear and speak...

Doctor: Look, this machine (hearing aid) amplifies the sound, which is a great help for speech and language development. You need to maintain it well (Explaining how to be use and taken care) Yes, you have to admit her to the Special school. There she will learn to read & write.

Jyoti: Doctor ji, I am very grateful to you for this great help.(Jyoti happily goes back to home. Prakash is restless at home.... Angry with his wife & daughter)

Praksh: (Angrily) Where did go with this deaf girl? What is in her ears?

Jyoti: This is hearing aid , with this she can hear.

Prakash: What a stupid, senseless! When God has not given her the ears, what can this two pieces of machine do? Remove this from her ears... (tries to remove it)

Jyoti: No.. No.. This is very precious, I will not allow you to remove this...

Prakash: (sarcastically) hy... this deaf & dumb will put this machine.. & hear....nothing will happen.. you are simply wasting time and money . Teach her some household works that at least we don't have keep any servant.

Jyoti: (Annoyed) No shame ... you are so cruel to speak like this.. you are her father.. see , I promise, she will bring up our family name & fame . I will admit her to school.(Jyoti takes Anjali to Special school for the deaf)

Jyoti: Namaste Madam!

Headteacher: Namste, what' the matter?

Jyoti: Doctor has given this hearing aid for her and told that she will start taking in the school.

Headteacher: Does she hear?

Jyoti: No, she does not hear anything.

Headteacher: OK. This is a special school for the deaf children. Here we teach children to listen to different sound and help them to speak. We use total communication methods. Come , I will show you her class.(Headteacher takes her to the junior class)

Headteacher: This is Miss Sarita, a class-teacher of pre-primary children.

Teacher: Hello, what's your name?

Jyoti: Anjali.

Teacher Good Anajali, who is this? (With signs) She is your Mummy.(Teacher introduces her to all other children in the class and continues her teaching with picture charts. Anjali, takes interest in all activities of the school . She shows quick improvement in her learning. Anjali takes part in the sports and craft competition held at District level for all the schools an she wins and gest the award. It is published in the newspaper)

Anajli : (Shows her gift) and calls mumm..yy...

Jyoti: My sweet , loving child... I knew, one day you will certainly gain in life..

Prakash: (enters) what is this... a piece of metal!

Jyoti: No shame to say like this, you are making fun with our child.. look (shows newspaper) it is all about our Anjali.. (Meanwhile, Prakesh is honoured and appreciated by the neighbours and relatives)

Anjali: (utters) papa.. papa....

Prakash: (astonished) great... say once again..

Jyoti: she calls you papa..

Anjali: Papa...papa.... Papa...

Prakash: ohh, my child (embraces her) my loving child... you are so cute, so sweet... I am so happy for you. Please forgive me, my child..I am very sorry.. I was always looking at your disability and never saw the abilities in you....you are such a wonderful child, I love you..... You have held my names up and have dignified me... I am proud of you...

Appendix- 6 Reply to open-ended questions:

1. How could the persons with hearing loss be more equal to his/her hearing peers?

The answers are summarised and indicated their form numbers.

1, 20, 53. Through education, the use of hearing aids and with the help of parents and teachers, with their hard work and interest to learn.

2, 26. Keeping a goal in life and striving towards it with the help of family, society and teachers. Need to use hearing aid. And hard work

3, 11., 12, 14, 15, 17, 18, 22, 25,33,34, 40,41,42, with expression, gestures, signs and writing and sign language.

13. The deaf children should be treated as equal to normal children, that they too are important like others. They are to be given equal respect.

16,35,38. Along with the benefits from governments schemes , social help and support to be given to them.

19,23, . With the help of hearing aids and make them speak.

20,28, 29,32,. With speech and writing.

43, With his intelligence and behaviour

27. deaf children should as much as possible mingle with their hearing peers and speak to them, work hard to reach the goal and develop their other abilities.

44. They should be given special education.

55. By learning different works of the society, they can be equal to their hearing peers.,

56. If they get enough support from family and society and work hard with determination he/she can be equal to normal children.

2. Are there any other comments you want to make?

1. People consider disability as a punishment from God. Therefore it needs to bring an awareness into people.

8 Governments has initiated various provisions for Persons with Disabilities (PWD). But it does not reach to the people in our villages. Persons PWD has to face lot of difficulties and they do not get enough success. Those who really deserve do not get the benefit of it.

9 With their abilities they become part of society.

15. A guy from our village had discharge of his ears at the age of 6-7, from that time he is deaf.

12,17, 29,32, 56. PWD should get help and sympathy from government and society in where they live.

13. The deaf children are also the human being and they should be treated accordingly and give them their rights. Governments should have some reservation for them.

18 The government should help them for mainstreaming. They should be given education at early age and should have extra provisions for them.

23. Some of the disable want to study further but they do not get sufficient financial help for education.

24, 25. Even though they deaf, but they are happy.

27. The deaf children should be included in all the activities of society, and consider them equal to normal children. They are to help to get benefits from governments schemes so that he/she may progress in life.

28. They should attract people through their behaviour.

30,53. The deaf people are very hard working, They concentrate on their work.

51. There should be proper treatment and facilities for the development of deaf children.

52. There should be special vocational training for deaf children.

55. There should be some institute , where they can be helped to develop their skills , which will be help them for life survival .

Suggestive questions:

1. How could the persons with hearing loss be more equal to his/her hearing peers?

6 persons : Through education, the use of hearing aids and with the help of parents and teachers, with their hard work and with determination and interest to learn.

4 persons : Keeping a goal in life and striving towards it with the help of family, society and teachers. Need to use hearing aid. And do hard work: deaf children should as much as possible mingle with their hearing peers and speak to them, work hard to reach the goal and develop their other abilities.

18 persons: with expression, gestures, signs and writing and sign language and spoken language. Since they cannot hear, by using hearing aids deaf children can able to hear and can speak like other normal children

One person : The deaf children should be treated as equal to normal children, that they too are important like others. They are to be given equal respect. My neighbour, deaf girl, wanted to join us for the festival of Diwali with her siblings for, but her father did not allow her”. So they are segregated in the family as well as in society.

3 persons: Along with the benefits from government’s schemes, social help and support to be given to them.

1 person. With his intelligence and good character/ behaviour. Schools should encourage them and give chances to be equal with their hearing peers. Other students should be sensitive to their needs for example, being friendly, understand their signs, speech and gestures and support them.

1 person: They should be given special education.By learning different works of the society, they can be equal to their hearing peers., My family was very happy to get the free pocket hearing aids for my brother. But for this we had to travel two hours by bus and to stand four hours in the queue and now it is lying in corner”.

2. Are there any other comments you want to make?

One person: People consider disability as a punishment from God. Therefore it needs to bring awareness into people.

Another person: Governments has initiated various provisions for Handicapped. But it does not reach to the people in our villages. Handicapped people and their family face lot of difficulties and they do not get enough success. Those who really deserve do not get the benefit from provisions

Next person: With their abilities they become part of society, discharge of the ear makes them deaf.

4 person said; Handicapped Persons should get help and sympathy from government and society where they live in.

1. The deaf children are also the human being and they should be treated accordingly and give them their rights. Governments should have some reservation for them.

1 The government should help them for mainstreaming. They should be given education at early age and should have extra provisions for them. Much is on papers, but nothing is being applied in our areas for handicapped children”

2. Some of the disable want to study further but they do not get sufficient financial help for education.

1, they deaf, but they are happy.

1. The deaf children should be included in the all the activities of society, and consider them equal to normal children. They are to help to get benefits from governments schemes so that he/she may progress in life.

1 Many handicapped children are very talented , they should be encouraged and they need to attract people through their behaviour.

2. The deaf people are very hard working, They concentrate on their work.

3 There should be proper treatment and facilities for the development of deaf children

1 There should be special vocational training for deaf children., There should be some institute , where they can be helped to develop their skills , which will be help them for life survival .

Appendix – 7 Interview consent form, Questions and responses

Dear all,

I am a master's student at the University of the Birmingham, U.K. This interview is a part of my master's course in 'Inclusion and special educational needs'.

Its purpose is to know your views , comments, opinion , and suggestions regarding the presentation of drama conducted on 11th May in St. Michael's School, Hazaribagh on creating an awareness of deafness..

All information given in this interview will remain confidential. I ensure, in writing up my final report the identity of individuals will be protected.

I would like to ask you whether you would be happy to have Skype exercise for about 25 minutes between 17th May and 20th May. Send me your preferences and I will try and adjust accordingly.

The focus of the chat will be around the drama which you have seen mainly the message and awareness that has brought to you, the role which you like most , what impact does it have on you?

I very much look forward to catching up with you time and generosity is very much appreciated.

Best regards and I look forward to hearing from you.

I will be happy to talk to you, or contact you, If you have any queries, please feel free to contact.

Email: christinadmello13@gmail.com

Mob. No. 07407106163

Thanking you,

With regards,

Sr. Christina Dmello

University of Birmingham.

United Kingdom.

Conducting telephone and Skype Interview (survey)

1. I had send an advance letter, providing a brief explanation of myself, the purpose, expectation, assures confidentiality and the schedule an appointment for an interview.
2. Introduction: Familiarize, give the respondent the estimate amount of time that the survey will take (one to one), informing about the tape –recorder, keeping in mind to be friendly, enthusiastic and positive and will be aware of appropriate speed of voice and tone.
3. Some questions are pre-decided orde as shown below. However, there will flexibility in response, allowing them to be more free to express what have in mind on topic, use of open/ closed/ scale response.
4. Asking Suggestions/ probes , This interview will take maximum 20 min.

The tentatives questions are:

Questions for the telephone and Skype Interview (survey)

- 1.. Did you see the drama?(Yes/ No)
3. How was it? Was it very good/good/ not good / not sure
4. Are you strongly agree/ agree /Disagree/ strongly disagree / not sure with the arrangement, the place (environment), sound and whole system of the drama?
5. What did you like in it most? And Why?
6. Which role was most effective in your opinion? why?
7. What message did you get from it/ what did you learn from it?
8. Do you think we should continue presenting such a programm of raising awareness in your community?
9. What are the benefits or drawbacks of it?
10. After viewing this drama what is your next plan for your community?

11. What suggestions have you / what could have been done better in your opinion?
12. Any other point you want add...
13. Thanks you very much for your valuable time, thoughts and suggestions. Bye.

The transcript Skype Interview

The interviews of six persons (four female and two male interviewees)

It was their first experience to have conversation on skype, so they were more enthusiastic and excited about it. Two of them knew me as the headteacher of their children. Initially I made them more comfortable with friendly chat. They were happy to talk freely especially female. The main topic of the conversation are transcript. It was in local (Hindi) language. Initially two respondent voice was not clear. I had to strain to listen to them. My voice was clear to them , as they said.

All of them said the drama was so nice, very well done. The actors were very clear. Two ladies said,

1st Person: Mr. Ram

Disable children are to be given value,. they are to given opportunity for further studies and their development.. If like this drama could be presented in different places, many could be aware of the reality. He further said, "We all were surprised watching the drama, It made us realise our role, especially me as a father of handicap child, how I treat my daughter. Really I was filled with tears in my eyes". [The father of deaf girl]

2nd Person (Miliyani) (Female)

M.: Disable children can grow , whatever it may be they are children whether disable/ normal (handicapped) .. disable children are capable of competing with normal children if given chance as we seen in the drama..We need to accept them.

It happens in all the houses , this is a reality of life. This drama has opened my eyes and I literally cried seeing and applying it to my life. I realized, I haven't given enough care and attention to these of my deaf daughters, I used to think, anyhow they are deaf, what good can expect from them, so better to spend some efforts, money and time to the other two hearing children that will have some benefits. But now, I am challenged and empowered, I have a greater responsibility towards these of my deaf daughters. Like a mother in the drama I will also make an effort to brighten their future.[Mother of deaf girl]

3rd person:

Mrs. Maggi replied that the dowry system could be one of the major reasons for it, which she indicated with a vivid example of a deaf girl from her village.

4 | दैनिक जागरण रांची, 22 मई 2012

मुझे माफ कर दो बेटी ...

- ♦ मूक बच्ची के अभिनय से हृदय परिवर्तन
- ♦ रंग ला रहा सिस्टर क्रिस्टिना का प्रयास



हजारीबाग, प्रतिनिधि : मुझे माफ कर दो बेटी ... की आवाज एक ऐसे पिता की है, जिसने अपनी मूक बधिर बेटी का परित्याग कर दिया था। गांव के समाजसेवी की मदद से वह बच्ची संत माईकल श्रवण मूक विद्यालय में पहुंची जहां उसे नई जिंदगी मिली। उसकी मां बराबर उसकी हौसलाफजाई करती रही तथा बाद में संगीत की दुनिया में उसने बेहतर

नाटक का मंचन करते कलाकार।

उपस्थिति दर्ज कराई। यह एक सच्ची घटना थी, जिसे सिस्टर क्रिस्टिना तथा सिस्टर रोशिनी ने लघु नाटिका के माध्यम से जीवंत किया तथा सदर प्रखंड के कई

गांवों में मूक अभिनय के माध्यम से विकलांगता को अभिशाप नहीं, बल्कि वरदान के रूप में बदल कर रख दी। प्राचार्य ने बताया कि बच्चे बधिर मूक की स्थिति में आते हैं। उनका अनवरत इलाज किया जाता है, उन्हें शिक्षा दी जाती है तथा समाज की मुख्यधारा से जोड़ने का प्रयास किया जाता है। उन्होंने बताया कि बच्चियां जब खुश होकर पापा, पापा की आवाज लगाती हैं तो सारा प्रयास सार्थक हो जाता है। प्राचार्या क्रिस्टिना ने बताया कि सामाजिक वर्जनाओं को तोड़ने का सशक्त माध्यम मंच की प्रस्तुति है, जिसका मंचन वे बेहरी, तरवा, सीतागढ़ा समेत कई गांवों में कर रहे हैं।

